

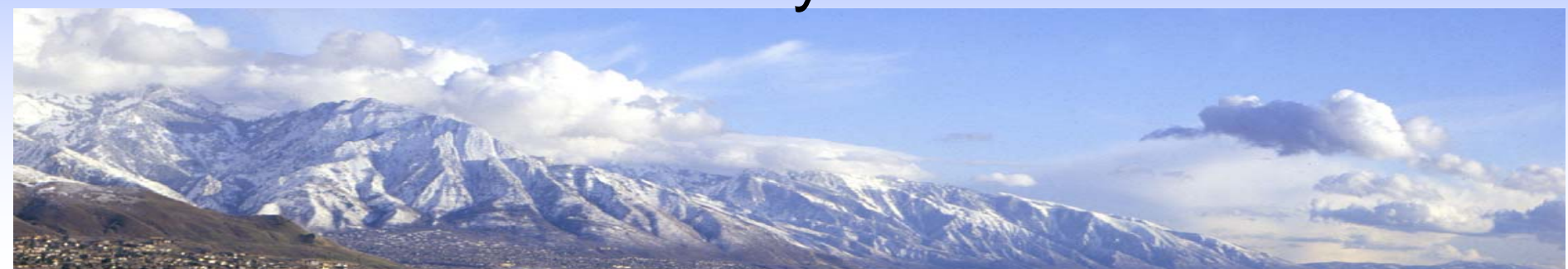


**The University of Utah**  
Department of Pediatrics

**Intermountain**  
Primary Children's  
Medical Center

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

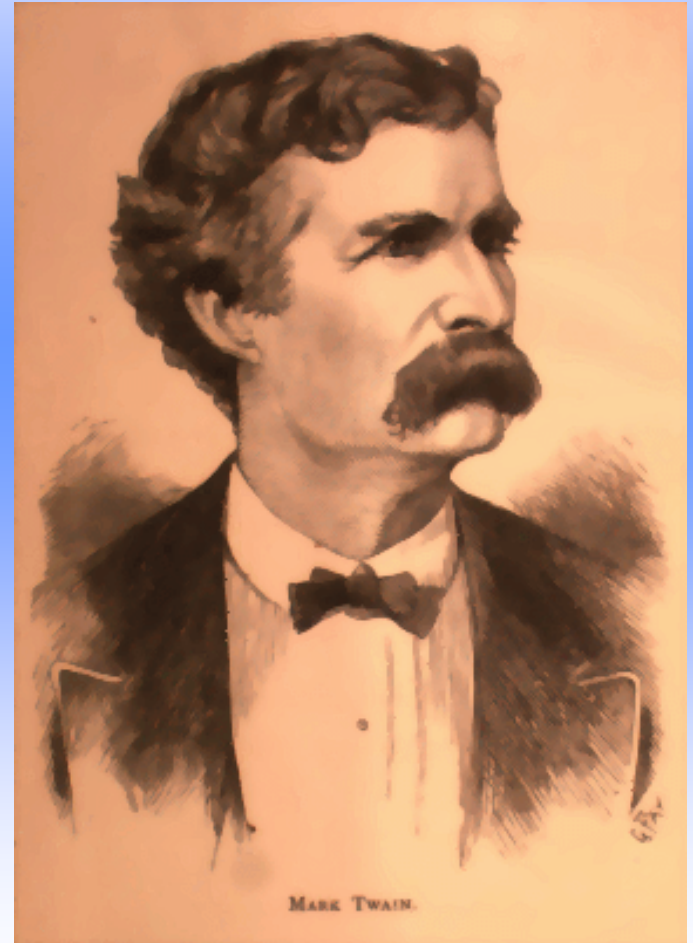
**Paul S. Carbone, MD, FAAP**  
Assistant Professor of Pediatrics  
University of Utah



# Thought for the Day

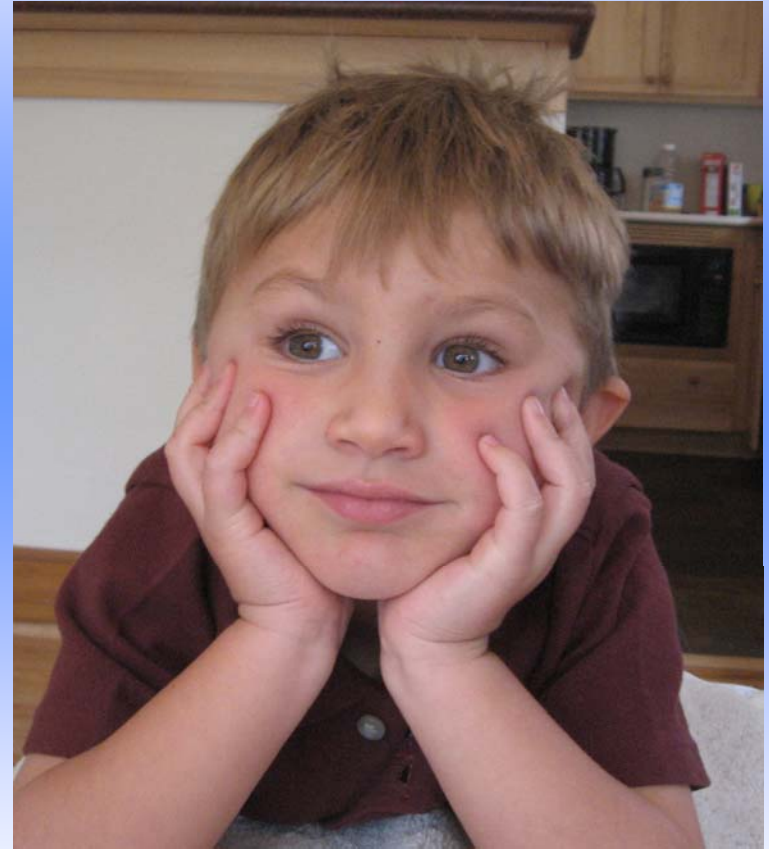
“It is better to keep your mouth shut and let people think you are a fool than to open your mouth and remove all doubt.”

Mark Twain



# My Perspectives

- Pediatrician
- Utah Regional LEND Autism Coordinator
- Children with Special Health Care Needs Clinics (Title V)
- Interagency Coordinating Council (Early Intervention Program)
- Autism Subcommittee (American Academy of Pediatrics)
- 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
- high levels of parental stress
- “wait and see” approach often breeds parental discontent (Howlin, 1999)



# Medical home for children with autism spectrum disorders: Parent perspectives

## Questionnaires (n=161)

Majority of families unsatisfied with their provider's:

- Ability to make appropriate referrals for diagnostic evaluation
- Ability to provide guidance about treatment
- Comfort level in providing advice about complementary and alternative therapies
- Willingness to address concerns about vaccines
- Knowledge of community support services
- Ability to address associated conditions (sleep, toilet training, feeding, anxiety, ADHD, sensory issues)



# 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



***“Our first pediatrician totally blew it as far as seeing the red flags, and she totally dismissed it when I brought it up. Over and over again she totally dismissed it.”***



