THE TELABILITY PROJECT

NEEDS ASSESSMENT

FOCUS GROUP REPORT

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NOTE: *THIS IS AN ABRIDGED VERSION OF THE FOCUS GROUP REPORT. ONLY THE OUTLINES AND NARRATIVE SUMMARIES OF PARENT AND THERAPIST FOCUS GROUPS ARE PRESENTED HEREIN. THE ACCOMPANYING TRANSCRIPTS ARE AVAILABLE IN THE FINAL HARD-COPY VERSION AND WILL BE POSTED ON THE TELABILITY WEBSITE.*

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[ABRIDGED]

CONTENTS

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INTRODUCTION

The TelAbility Project is an innovative, interdisciplinary healthcare delivery system that will utilize telecommunication technologies to improve the lives of children with disabilities. Using real time video-conferencing and web-based instructional technologies, the goal of the project is to provide comprehensive, coordinated, family-centered clinical consultations to children with special health care needs in a community-centered program. At the same time, we will provide local educational and training opportunities for their primary care providers, allied health professionals, and community service providers.

The core value of TelAbility is to utilize new information and communication technologies in ways that are responsive and accountable to the needs of children with disabilities, their families, and the health care professionals who care for them in the state of North Carolina. Accordingly, the first phase of the project has been to meet with families and therapists throughout the state and find out directly from them the key areas where they require assistance. This report summarizes the results from the focus groups and will serve to guide the development and design of services and resources that will be offered to families and therapists.

THE FOCUS GROUPS

Victor Braitberg (UNC Dept. of Anthropology) and Lynn Whitener Ph.D, (Cecil G. Sheps Center for Health Services Research) conducted the focus groups. They held a total of six sessions: five at United Cerebral Palsy sites in Raleigh, Sanford, Charlotte, Wilmington and Fayetteville, and one at the Developmental Evaluations Center in Boone. At each site, they met with parents and therapists, separately, and for one hour each. Therapist groups ranged anywhere from 4 to 12 and parent groups ranged from 1 to 6 in attendance. Victor led the sessions and Lynn provided support (consent forms, tape recorder, notes). The questions were open-ended, allowing participants considerable freedom to choose the issues and concerns they wished to discuss. The following questions structured the sessions.

FAMILIES

- What are the major challenges in meeting the needs of your child?
- What resources do you use and how do you access those resources?
- Are there needed health services that you do not have access to or have insufficient access to?
- What additional resources do you need?

THERAPISTS

- What are the major challenges you face in providing quality services to children?
- How do you meet these changes?

- What resources do you use to assist you?
- How do you access these resources?
- What are the resources that you need that are not available to you?

SPECIFIC PROBES

- How often do you consult with other practitioners?
- How do you select practitioners for consultation?
- How frequently do you attend (access) continuing education programs?
- Do you need additional access to continuing education?
- Are you satisfied with your current level of access to consultation and continuing education?

THE REPORT

This report documents how North Carolina parents and therapists view the many challenges involved in providing care and support to children with special needs. Described are the challenges that they face, the resources they rely on for support, and their unmet needs. The report is composed of short narrative summaries of parent and therapist focus groups as well as longer edited transcripts that provide the reader a more in-depth account of the challenges faced by therapists and parents—in their own words.

The report is composed of the following two sections.

Section One contains:
* Outline of parent focus groups.
* Narrative summary of parent focus groups.
* Edited Transcript of parent focus groups.

Section Two contains:
* Outline of therapist focus groups.
* Narrative therapist of parent focus groups.
* Edited Transcript of therapist focus groups.

