# What Do Parents Want Us to Know?



2009 Annual Early Hearing Detection & Intervention Conference March 9-10, Dallas TX

### **Research Study**

**Funded through:** 

Association of University Centers on Disabilities Cooperative Agreement with CDC's National Center on Birth Defects and Developmental Disabilities

## **Principal Investigators**

Kathleen Bodisch Lynch, Ph.D. Partnership for People with Disabilities at Virginia Commonwealth University

#### Derek Chapman, Ph.D. Epidemiologist, Office of Family Health Services, Virginia Department of Health

## **Purpose of the Research**

- Database linkage
- Impact of diagnosis
- Service improvement



# **Today's Focus**

- Qualitative phase of study
- Method
- Sample



# **Interview Questions**

- 1. Demographics
- 2. Child's health status
- 3. Screening, assessment, and diagnosis
- 4. Intervention decisions



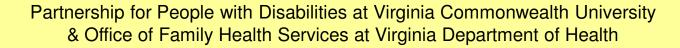




# **Key Questions**

What do parents want other parents to know?

What do parents want <u>health</u> professionals to know?





# What Parents Should Know

- Accept reality and move forward
- Educate yourself
- Make your own decisions



#### What Parents Should Know (cont'd)

- Seek out specialists
- Get early intervention
- Be your child's advocate



Connect with other parents

# **Most Important for Parents**

- Be positive
- Hold high expectations
- Enjoy your child!!



#### What Health Professionals Should Know

- Make the process less daunting
- Provide information early on
- Coordinate with each other



#### Most Important for Health Professionals

- Respect parent choices
- Put yourself in our shoes
- See the child's possibilities



# Other

- Quality of care
- Quality of services
- Health insurance

coverage



# **Other Project Personnel**

- Susan Murdock, Ph.D., VCU
- Natsuko Ryosho, MSW, VCU
- Monica Uhl, M.A., VCU
- Andrea Alvarez, MPH, VA Dept. of Health
- Caroline Stampfel, MPH, VA Dept. of Health

# **Contact Information**

- Kathleen Bodisch Lynch, Ph.D.
  Partnership for People with Disabilities at Virginia Commonwealth University kblynch@vcu.edu
- Derek A. Chapman, Ph.D.
- Office of Family Health Services
- Virginia Department of Health
- Derek.Chapman@vdh.virginia.gov