



The Family Voices in SCHIP Telemedicine Report

Bridges, Not Boundaries The Value and Use of Telemedicine for Children/Youth with Special Health Care Needs

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Preface

The Family Voices in SCHIP Telemedicine Report has grown out of an interest by Family Voices members in health care policy that impacts children/youth with special health care needs. Many families have become involved over the past few decades in assuring family-centered care at their hospitals, making sure they could be available to their babies and children/youth while they were receiving needed medical attention. Some have also become active on committees addressing topics such as health care planning and policy within their state health programs, the development of managed care plans' policies, and the implementation of health insurance under the SCHIP legislation in their states. Since Telemedicine is now becoming more common and can be covered by Medicaid and SCHIP in more states, the Family Voices in SCHIP Implementation staff started to look at the issues for providers and families around the use of telemedicine. Most of the available literature stressed its value and usefulness, so FV decided to look more closely to be sure that families were being involved in the planning, implementation and ongoing progress of these telemedicine programs. Many hospitals serving children/youth and neonates were designed and developed without family input only to open to disappointment when families found their own preferences and needs were not addressed. But families have been increasingly involved with hospitals and health departments as advisors over the years. (1) One hospital planner stated that it was usual to consult hospital users, but the term "users" meant doctors and nurses. A parent advisory committee worked with the planners on the design of the Children Hospital in Boston in the 1980's to the benefit of all. (2)

Like other design projects, a telemedicine innovation at a clinic, hospital, or school requires equipment, staff, and program planning. Our report consolidates information from many projects whose staff generously and honestly shared their ideas and experiences with us. We have also asked families whose children/youth have special health care needs to list what information and conditions would be important to them in a new telemedicine experience if it were available. In addition, we have asked parents, both with and without direct telemedicine experience, to be reviewers and participants in evaluating and making suggestions to the family materials within. (The Family Checklist and Family Satisfaction Instrument.) We believe this report will be useful to those considering or implementing a project, as well as those with ongoing projects. They can incorporate family views, those expressed in this report, and by seeking out and obtaining input from the families who might be likely to be served. While caring health professionals can be practical about areas families might find crucial, only when presented with the plans can families give their own opinions. Often, the type of suggestions families have can be insightful and even less expensive than others expect. Also, since telemedicine will include in its planning the skills and background of more technical staff who set up equipment, run the machinery, and keep the programs quality high, there will be a need to orientate those new staff to the basic issues of pediatric development, family-centered care principles, and aspects of privacy and confidentiality as they apply to minors. The recommendations developed for this report reflect the views of many parents who have been in many health settings with their children and who acknowledge that telemedicine reflects the current technological progress of our

times. They also are committed to family-centered care that recognizes the importance of family determination in the care of their children.

Over a period of six months, questionnaires were sent to 20 telemedicine projects. After interviewing 12 project directors/providers at length nationwide; culling information from several pertinent articles, project reports and websites; speaking informally with several well-informed and well-respected leaders in the field of children/youth with special health care needs and telemedicine; and meeting with three physicians involved in telemedicine initiatives, we developed a report to share insights regarding the potential, the pitfalls, the realities and the hopes for telemedicine's role in providing medical care to children/youth with special health care needs. This report points out the strengths as well as the caveats of telemedicine, provides answers as well as asking important questions. Its audience is intended to be families, who are always striving to seek out care that is accessible, affordable, family-centered, competent and collaborative. This report is also for the project directors of telemedicine initiatives, old, new and incipient, who were very willing to entertain suggestions and comments from us as to how to improve their programs from a family viewpoint. We also wrote this for the federal agencies that funded us to give them information, delineate pros and cons of telemedicine, and examine the family perspective as well as Family Voices recommendations for the future. Families will help shape the future of telemedicine as it pertains to children with special health care needs. The best result would be for these groups to work together to develop policy and programming for future directions in the best interests of children.