# 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



# A Vicious Cycle

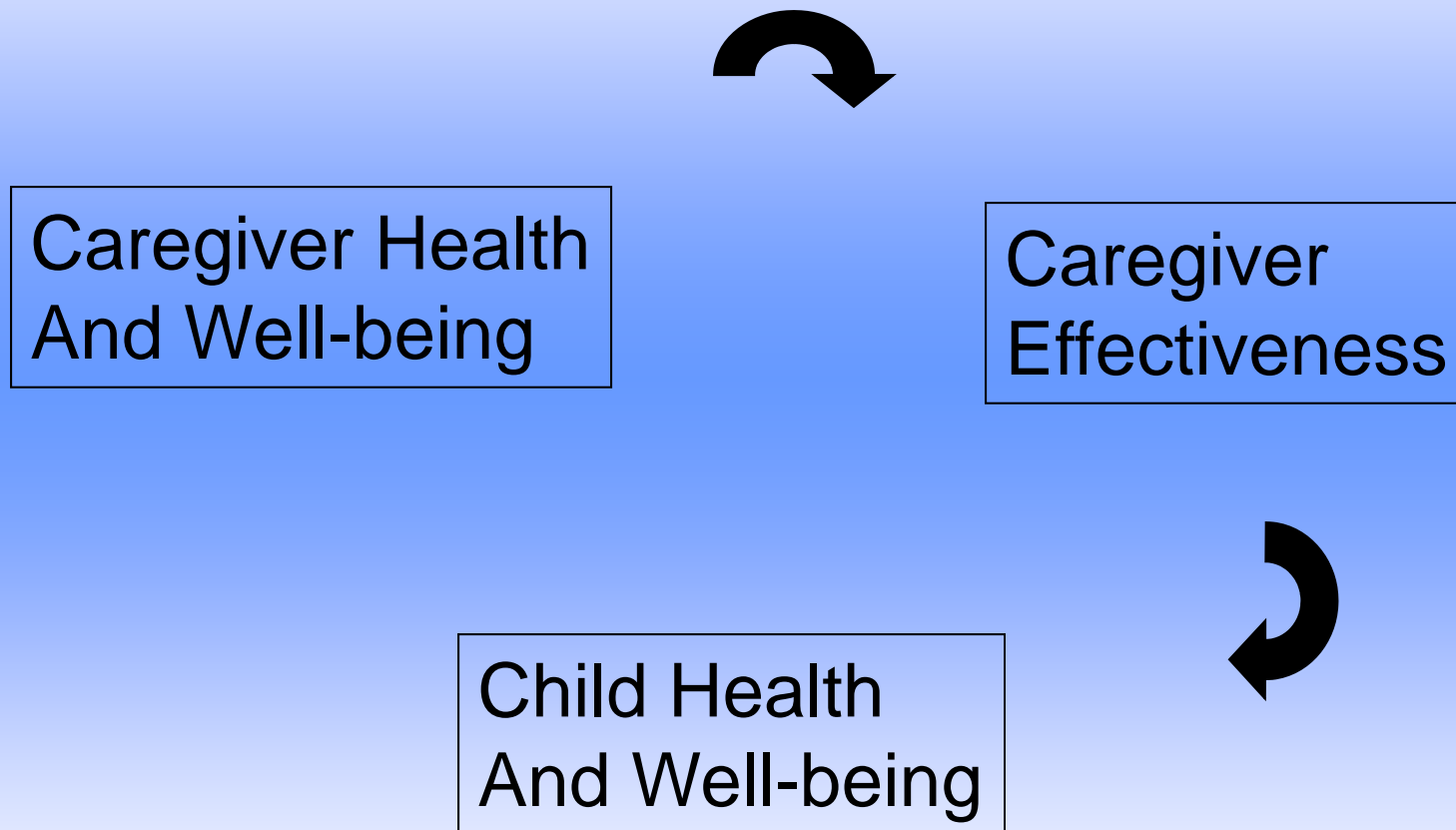


Caregiver Health  
And Well-being

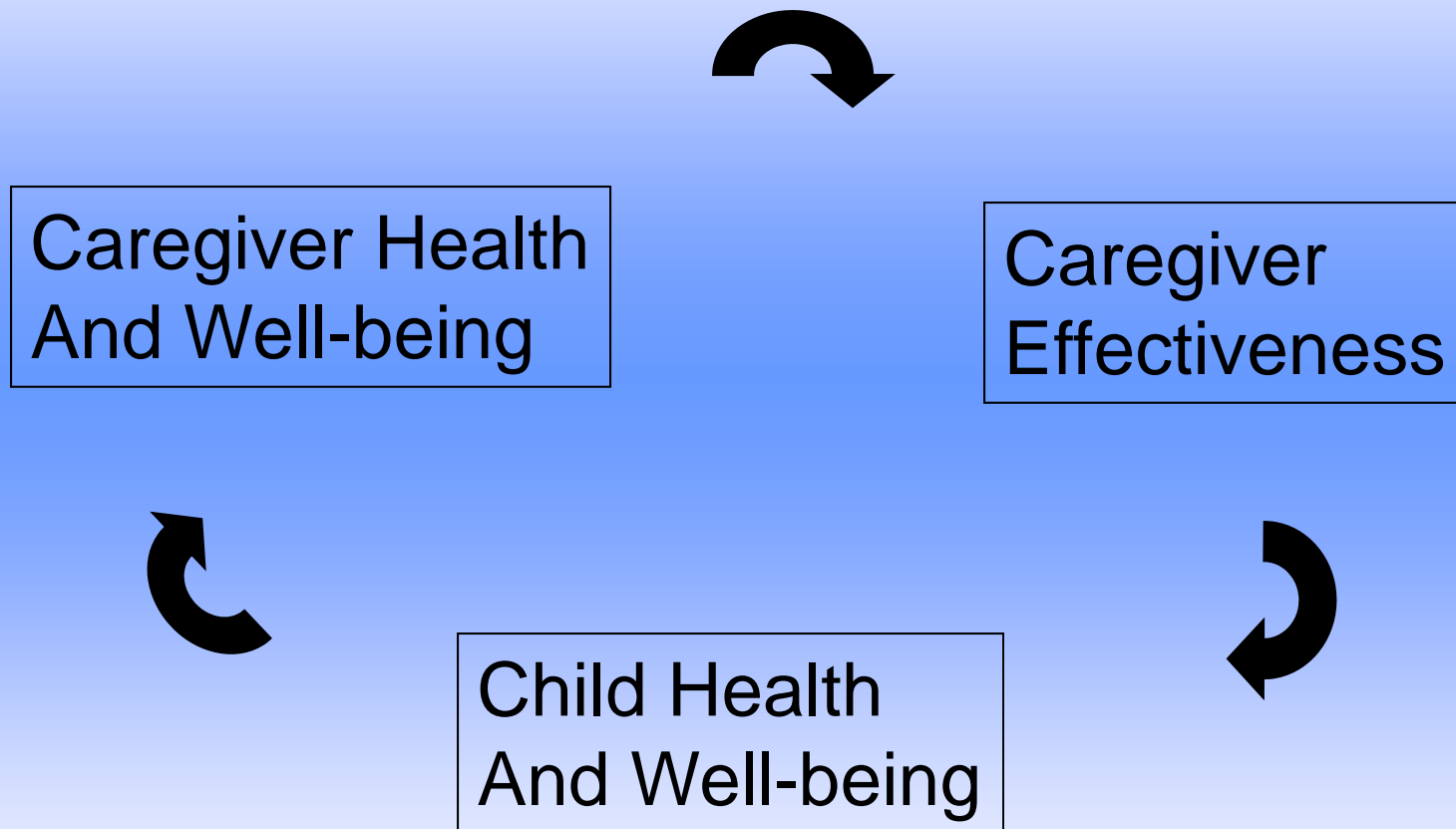
Caregiver  
Effectiveness



# A Vicious Cycle



# A Vicious Cycle



# 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. 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**



***“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 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:

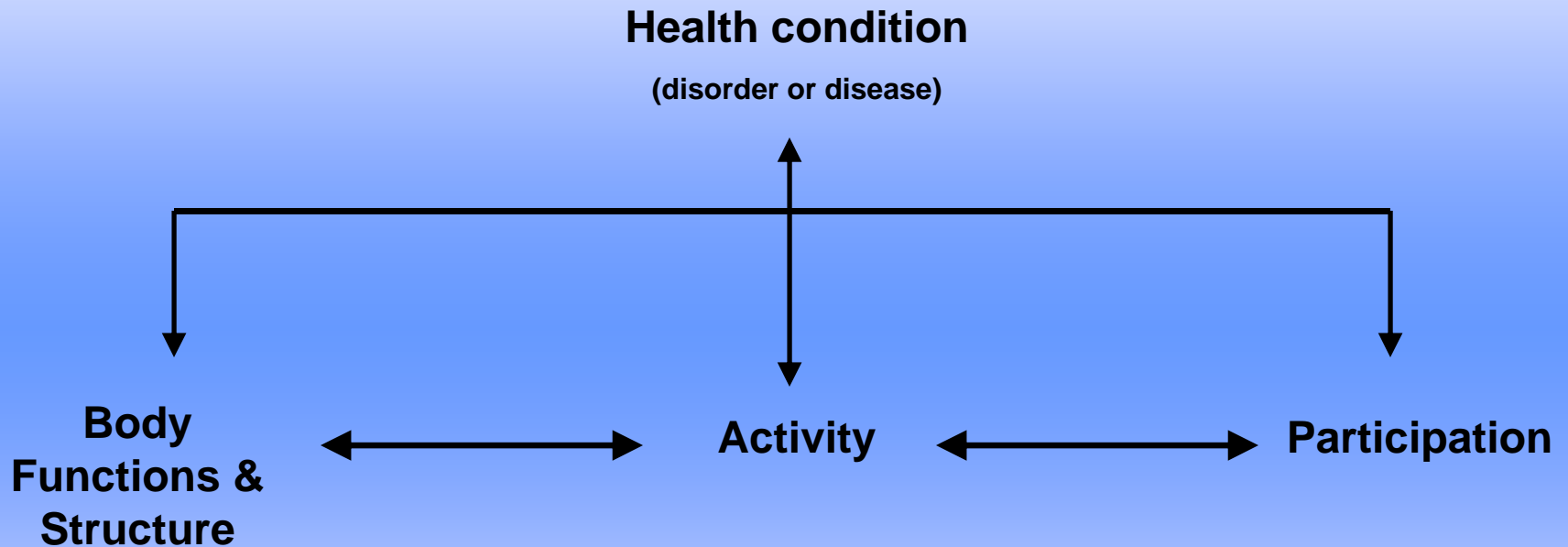
A. Know their rights (76 %)