SECTION ONE

OUTLINE OF PARENT FOCUS GROUPS

A. CHALLENGES

A 1.0 LEARNING TO LIVE WITH A DISABILITY
- **A 1.1** The Struggle to Redefine What's Normal

A 2.0 ACCESSIBILITY OF MEDICAL SERVICES
- **A. 2.1** Inadequate Insurance Coverage and Delays in Obtaining Services
- **A 2.2** The Financial Burden of Obtaining Services
- **A 2.3** Accessing the Tertiary Medical Center is a Hardship

A. 3.0 QUALITY OF MEDICAL SERVICES
- **A 3.1** Local Providers Lack Expertise
- **A 3.2** Coordinating Service-Delivery

A 4.0 STEPS TOWARDS A PARENT-CLINICIAN PARTNERSHIP
- **A 4.1** Physicians Need to Take a More Collaborative Approach to Working with Parents
- **A 4.2** Too Many Choices, Not Enough Opinions
- **A 4.3** Support for Getting the Most Out of Therapy and Equipment
- **A 4.4** Clinicians Often Fail to Consider the Emotional Impact/Therapeutic Value of Diagnoses and Prognoses

B. RESOURCES FOR MEETING CHALLENGES

B.1.0 PARENTS DRAW ON A WIDE RANGE OF PUBLIC, PRIVATE, AND PERSONAL REOURCES

C. UNMET NEEDS

C 1.0 CASE MANAGEMENT
- **C 1. 1** Help with Planning and Managing Services

- **C 1.2** Insurance Advocate
- **C 1.3** Mental Health Support

C 2.0 FAMILY SUPPORT

- **C 2.1** Getting Husbands More Involved
- **C 2.2** Siblings in Need
- **C 2.3** Respite Care

C 3.0 COMMUNITY INTEGRATION

- **C 3.1** Transitioning to the Public Schools
- **C 3.2** Access to Recreational Opportunities

C 4.0 NEED CONVENIENT AND RELIABLE ACCESS TO INFORMATION ON SERVICES AND RESOURCES

- **C 4.1** Need Access to Information on the Availability of Therapy, Equipment, and Services
- **C 4.2** Lack of Reliable Info on Internet
- **C 4.3** Networking with Other Parents

SECTION ONE

NARRATIVE SUMMARY OF PARENT FOCUS GROUPS

A. CHALLENGES

A 1.0 LEARNING TO LIVE WITH A DISABILITY

- Parents are faced with the considerable challenge of learning how to balance their work-life and family-life with negotiating a never-ending series of appointments and assimilating mountains of information.

- Equally difficult, is to adapt and redefine their lives in meaningful ways that challenge the social stigma of having a child with a disability.

A 2.0 ACCESSIBILITY OF MEDICAL SERVICES

- Many parents with modest incomes and private insurance are caught in the double- bind of not having therapy services reimbursed by their insurer while at the same time being ineligible for entitlement programs due to their income level. Consequently, those children whose parents lack adequate insurance and/or the means to pay for therapeutic services will fail to gain access to the treatments and equipment that they require during critical phases of their development.

- Parents are frustrated with the delays and complexities of applying for entitlement programs and insurance reimbursement. Waiting lists for entitlement programs can take up to two years. Those parents who do benefit from entitlement programs are discouraged by the lengthy delays they experience when requesting augmentative communication devices and/or assistive technologies. And in other cases, requests are simply refused.

- Parents without adequate insurance coverage are faced with a considerable financial burden.

- The trip to the tertiary medical center is time consuming and costly. This presents a particular hardship for working parents. The medical center experience is characterized as a confusing and intimidating maze of corridors and buildings. Many parents would rather not make the trip to the Medical Center, especially for routine follow-ups.

A 3.0 QUALITY OF MEDICAL SERVICES

- There is a strongly expressed need among these parents for improved access to professionals with greater expertise in dealing with children with special needs. Local providers and facilities are ill-equipped to address the child's needs and in many cases are unable to provide information on where or how to obtain needed resources. local physicians are far from consistent in providing referrals when they are most needed.

- ❖ Parents face the hardship of having to plan, manage, and prioritize appointments with a broad range of widely scattered services and providers. With separate institutions and care providers seeing their child for discrete issues, parents often they find themselves playing the role of service coordinator.

A 4.0 STEPS TOWARDS A PARENT-CLINICIAN PARTNERSHIP

- ❖ Parents feel that medical professionals should make more of an effort to collaborate with them in addressing and managing the needs of their child. Physicians should recognize the expertise of parents and include them as true partners in the treatment of their child.

- ❖ Physicians are reluctant to give opinions or directives and therapists too often defer to the physician's authority. Parents are given a bewildering array of choices instead of opinions regarding the best course of treatment. Clinicians feel more comfortable "dropping hints" regarding needed treatments and services, rather than making direct suggestions. In other cases, parents need to receive clinical feedback in a more timely fashion.

