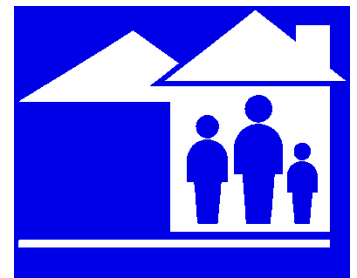


Opening Doors





**Judith Palfrey, Susan Foley,
Abdirahman Yusuf,
Deborah Leuchovius
SOS Meeting, Bethesda
November, 2008**

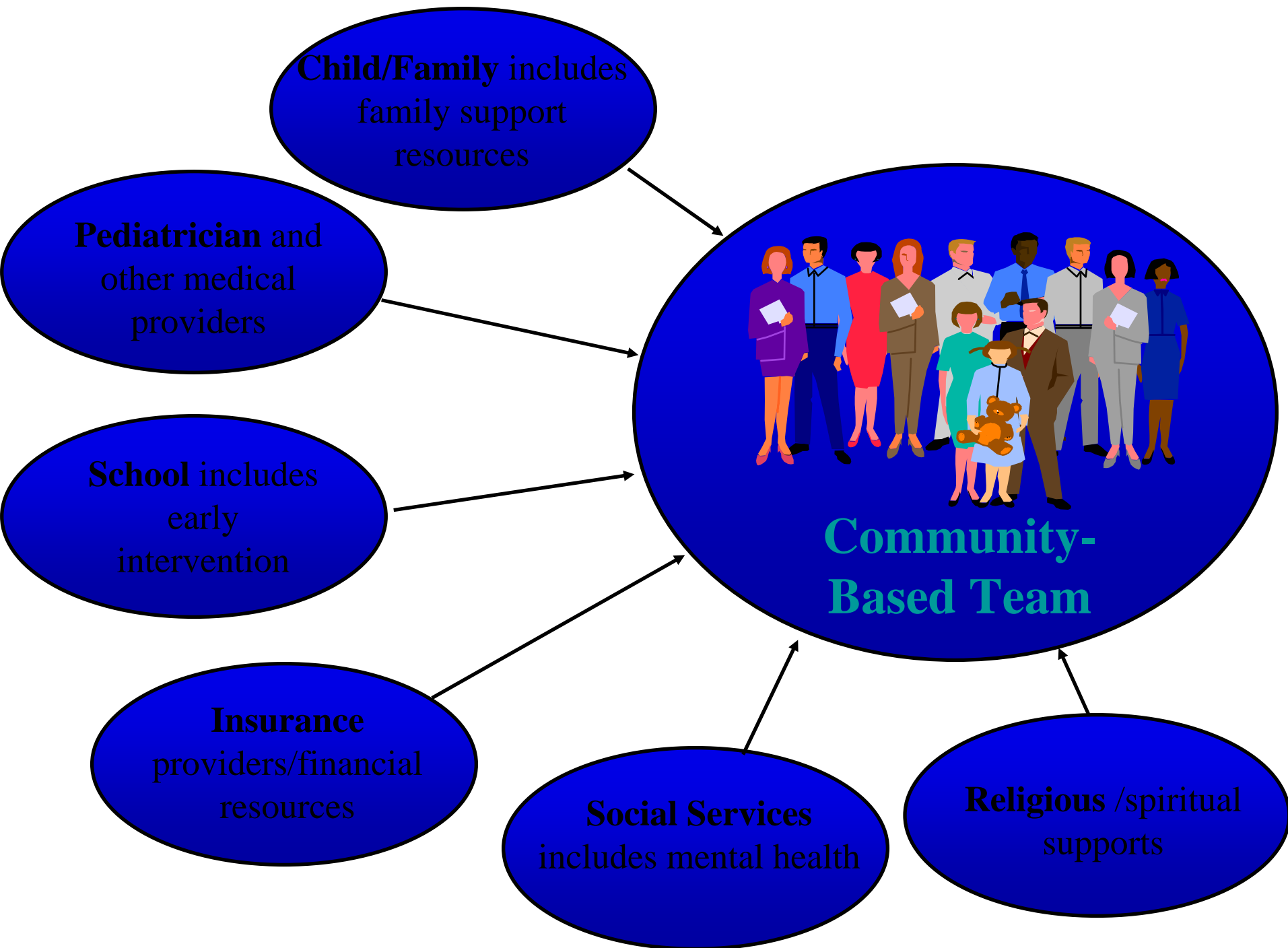
Introduction

- **A Focus of Medical Home is Community**
- **Data from National Surveys point to needs for community focus**
- **Working with Community Based Organizations on the National Center for Children with Special Health Care Needs and Disabilities**

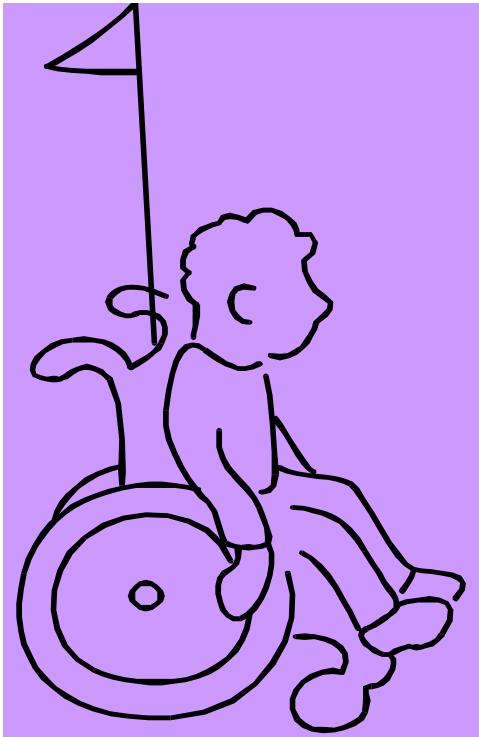


A Community Focus

-  **Children live and play and go to school in the community (“function, quality of life”)**
-  **Many health and health related services are now routinely delivered in the community**
-  **Prevention efforts are most effective when they involve local community partners**
-  **Increasing sophistication of families and communities in understanding of health**



Children with Special Health Care Needs



- Physical disabilities
- Blindness/deafness
- Mental retardation
- Developmental disability
- Complex medical conditions
- Assistance by medical technology

Family Centered, Community Based



- ☺ Family Counsel
- ☺ Social Services for Families
- ☺ Sib-ship Programs
- ☺ Respite Services
- ☺ Educational Workshops
- ☺ Group Sessions
- ☺ Parent to parent outreach
- ☺ Parent library and resources

Opening Doors

- **Reaching Out to Traditionally Underserved Communities**
- **Working with Parents, Youth and CBOs**
- **Three Projects:**
 - **Screening for Developmental Disabilities**
 - **Mentored Inclusive Recreation**
 - **Opt4College**

Questions for the Future

- **How do we move the research agenda forward to ask the questions most on the minds of families and the community?**

Questions for the Future

- **How do families and community based organizations use research such as Opening Doors and the other projects presented here in their daily lives?**

Questions for the Future

- **What recommendations for funders and policymakers do we as partners in research have to make?**