B. Effectively communicate their children's needs (73%)

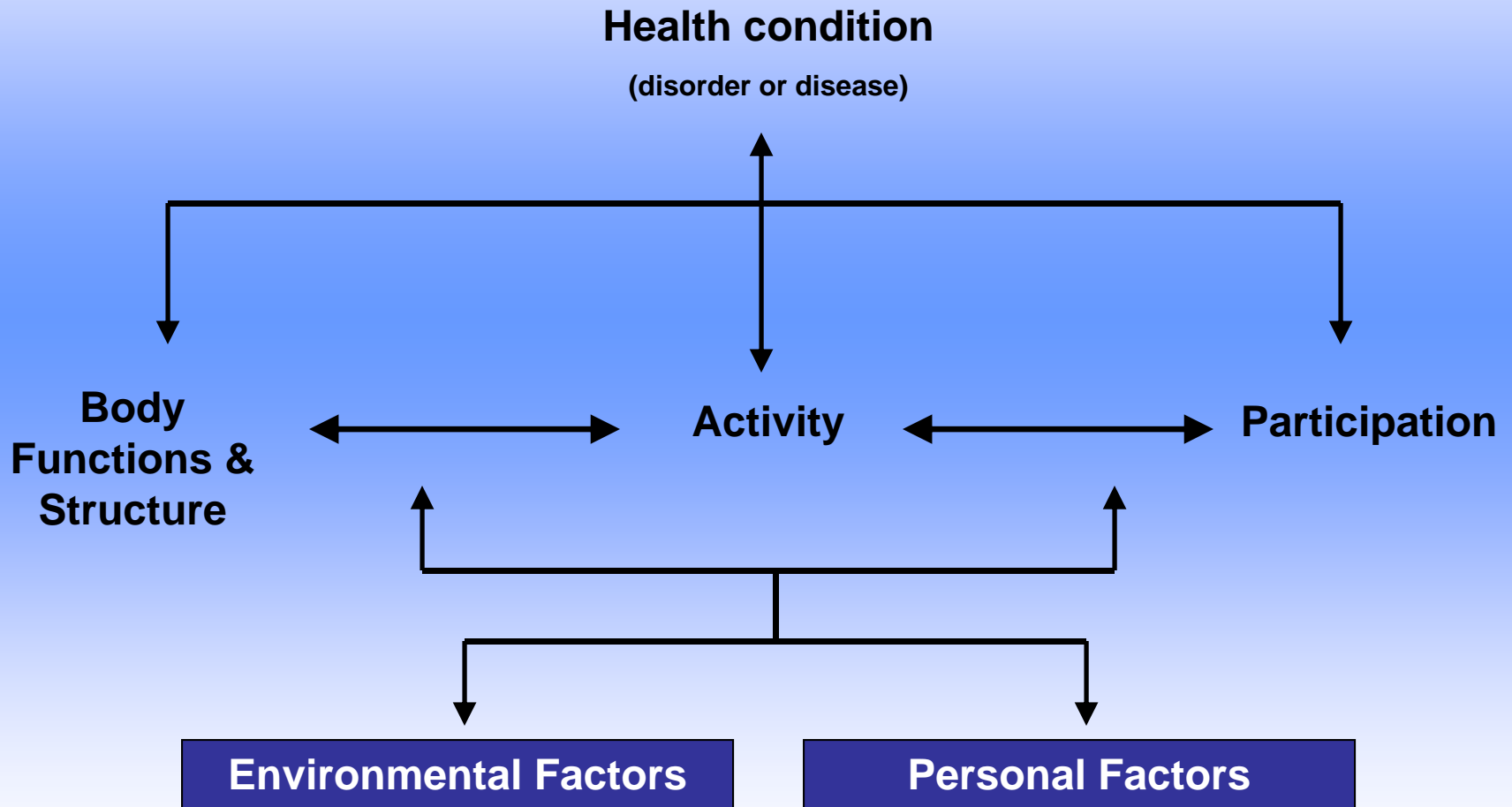
C. Help their children develop and learn.  
(83%)



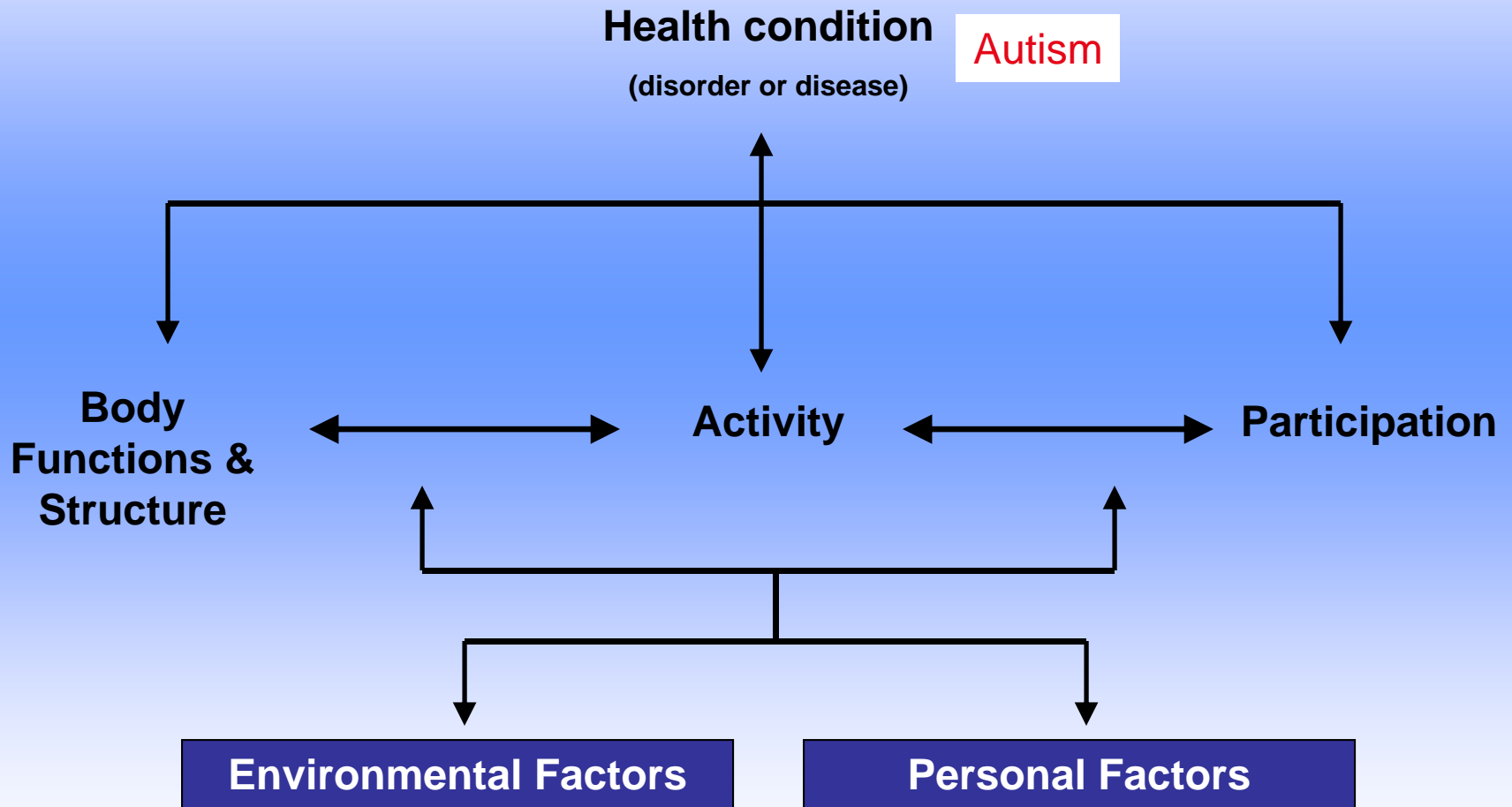
# World Health Organization's International Classification of Function (ICF)



