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
5. Impact on family life
Key Questions

What do parents want other parents to know?

What do parents want health 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