What Do Parents Want Us to Know?



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Research Study

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

Principal Investigators

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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



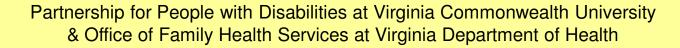




Key Questions

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

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