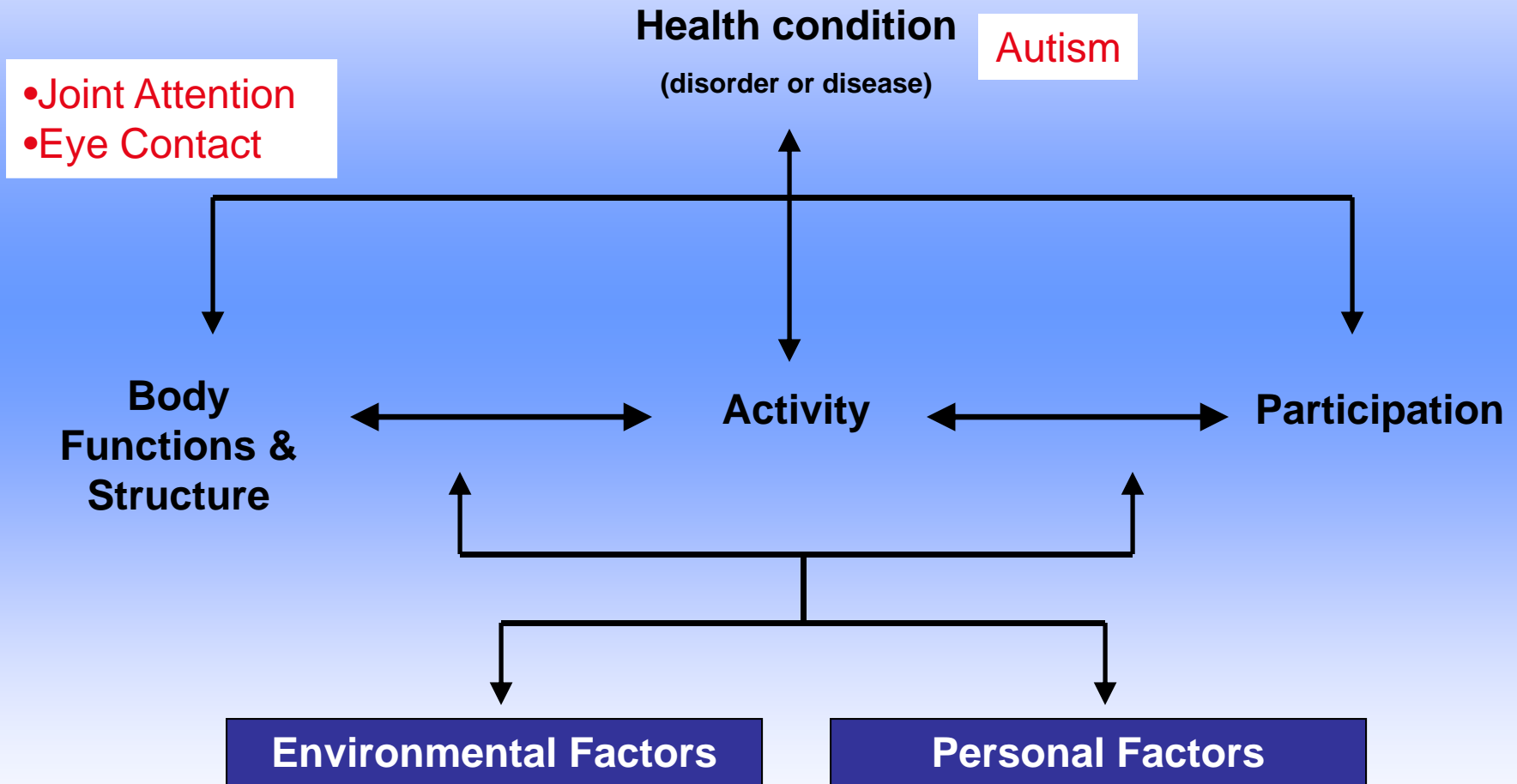
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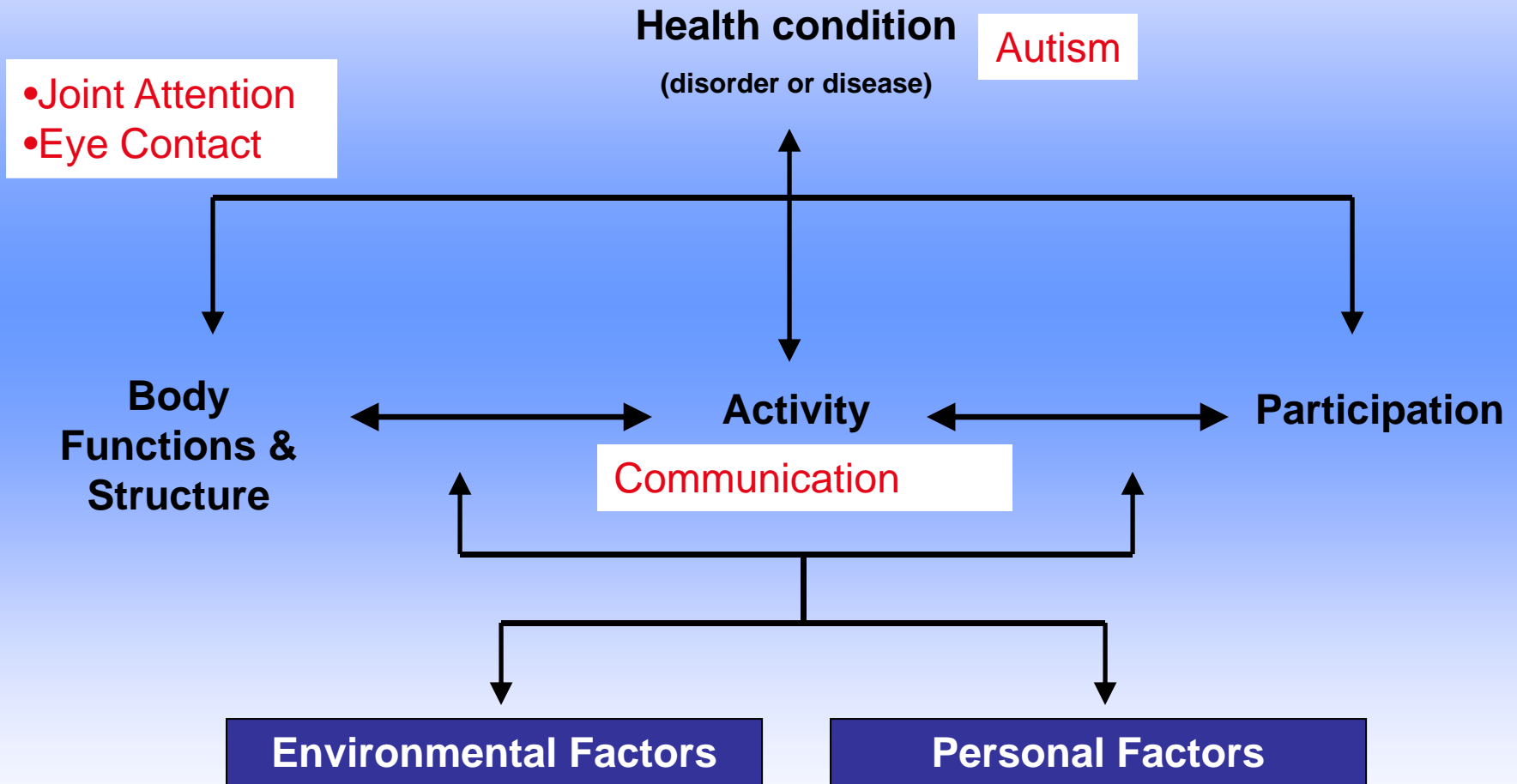
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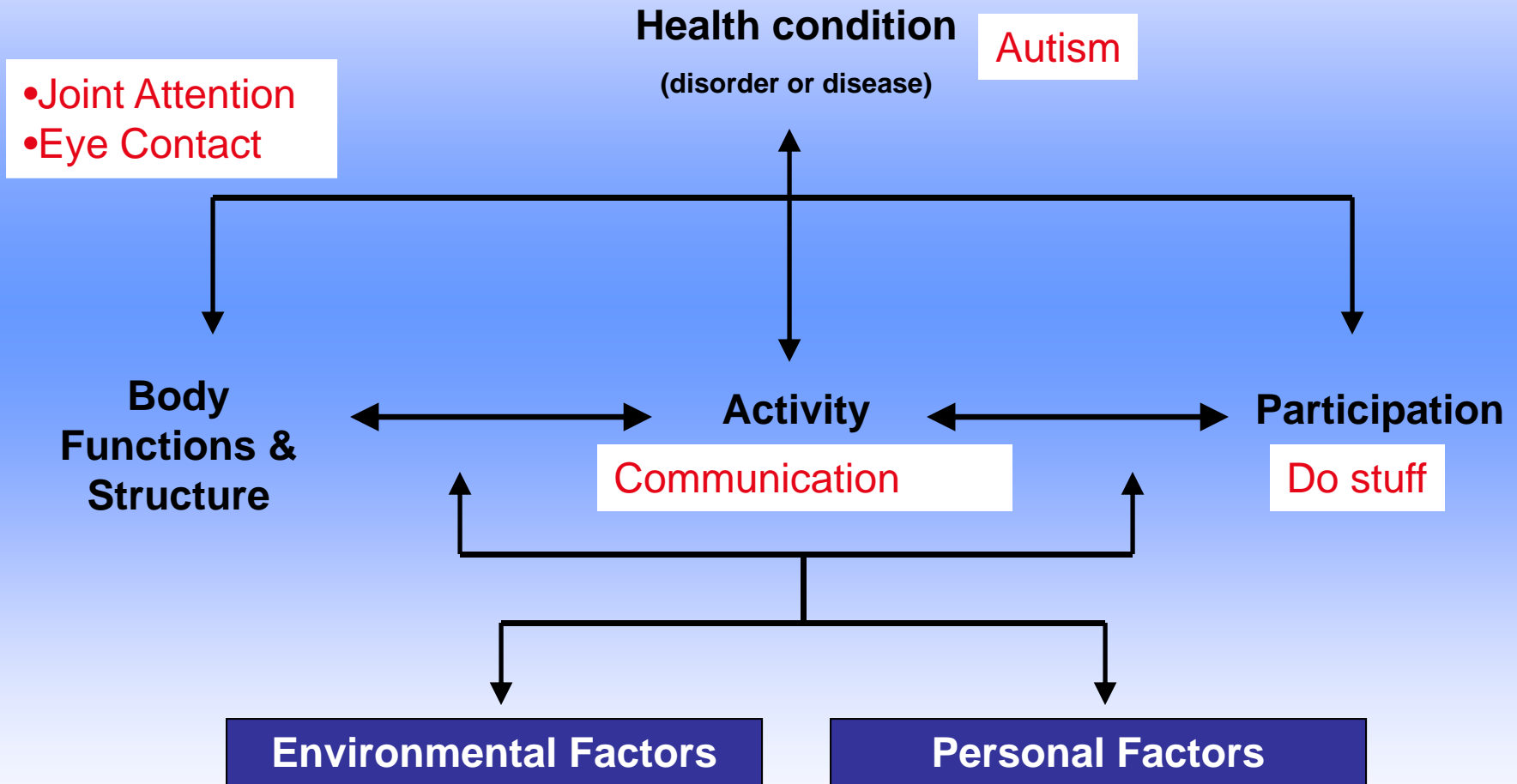
