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

The University of Utah
Department of Pediatrics

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My Perspectives

- Pediatrician - Medical Home Provider
- LEND Trainee 2006-7
- Pediatrician for CSHCN clinics (Title V)
- Interagency Coordinating Council (Early Intervention)
- Autism Council of Utah
- Parent of a child with autism
Parents of Children With Autism Spectrum Disorders

- less satisfied with their medical home than other parents (Liptak, 2006)
- less prevalent: family-centered, comprehensive and coordinated care
- “wait and see” approach often breeds parental discontent (Howlin, 1999)
- high levels of parental stress
Parents of Children With ASDs
Why so stressed?

• High level of functional impairment
• High amount of maladaptive behaviors
• Many options for treatment
• Predictors of prognosis uncertain
• Services are patchy
• Debate surrounding the cause
A Vicious Cycle

Caregiver Health And Well-being

Caregiver Effectiveness

Child Health And Well-being

Murphy et al., 2006
Evidence of Resilience in Families of Children With ASDs

- Making positive meaning of disability
- Mobilization of resources
- 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. Families and professionals **work together** in the best interest of the child and family
2. Everyone **respects** the skills and expertise brought to the relationship
3. **Trust** is acknowledged as fundamental
4. **Communication** and information sharing are open and objective
5. Participants make **decisions together**
6. There is a willingness to **negotiate**
What Do We Mean by FCS?
A conceptual framework with 3 premises

(i) Parents know their children best and want the best for their children…

GUIDING PRINCIPLES:
* Parental involvement in decision-making
* Parents should have ultimate responsibility for the care of their children
What Do We Mean by FCS?

(ii) Families are different and unique...

GUIDING PRINCIPLE:

* Each family and family member should be treated with respect (as individuals)
What Do We Mean by FCS?

(iii) Optimal child functioning occurs within a supportive family and community context. The child is affected by the stress and coping of other family members...

GUIDING PRINCIPLES:
* The needs of all family members should be considered
* Involvement of all family members should be supported and encouraged
World Health Organization’s International Classification of Function (ICF)

Health condition
(disorder or disease)

Body Functions & Structure

Activity

Participation

Environmental Factors

Personal Factors

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

Health condition
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Autism

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Health condition
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Brain Disorder

Body Functions & Structure

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Activity

Participation

Autism

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

- **Health condition (disorder or disease)**: Autism

- **Body Functions & Structure**
  - Brain Disorder

- **Activity**
  - Communication

- **Participation**

- **Environmental Factors**

- **Personal Factors**
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FCS

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- Health condition (disorder or disease): Autism
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- Activity
- Participation
- Environmental Factors
- Personal Factors
- Associated Conditions

Brain Disorder

FCS

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WHO, 2001
Components of the Medical Home

- accessible
- continuous
- comprehensive
- family-centered
- coordinated
- compassionate
- culturally effective
The Healthy Child

Support Family & Friends

Medical Home Provider & Staff

Daycare

FAMILY
Medical Home Provider Care Coordinator

Medical Specialists
- Developmental Pediatrician
- Child Neurologist
- Geneticist

Mental Health
- Child Psychiatrist

Community Support
- Parent Groups
- Recreational Programs
- Respite

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

Funding
- Insurers
- Medicaid
- SSI

Title V CSHCN Clinics

The child with autism or other developmental disability
Care that is not coordinated results in...

- Mixed messages from team members
- Different eligibilities
- Duplication/ gaps in services
- Misunderstandings
- Frustrated caregivers
- Frustrated providers
“I have challenges in meeting the medical needs of my child and being taken seriously about any of my concerns.”
Autism has exposed our weaknesses...

- We traditionally have not worked well 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 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
  – Better quality
  – Higher 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?
The Utah Medical Home Project

- 12 Utah pediatric practices
- Team: MD, nurse, office manager, care coordinator and parent partner
- Regular meetings
- PDSA cycle
- Evaluative component
- Systems level approach
The Medical Home Project
Practice successes

- Autism Support Group
- Home visits for CSHCN
- Family meetings with community based programs
- EMR Care Plans developed
- Identification of different intensity levels of CSHCN (appointment times)
- Care coordinators for Spanish speaking families
- IMPROVED CARE
The Utah Medical Home Project
Lessons Learned

• Parents are vital to the process and bring…
  – Focus on the true goal – improved patient care (what really matters)
  – Knowledge of the system
  – Accountability, follow-through
  – Energy and passion
  – Willingness to help
  – Time
Utah Department of Health
CSHCN Traveling Clinics

• Interdisciplinary teams, nine sites
• Comprehensive assessment and case management services for children with special health care needs
• Coordinate the delivery of services with the medical home and local agencies
• Autism: diagnostic testing, treatment of associated conditions
Lessons learned...

- Interdisciplinary care even be delivered 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
  - Interdisciplinary collaboration
  - Family-centered services
  - 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
Looking back...

1985

- Prevalence of ASDs was 1 in 2,500
- Little or no awareness of the disorders
- PDD-NOS and Asperger’s not DSM diagnoses
- Autism was not an educational diagnosis
- No developmental screening within the medical home
- No studies of therapies demonstrating positive outcomes
Today...

- ASD prevalence 1 in 150
- Explosion in autism awareness
- National campaigns by CDC, AAP
  - Parent groups: Autism Society and Autism Speaks
- Average age of diagnosis is declining
- Growing body of literature about effective therapies
- Individuals with Disabilities Education Act
- Autism specific legislation at the federal level
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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