- ❖ Parents need more support with integrating treatment recommendations as well as assistive and communicative devices into the child's daily routines.

- ❖ Too often, physicians to be emotionally insensitive when giving them feedback regarding their child's development. Clinicians need to make more of an effort to consider how the emotional impact of the child's diagnosis will affect the ability of parents to cope with their situation.

B. RESOURCES FOR MEETING THE CHALLENGES

B 1.0 PARENTS DRAW ON A WIDE RANGE OF PUBLIC, PRIVATE, AND PERSONAL RESOURCES

- ❖ For therapy services they rely on staff at United Cerebral Palsy and other developmental day-centers, Tertiary Medical Centers, some of the DECs, and contract therapists from the community.

- ❖ For equipment, they rely on sources such as Rehab Solutions, CAP and other parents.

- ❖ For general information on the availability of services, treatments, financial reimbursement, and family support, parents rely on a wide variety of sources including but not limited to:

  - Local and medical-center physicians.
  - Staff at the UCPs, DECs, and tertiary medical centers.
  - Other parents.
  - Family Members and friends.
  - Family Support Network.
  - DHSS, County Health Department, Mental Health

C. UNMET NEEDS

C 1.0 CASE MANAGEMENT

- ❖ Parents need to be supported in their struggle to adapt their lives to the demands of planning and managing services for their child. They need advocacy support in finding strategies for getting necessary services and equipment from insurance companies and/or entitlement programs. Much needed mental health services to support the emotional burdens of caring for a special needs child remain largely unavailable.

C 2.0 FAMILY SUPPORT

- ❖ Mothers are struggling to find ways of getting their husbands to become more involved and take greater responsibility for the care f their child

- ❖ The impact of their child's disability on siblings is an issue parents have received little if any support for.

- ❖ Respite care is a much needed service that is difficult to obtain.

C 3.0 COMMUNITY INTEGRATION

- ❖ Parents whose children have aged out of UCP and gone on to public school have felt ill-equipped to handle the transition well.

- ❖ Access to recreational opportunities in the community are very limited. Parents would like their children to have greater access to opportunities for socialization and community based activities.

C 4.0 CONVENIENT AND RELIABLE ACCESS TO INFORMATION ON SERVICES AND RESOURCES

- ❖ Access to information on the availability of therapies, equipment, and funding sources remains a continuing struggle. Parents often don't know where to go to find needed information.

- ❖ Parents would like to have enhanced access to information on training's and educational seminars that address feeding, communication, and mobility issues.

- ❖ Many parents look to the internet as a means of overcoming the information deficit but are often disappointed due to the poor quality of available information.

- ❖ Parents would like to have more opportunities to meet and help each other address issues and access resources.

SECTION TWO

OUTLINE OF THERAPIST FOCUS GROUPS

A. CHALLENGES

A 1.0 FUNDING SOURCES: INSURERS AND ENTITLEMENT PROGRAMS
- **A 1.1** Inordinate Amount of Time Spent On Paperwork.
- **A 1.2** Inadequate Coverage and Delays in Obtaining Services

A 2.0 NEGOTIATING A FRAGMENTED SYSTEM
- **A 2.1** Parents Don't Understand the System
- **A 2.2** Coordinating Services Between Providers / Institutions
- **A 2.3** Inadequate Communication with Medical Professionals
- **A 2.4** Obtaining Records in A Timely Manner
- **A 2.5** Recognizing the Expertise of Local Therapists

A 3.0 LIMITS TO QUALITY AND ACCESSIBILITY OF MEDICAL SERVICES AND EXPERTISE
- **A 3.1** Poor Quality of Local Pediatric Resources
- **A 3.2** Local Medical Providers are Unfamiliar with Available Services and Resources
- **A 3.3** Patient Access to Services is Limited by Inadequate Transportation
- **A 3.4** Inadequate Access to Augmentative Communication and Assistive Technologies
- **A 3.5** Difficulties Accessing Information on Specialized Diagnoses and Treatments
- **A 3.6** Inadequate Access to Consultations
- **A 3.7** Limits to the Quality and Accessibility of Continuing Medical Education