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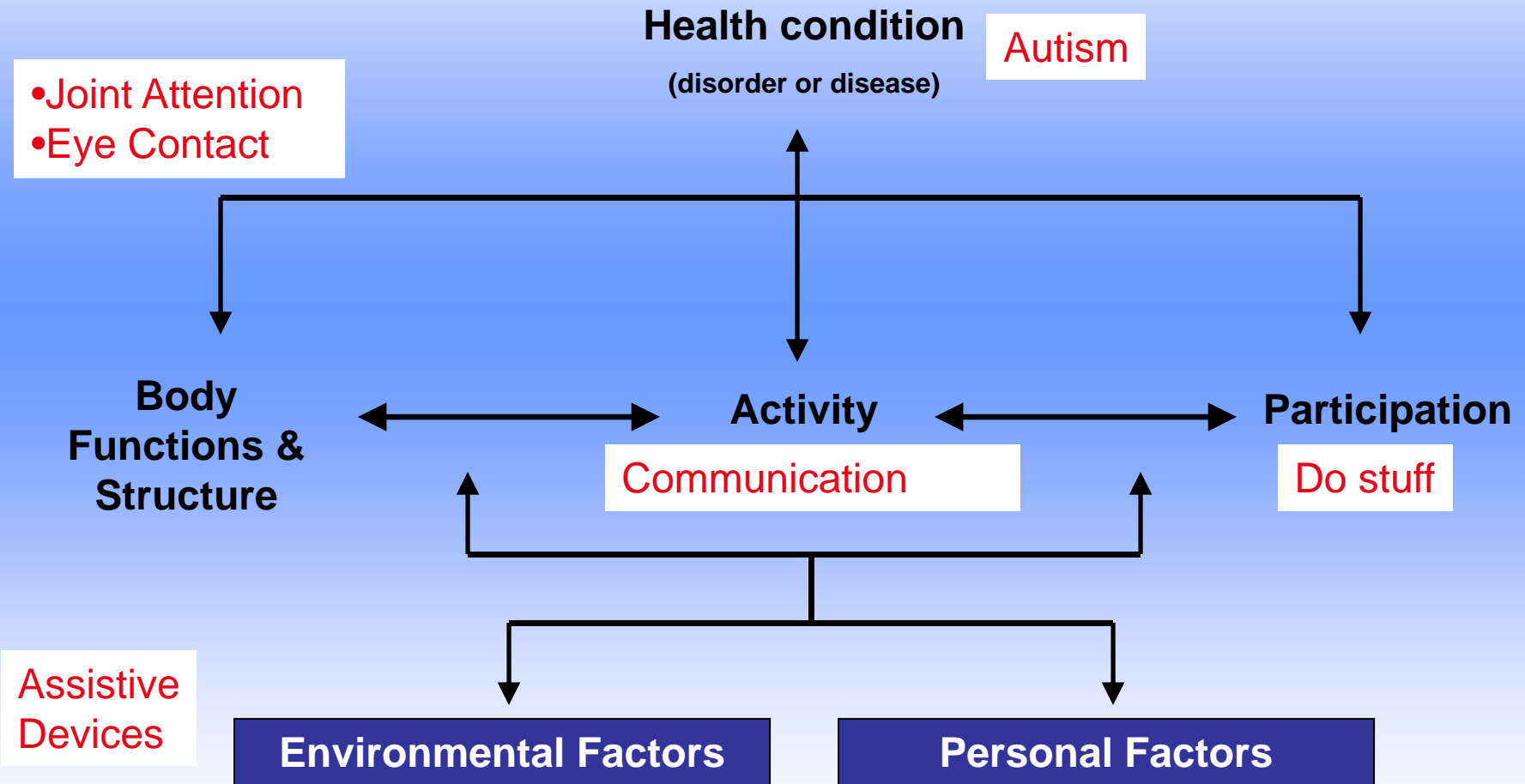
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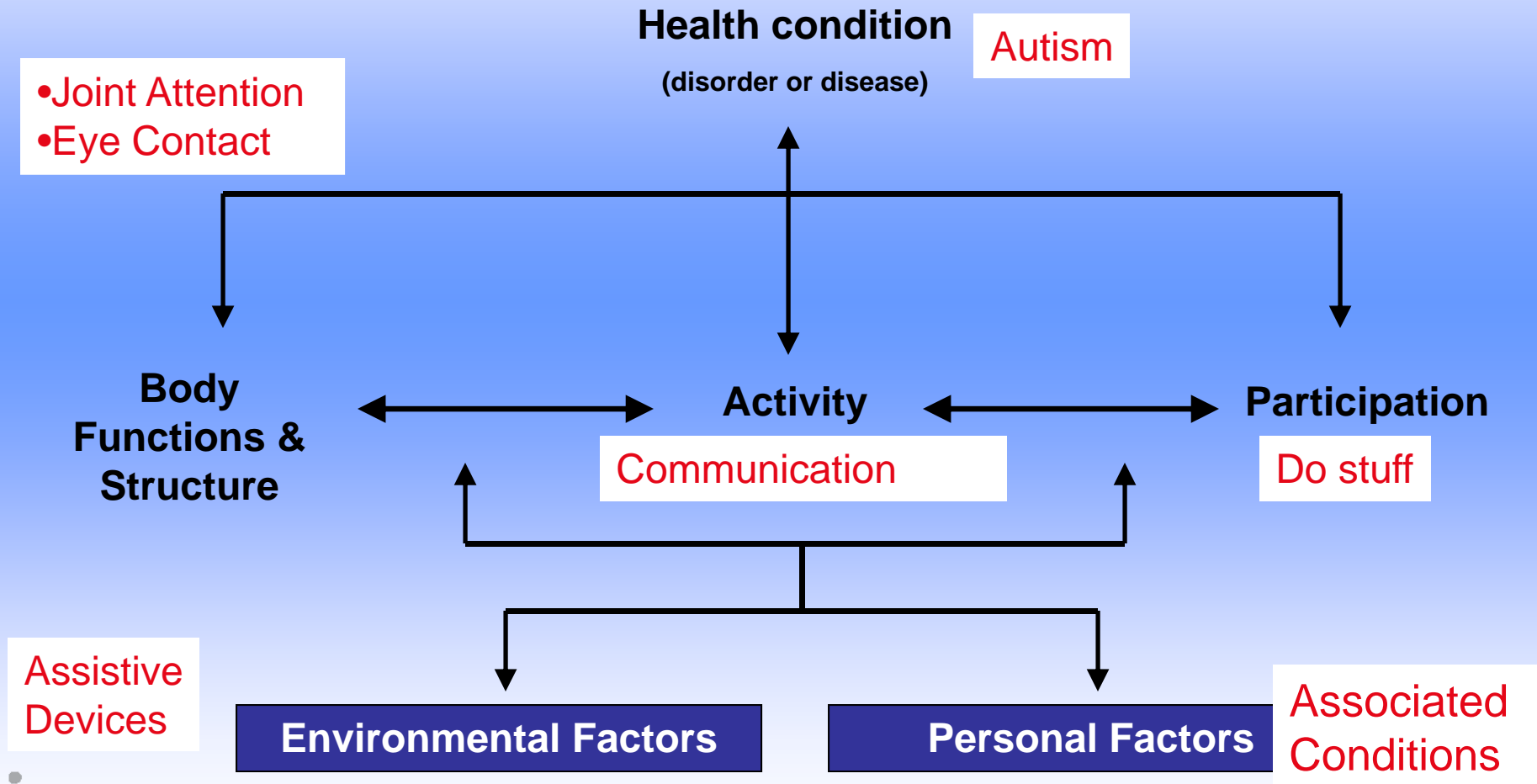