Beyond the definitions of telemedicine, we looked at what telemedicine projects had to say in response to our survey instrument. The questions included the following: What do you see as the benefits of telemedicine for children with special health care needs? What do you see as detriments? What are the advantages of telemedicine for doctors/health care providers? Are there any disadvantages?; What is your environment like: Is it child friendly?; Are parents allowed to be present at all times?; How do you protect privacy and confidentiality?; Which types of health and educational professionals participate in telehealth sessions?; Who runs the session?; Do you have any advisory committees relate to your project?; Who comprises the committee?; How do you prepare kids/parents for a telehealth visit?; Do you have any program for preparation?; What is the level of satisfaction among parents?; Is it surveyed?; How do you see the caregiver-patient-family relationship being affected?

We also gathered information from parents who have utilized telemedicine services as well as from parents who have had considerable experience with health care. They shared positives and negatives of their visits as well as important things to think about when deciding to use telemedicine including preparation and parents' roles. We spoke with practitioners as well as made site visits to programs utilizing unique telemedicine/telehealth applications in emergency rooms, day care facilities and Neonatal Intensive Care Units and got some important insights as to the helpfulness and usefulness of this technology to families in these special situations.

Family Voices' recommendations are included as conclusions from this study.

- 1. Medical Home --Well-designed Telemedicine programs, as part of an integrated health services delivery system, can help create Medical Homes for children/youth with special health care needs.**
- 2. Access for Everyone --Telemedicine eliminates barriers and brings together subspecialists with unique expertise with children/youth with special health care needs and their primary care team.**
- 3. Family Advisory Roles--As telemedicine projects become more fully realized and funded, and as they become a more recognized part of an integrated health care delivery system, folded into the every day care of patients and not just a stand-alone service, the role of families will be crucial. Family advisory committees will need to be formed, if not already in existence.**
- 4. Privacy and Confidentiality—Families require guarantees of privacy and confidentiality protections in these new settings from all professionals.**
- 5. Preparation of Family—The more information and preparation families and children/youth have, the better and more comfortable the visit and, possibly, the more accurate the results.**
- 6. Technology—Because technology is at the crux of a telemedicine visit, providers and families alike need to look at and understand the ways that telecommunication technologies can both enhance and hinder a visit.**
- 7. Neonatal Intensive Care Unit (NICU)—Use of telecommunications in the NICU is worthwhile for families in terms of family contact, support, information and education.**

Bridges, not Boundaries: The Value and Use of Telemedicine for Children/Youth with Special Health Care Needs

If family- centered coordinated care is a goal of medicine, and most surely it is for children/youth with special health care needs, then telemedicine is one vehicle that can move that goal forward.

As parents and professionals, as caregivers and caretakers, we know what serves children/youth with special health care needs and their families well. This model of integrated delivery and comprehensive systems of care is a goal that has inched its way towards reality, slowly but surely. The *American Academy of Pediatrics* (AAP) and the federal Maternal and Child Health Bureau are promoting the concept of a Medical Home for each child with a special health care need (www.aap.org). While not a building or place, a Medical Home is a set of services that assure care that is accessible, family-centered, comprehensive, continuous, coordinated, compassionate and culturally effective. With these conditions met, children/youth would be able to live in the community with their families having care readily available to meet their health needs. While the list of components seems long, these descriptions describe what most of us assume is already taking place. But for families living in poverty, far from a medical center, or having transportation difficulties, even routine care for a child with special health care needs could be fragmented and inadequate. A great deal of effort is being placed on a program to educate providers and families about the Medical Home.

As we move past the infancy of the 21st century, technological progress booms and the medical world has kept pace. Telemedicine, which has been utilized in the health care field for well over a decade, but only fairly recently for the population we focus on, is one such a technological advance. For the child with special health care needs and his/her family, it has the remarkable potential to help address and meet medical and non-medical needs precisely because of the capabilities of this technology. To be sure, there are glitches and concerns. Can high-tech and high-touch work together? Can distance care elicit comfort and confidence in a patient and his/her family? But one thing we do know. As delivery of health care to unserved and underserved children/youth with special health care needs is improved and redefined, and the insurance reimbursement picture becomes clearer; telecommunications technology can bridge the gaps and blur the boundaries of who gets served, where they are served and how well they are served.