B. RESOURCES FOR MEETING THE CHALLENGES

B1.0 RETHINKING THE DELIVERY OF SERVICES
- **B 1.1** Training Parents, Teachers, and Early Interventionists
- **B 1.2** Reaching out to Under-Served Children
- **B 1.3** Educating the Medical and Lay Communities

B 2.0 RESOURCES FOR CONSULATIONS AND CONTINUING MEDICAL EDUCATION

- **B 2.1** Consultations
- **B 2.2** In-House Resources
- **B 2.3** Community Resources
- **B 2.4** Continuing Medical Education

C. UNMET NEEDS

C 1.0 COORDINATING SERVICES AND ACCESSING EXPERTISE

- **C 1.1** Case Management/ Coordination of Services
- **C 1.2** Consultation
- **C 1.3** Shortage of Pediatric Services
- **C 1.4** Reliable Sources of Medical Information from the Internet

SECTION TWO

NARRATIVE SUMMARY OF THERAPIST FOCUS GROUPS

A. CHALLENGES

A 1.0 FUNDING SOURCES: INSURERS AND ENTITLEMENT PROGRAMS

- Insurers and entitlement programs determine how much therapy can be provided and what kind of equipment and/or devices will be made available. Therapists are frustrated with having to deal with the resulting increase in paperwork demands that take time away from providing direct services. Complicated and lengthy applications for equipment frequently delay the arrival of devices that are developmentally-specific and crucial to making therapeutic progress. Most importantly, many children are under-served because of inadequate insurance coverage.

A 2.0 NEGOTIATING A FRAGMENTED SYSTEM

- Therapists struggle on a daily basis to ensure that all the various providers and institutions involved in providing care for children and their families are aware of what each is doing. They work with parents on a daily basis to help them understand how different services and providers are connected and how they can be used to improve their child's outcome.

- Therapists find it difficult to coordinate what they are doing with the child locally with the therapeutic interventions initiated by outside providers. Communicating with physicians, especially those from the tertiary medical center, is difficult and time consuming. Medical records are often difficult to obtain in a timely manner.

- Therapists would like medical professionals from the tertiary medical center to recognize their expertise and make more of an effort to include them in decisions regarding the child's treatment.

A 3.0 LIMITS TO QUALITY AND ACCESSIBILITY OF MEDICAL SERVICES AND EXPERTISE

- Local pediatric services are limited in scope. Children are treated by inexperienced therapists that result in questionable outcomes. Local medical professionals are unfamiliar with available services and resources that are relevant to the special needs population. This has a negative impact on timely and appropriate referrals.

- Due to inadequate transportation, parents have difficulty accessing services located outside of their area. Access to augmentative communication devices and assistive technologies is limited. Information on specialized diagnoses and treatments is difficult to obtain.

- Access to consultations is limited due to time constraints and accessibility of therapists. Accessibility of continuing medical education is limited by cost and time constraints.

B. MEETING THE CHALLENGES

B 1.0 RETHINKING THE DELIVERY OF SERVICES

- In their attempts to deal with the challenges of insurance, reimbursement, and the fragmentation of services, therapists have had to rethink how they provide services to children who are often under-served.

- The strategies they have adopted range from training parents, teachers and early intervention workers to take on a greater percentage of therapy, to educating the local medical and lay communities about the needs of children with disabilities and the range of providers that serve them.

C. RESOURCES

C 1.0 RESOURCES FOR CONSULATIONS AND CONTINUING MEDICAL EDUCATION

- We found that all of the United Cerebral Palsy sites, except for Charlotte and Sanford, expressed satisfaction with access to pediatric therapists for consultation.

- Therapists from different disciplines routinely consult with colleagues from their home UCP as well as the local DEC. Each site has access to a varying range of study groups, associations and consortiums of pediatric therapists. A broad range of in and out-of-state resources are relied upon for meeting the continuing medical education needs of therapists. AHEC was most often cited by DEC therapists as a cost-effective resource. DEC therapists have access to the internet and some utilize it for accessing clinical information. UCP therapists in Charlotte, Raleigh, and Wilmington have access to the internet and some use it for clinical information.