# World Health Organization's International Classification of Function (ICF)





# World Health Organization's International Classification of Function (ICF)



# 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

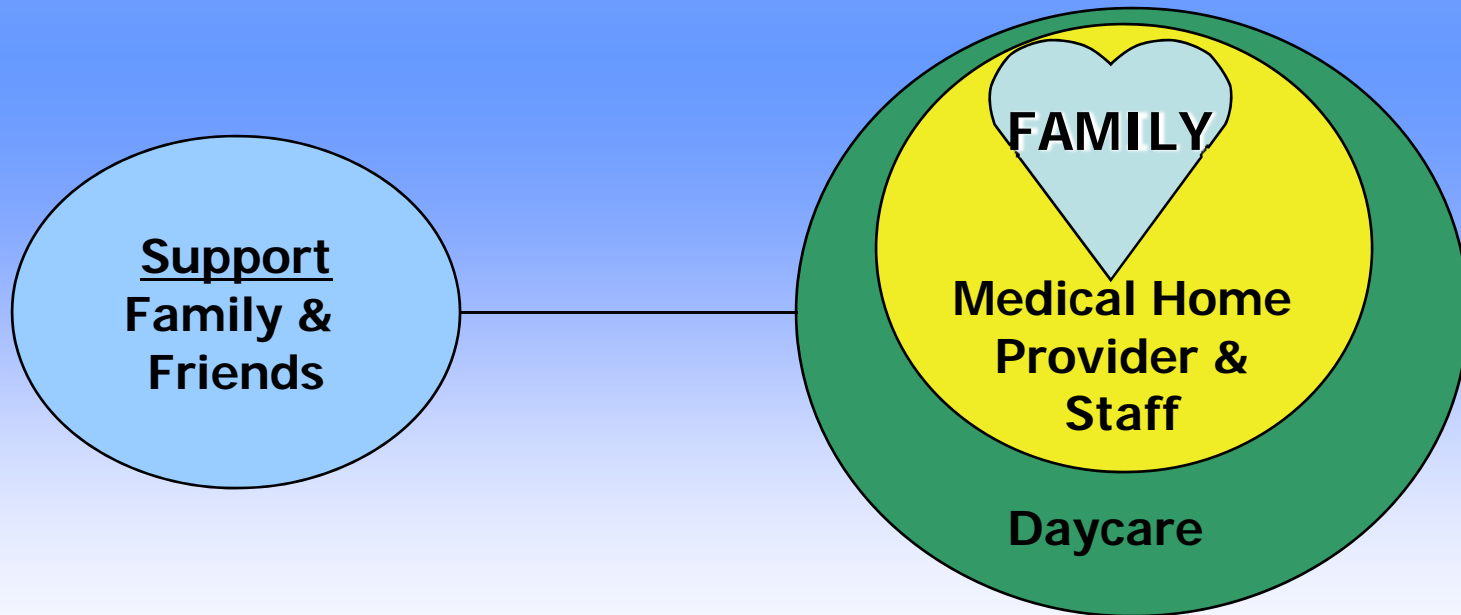


# Components of the Medical Home

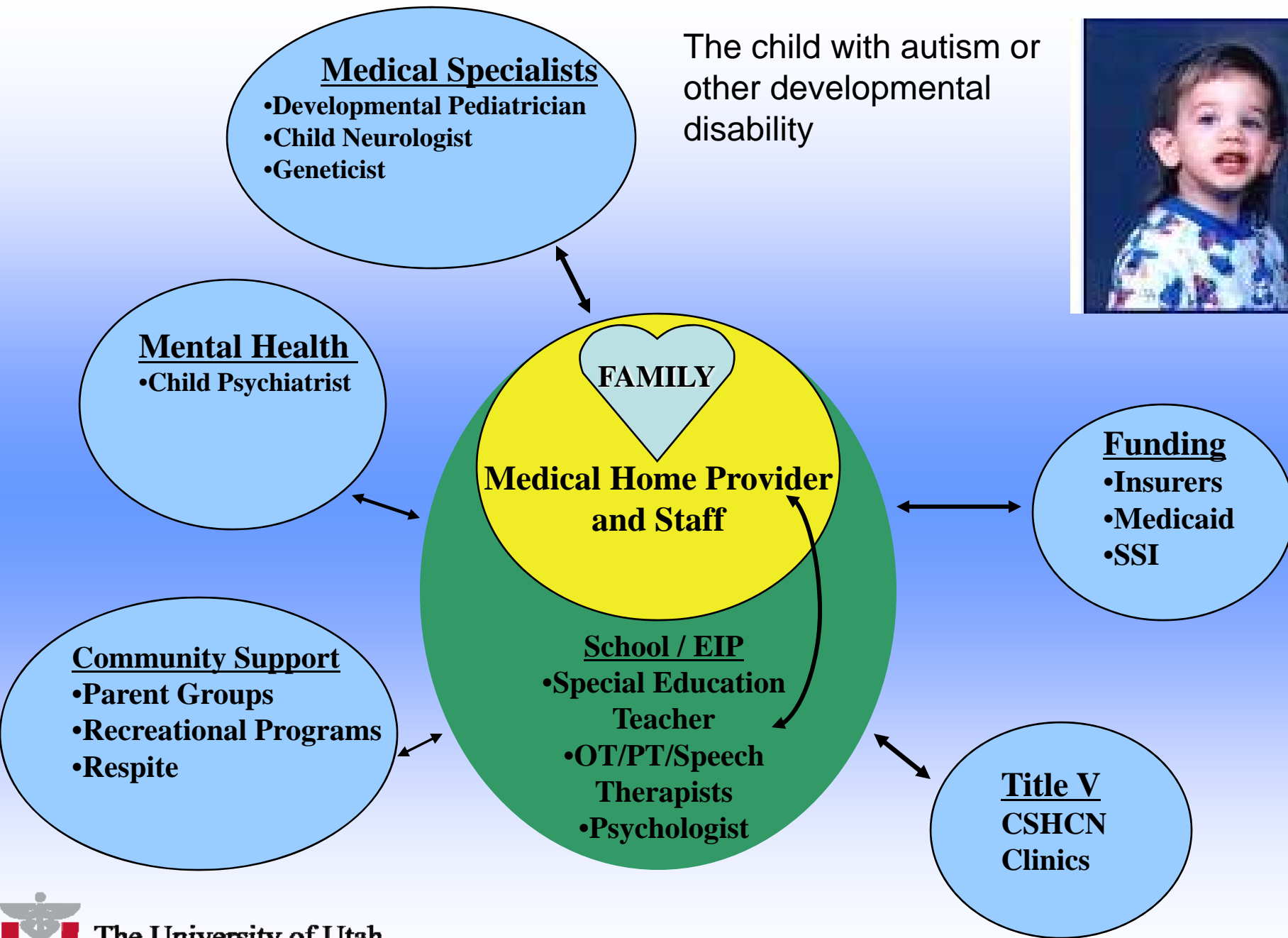
- **accessible**
- **continuous**
- **comprehensive**
- **family-centered**
- **coordinated**
- **compassionate**
- **culturally effective**