We know the challenges that we've faced with our children/youth, the challenges that lie ahead: inadequate access, lack of quality care, segmented services, time and undue delays in scheduling, travel expenses, family separation, and insurance. Can we overcome some of these hurdles utilizing telemedicine? In this paper we will discuss all of these things. From the provider perspective and from the parent viewpoint, we will offer insights into this technology. We will offer the Family Voices perspective on what we've learned from research into this area. We will make recommendations to projects based on our interviews and research and we will also make recommendations to parents to help think about utilizing this system of health care delivery. And we will look at the potential of telemedicine to be an integrative part of an effective, efficient and family-oriented health care delivery system for the child with special health care needs.

The first step, however, is to briefly define what exactly telemedicine and telehealth are.

Telemedicine

- **Telemedicine refers to the use of electronic communication and information technologies to provide or support clinical care at a distance. (3)**

Telehealth

- **Telehealth, a broader concept refers to the use of electronic information and telecommunications technologies to support long-distance clinical health care, patient and professional health-related education, public health and health administration. (3)**

As we look at the definitions, we should be looking at what telemedicine *really* means for families, patients and providers.

Well-designed telemedicine offers:

- a community based service system
- a way to lessen costs including travel and child care
- less missed work or school
- a more collaborative approach to medical care
- a natural means of improving communication between families, local providers and subspecialty providers
- increased access to medical specialists and pediatric subspecialists
- technology providing viable solutions to improving the quality of health care
- unserved and underserved populations becoming well-served by an integrated delivery system
- a virtual Medical Home* where interdisciplinary care can occur easily in a coordinated family-centered manner.
- a way to establish partnerships, including families
- health care providers, through various means of telecommunications, can provide medical services to patients at remote sites or between two or more sites.

At its best, telemedicine helps develop a true partnership between the family, the primary care physician and/or nurse, the community and the specialists. At one time, at one place, all eyes focus on the child.

Telemedicine AND telehealth offer the following applications through videoconferencing, which usually is an interactive give and take using audio, video and other electronic media:

- developing Medical Homes through consultation and coordination between specialists, community based care providers and the family
- assessments
- evaluations
- consultations
- follow-up appointments
- diagnosis and treatment
- patient education
- distance learning for health care professionals
- staff development
- newborn baby/parent contact
- discharge planning
- family support
- preventative care
- post operative care

Telemedicine has its own terminology, some of it quite technical. For those new to this area of telecommunications, and for those families interested in obtaining a telemedicine visit for their child here are a few terms that might be useful for the layperson. Thank you to the Office for the Advancement of Telehealth, the Association of Telehealth Service Providers and the projects themselves for providing much of this information.

On average, telemedicine involves physicians, both primary care and specialists, nurses and other health care professionals using technology to treat, evaluate, consult with, and diagnose patients who are at another, not necessarily a remote site. The interactive video and audio components (videoconferencing) that are used to communicate between patients, families, medical and other collaborative personnel are generally and simplistically, television monitors, telephones, keyboards, microphones and cameras. Besides this real-time communication, which means sending and receiving voice, picture and data in less than a fraction of a second, there are store and forward mechanisms which transmits audio/video clips as well as data such as x-rays and other patient information at a later date for review and examination by a practitioner.

The most common types of phone service used by telemedicine/telehealth programs to transmit images and data are:

T-1 line: A leased communication line that is dedicated from point-to-point 24 hours a day.

ISDN (Integrated Services Digital Network): Allowing a dial-up connection providing digital phone service at high speed.

POTS: Plain Old Telephone system: The analog, public switched telephone network in common use for voice, fax and modem use. Allows limited videoconferencing.

Videophone: Small, stand-alone video appliance with a small camera and circulation, not part of a computer, enabling limited and low resolution interactive audio-video communications

technology progresses in a lightning fashion and telemedicine becomes more useful and better integrated into the medical care continuum for children/youth with special health care needs, we, as parents and professionals, need to keep technological pace with the ways that telemedicine makes sense for our population, in terms of the clarity, resolution and speed of the transmission as importantly as what is being transmitted itself. Even since we began our research new applications have begun to emerge. In addition, and of no small importance, are issues of privacy and confidentiality of the telemedicine session itself, of the environs, of data transmitted and of the training of personnel (not just health care personnel, but technical staff), as well as safeguards in place to protect highly sensitive personal information.

