Implementing Community-Based Systems of Care for Children With Autism Spectrum Disorders

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No disclosures
Thought for the Day

“It is better to keep your mouth shut and let people think you are a fool than to open your mouth and remove all doubt.”

Mark Twain
My Perspectives

- Pediatrician
- LEND faculty
- Title V Program
- Early Intervention Program
- AAP Autism Subcommittee
- Parent of a child with autism
Parents of Children with ASD
The Diagnostic Odyssey

- 40% not satisfied with the process (Goin-Kochel, 2006)
- 4 to 5 different clinicians en route to a diagnosis (Goin-Kochel, 2006)
- Early developmental concerns minimized or dismissed (Howlin, 1999; Carbone, 2009)
- Perceived delay in diagnosis is 9 - 18 months (Harrington, 2006)
- Recommended screening has not been universally adopted (Sand, 2005; Zeiger, 2009)
Parents of children with ASDs and medical care

- Dissatisfaction with medical care
- Care is not family centered
- Care is not coordinated
- Difficulty accessing specialty care
- Higher out of pocket expenses and financial problems
Medical home for children with autism spectrum disorders: Parent perspectives

Focus Group

Parents perceived that primary care providers:

- had not respected their initial concerns about development
- lack expertise in autism management
- do not ask about how autism affects other family members
- are uninformed and unsupportive of complementary and alternative medicine (CAM)
- do not coordinate care with other providers
- do not ask about transition plans
Parents of children with ASDs and school/community services

- Dissatisfaction with school/community services
- Not enough qualified providers
- Long waiting lists
- Services not available in the area
- Unmet need for family support services
- Higher levels of stress
Parents of Children With ASDs
Why so stressed?

- Functional impairment
- Maladaptive behaviors
- Treatment options
- Uncertain prognosis
- Services are patchy
- Debate surrounding the cause
A Vicious Cycle

Caregiver Health And Well-being
A Vicious Cycle

Caregiver Health And Well-being

Caregiver Effectiveness

Benson, 2009
A Vicious Cycle

Caregiver Health And Well-being

Child Health And Well-being

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Caregiver Effectiveness

Benson, 2009
Evidence of Resilience in Families of Children With ASDs

- Mobilization of resources
- Making positive meaning of disability
- Becoming united and closer as a family
- Building friendships, developing new interests
- Feelings of greater personal accomplishment in parenting
Definition of family-centered services

Partnership is the foundation

1. Work together
2. Mutual respect
3. Trust
4. Open Communication
5. Decisions are made together
6. Negotiate
“I have challenges in meeting the medical needs of my child and being taken seriously about any of my concerns.”
Family Centered Services in Early Intervention and Special Education

- Individual Education Plan (IEP)
  - Specifically designed to meet the unique needs, talents and experiences of each child
  - Emphasizes collaboration of parents and professionals

- Individual Family Service Plan (IFSP)
  - Services in the natural environment
  - Improved child AND family function
Got Family Centered Services?  
Utah’s Early Intervention Program  
Annual Performance Review 2007

Percent of families participating in Part C who report that early intervention services have helped the family:

A. Know their rights (76 %)  
B. Effectively communicate their children's needs (73%)  
C. Help their children develop and learn. (83%)
World Health Organization’s International Classification of Function (ICF)

Health condition
(disorder or disease)

Body Functions & Structure  Activity  Participation
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Environmental Factors

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Joint Attention
Eye Contact
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Body Functions & Structure

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Activity

Communication

Participation

Do stuff

Environmental Factors

Personal Factors

WHO, 2001
World Health Organization’s International Classification of Function (ICF)

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- Communication

Participation
- Do stuff

Environmental Factors

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Assistive Devices

- Joint Attention
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Associated Conditions

WHO, 2001
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The University of Utah
Department of Pediatrics

WHO, 2001
A Medical Home…

• Is not only a place
• But a process of care
• That emphasizes “home” as a:
  – Headquarters for care
  – Place to feel recognized, welcomed, supported
  – Part of a community of services
Components of the Medical Home

• accessible
• continuous
• comprehensive
• family-centered
• coordinated
• compassionate
• culturally effective
The Typically Developing Child

Support
Family & Friends

FAMILY
Medical Home Provider & Staff

Daycare
FAMILY Medical Home Provider and Staff

Medical Specialists
- Developmental Pediatrician
- Child Neurologist
- Geneticist

Mental Health
- Child Psychiatrist

Community Support
- Parent Groups
- Recreational Programs
- Respite

School / EIP
- Special Education Teacher
- OT/PT/Speech Therapists
- Psychologist

Title V CSHCN Clinics

Funding
- Insurers
- Medicaid
- SSI

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Medical Home Provider and Staff
FAMILY

Medical Providers

- Medical Home Provider and Staff
  - School / EIP
    - Special Education Teacher
    - OT/PT/Speech Therapists
    - Psychologist
  - Title V CSHCN Clinics

Specialists

- Medical Specialists
  - Developmental Pediatrician
  - Child Neurologist
  - Geneticist

- Mental Health
  - Child Psychiatrist

Support

- Community Support
  - Parent Groups
  - Recreational Programs
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Care that is not coordinated results in...

- Mixed messages from team members
- Different eligibilities
- Duplication/ gaps in services
- Misunderstandings
- Frustrated providers
- Frustrated caregivers
“My wife is the medical home - she gets referrals and coordinates between physicians, two OTs, two SLPs, teachers at school, consultant, a behavioral specialist.”
“I found out about the Early Intervention Program by chance; no doctor ever mentioned it to me ... almost everything I found out from other parents or by chance.”
Autism has exposed our weaknesses...

- Management requires collaboration across disciplines
- Our roles in the coordination of care are not well defined
- We are not accustomed to the interdisciplinary model of caring for patients
What Leadership Education in Neurodevelopmental Disabilities (LEND) has taught me...

- I learn when I listen
- I don’t have all the answers...and that’s okay
- Interdisciplinary care results in:
  - More efficiency, quality, satisfaction
- Sustainable change is achieved at the systems level
“These are often high need children and they wear out their parents and people working with them. I do what I can but many times feel that the family needs so much more.”
Changing systems of care is like trying to change the tire on a bicycle while you are riding it.
There are also opportunities ... Where to begin?
Early Autism Detection and Referral in the Medical Home

- 6 month learning collaborative
- Teams from 32 practices
- Improved surveillance and screening
- Expanding to dental practices
- Parent involvement
UPIQ Projects - Lessons learned

- Parents are vital to the process and bring...
  - Focus on the true goal: improved patient care
  - Knowledge of the system
  - Accountability, follow-through
  - Energy and passion
  - Willingness to give their time
Utah Department of Health
CSHCN Traveling Clinics

- Interdisciplinary team, eight sites
- Comprehensive assessment and case management
- Coordinate the delivery of services with the medical home and local agencies
- ASD: diagnostic testing, treat associated conditions
Lessons learned...

- Interdisciplinary care can be delivered even in more rural locations with less resources
- Autism: Integrating the family, health care and educational professionals creates success
The Challenge

• Create system level change that emphasizes...
  – Improved functional outcomes
  – Family-centered services
  – Interdisciplinary collaboration
  – Coordinated care
“Never let the fear of striking out get in your way.”

George Herman "Babe" Ruth
Who Benefits…

- Families of children with ASDs
- Children with other developmental disabilities
Everything I ever learned I learned from my patients with autism…

• Change can be scary.

• Interaction with new people can be scary.

• You can do it.
Thank You

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