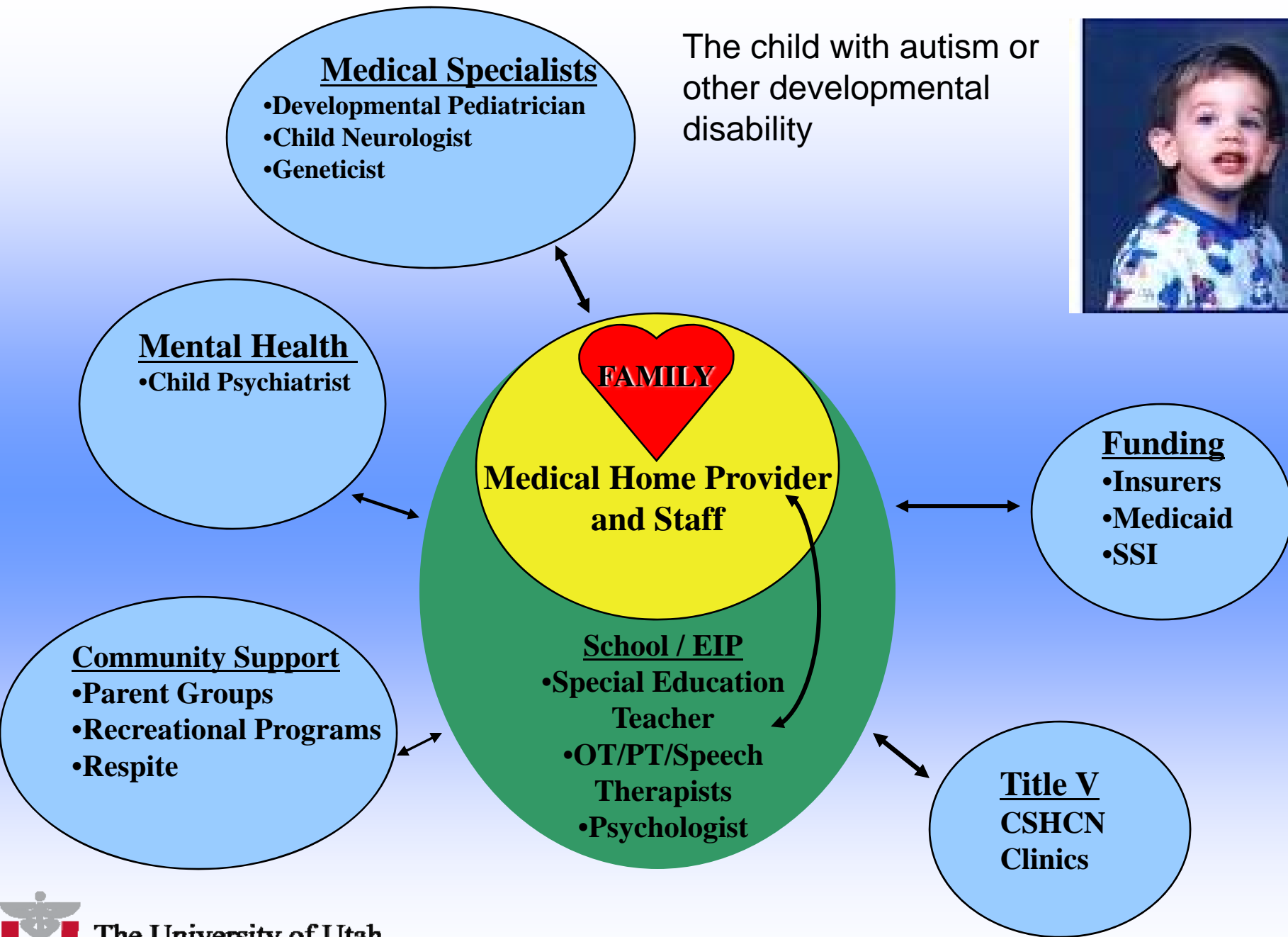
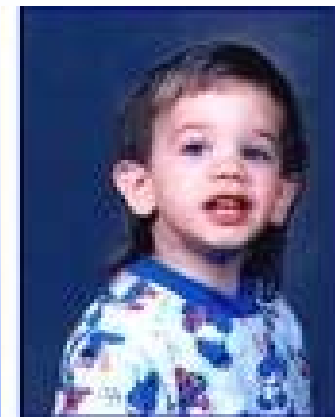
# The Healthy Child



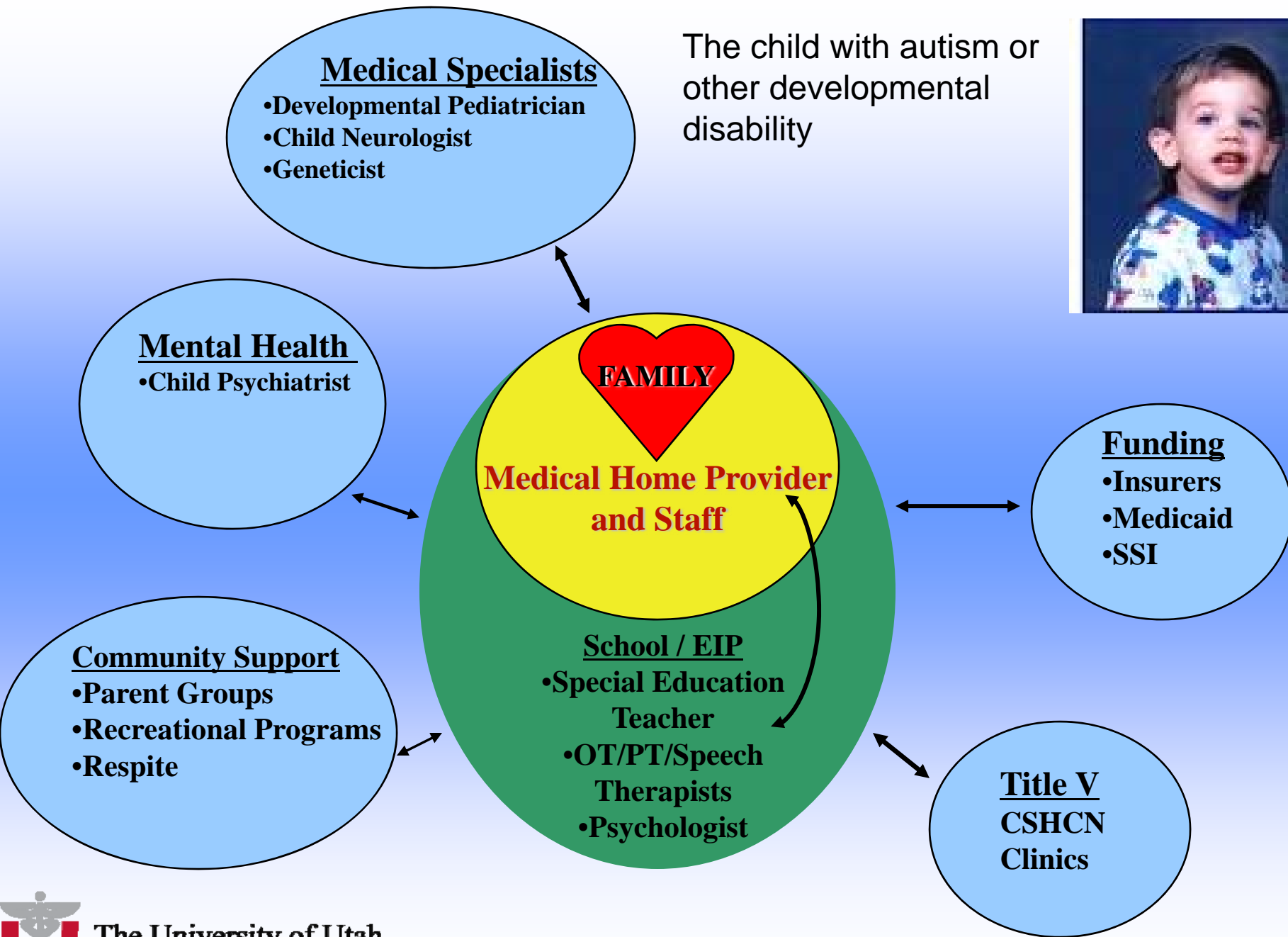
The child with autism or other developmental disability



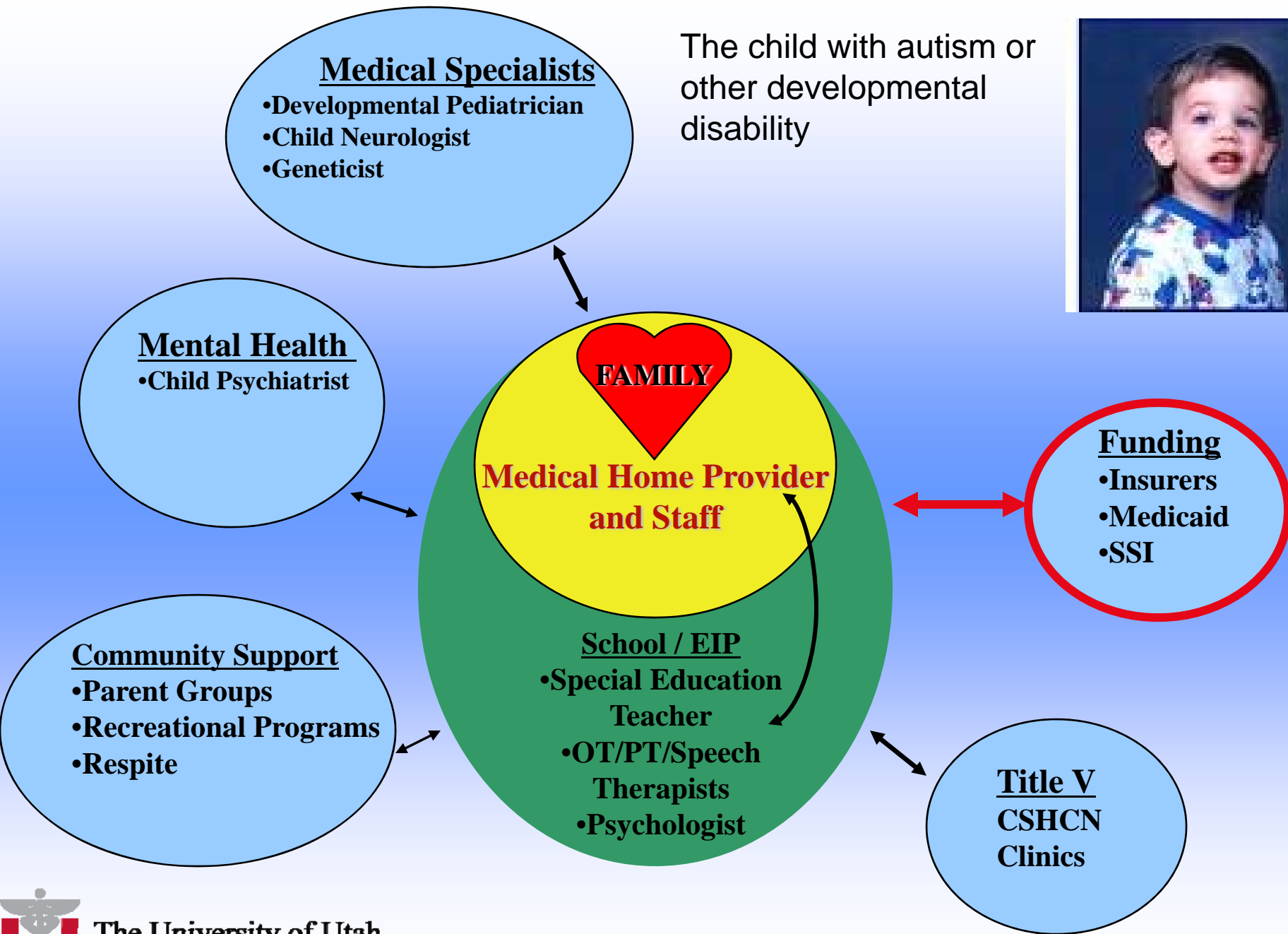
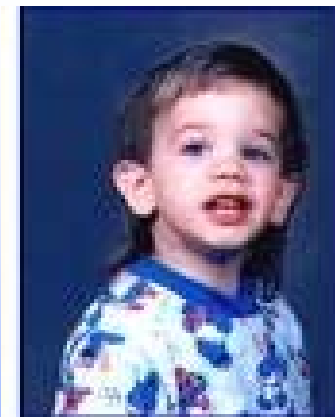
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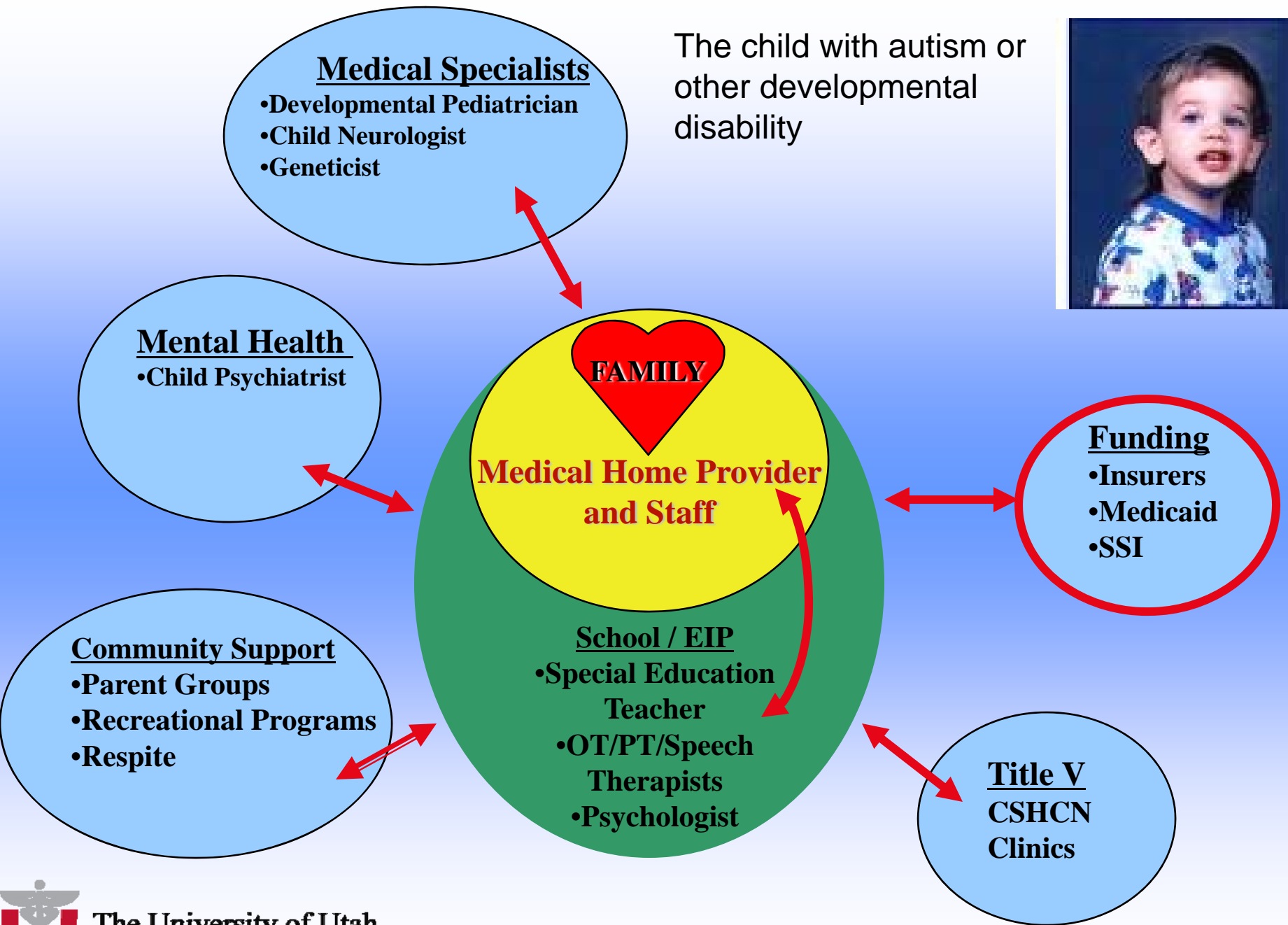


The child with autism or other developmental disability





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 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
  - 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?





- 32 pediatric practices each participate in a 6-month learning collaborative on autism and the medical home
- Expectations of Participants:
  - Learn the signs of autism spectrum disorders (ASD)
  - Perform ASD/DD screening during ALL 18-month and 24 month well visits
  - Develop a registry of children with ASD/DD
  - Implement a medical home approach for children with ASD and their families
  - Identify and partner with a parent in your practice



# 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 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 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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