We also need to keep pace with changes in insurance, funding sources, licensure issues, policy, and program issues. In this respect, if telehealth programs are to be family-centered, then parents can offer great expertise, knowledge, and, most of all, drive, in helping these programs develop and thrive. Interchanges between projects and parents, with parents in multitudes of advisory roles, will all push forward an agenda where the best interests of children/youth are served when it comes to access to good quality medical care. Telemedicine/telehealth can accomplish many, many things. There may be obstacles, but as they are overcome with a true partnership between projects and families, the boundaries will blur and the special health care needs of children/youth will be confidently met.

What Providers are Saying: The Findings of Projects/Providers

Over a period of six months we sent out questionnaires to 20 telemedicine projects. After interviewing 12 project directors/providers at length nationwide; culling information from several pertinent articles, project reports and websites; speaking informally with several well-informed and well-respected leaders in the field of children/youth with special health care needs and telemedicine; and meeting with three physicians involved in telemedicine initiatives, here are some insightful thoughts that were shared regarding the potential, the pitfalls, the realities and the hopes for telemedicine's role in providing medical care to children/youth with special health care needs. Listed are the questions followed by summaries of the discussions.

1. Does your project provide telehealth services to children/youth? Is there a focus on children/youth with special health care needs?

All of the programs we spoke with offer telemedicine services to children/youth in general and several offered dedicated services to children/youth with special health care needs. However, while we targeted those programs servicing this particular population, it should be noted that most hospitals/providers nationwide do not address the medical concerns of this group on a telemedical basis.

Services are provided across and within the disciplines: autism spectrum disorders, dermatology, plastics, child psychiatry, allergy/immunology, pulmonology, endocrinology, social services, nutrition counseling, behavioral, mental health, swallow/feeding, assistive technology, neuromuscular (traumatic brain injury, cerebral palsy, severe physical, sensory impairments), developmental disabilities, chronic conditions (diabetes, asthma), self-injury, neonatology visits, discharge planning, fetal ultrasounds, echocardiograms, and common childhood illnesses.

Services are provided in schools, day care facilities, in homes, in rural clinics, in community hospitals, in doctor's offices, in mental health centers, in emergency rooms, in tertiary care hospitals, Neonatal Intensive Care Units (NICU) and Pediatric Intensive Care Units (PICU).

2. How are you using telemedicine?

Most telemedicine directors discussed the importance of community-oriented medical care and making viable connections between subspecialists, family and local practitioners to ultimately provide the best health care for these children/youth. In that respect, they all felt telemedicine is a tremendous conduit.

Providers are using telemedicine for:

- Enhancing the development of the medical home model
- Follow-up in the community to in-person care received at large medical centers (tertiary care)
- Developmental evaluations/assessments
- Real-time consultation
- Regular pediatric care
- Multipoint conferences (i.e. state DOE, developmental specialists, children/youth and their families, psychiatry, speech, neurology all partnering together through videoconferencing)
- Case management
- Interdisciplinary care/evaluations/consultations
- Second opinions
- Feedback
- Treatment plans
- Medication management
- Physician-to-Physician Interactive collaboration
- Home care/self care

Telehealth, as telecommunications focusing on non-clinical aspects, is being utilized for:

- Web-based parent education
- Training of rural case managers/staff
- Distance learning/educational opportunities for rural health providers
- Peer support
- Health based chat rooms
- Medical education to rural providers
- Education conferences
- Physician to physician consultation
- Parent-to-hospitalized child televisits

3. What do you see as the benefits of telemedicine for pediatric patients and, specifically, children/youth with special health care needs? What do you see as detriments?

The benefits that were unanimously agreed upon by all projects and providers were access to specialty care, time savings, cost benefits, and community-based care. The other major advantage that providers and project directors were enthusiastic about was the ability of telemedicine to facilitate collaboration and multidisciplinary care and to involve all members of the child's TEAM, including the parents, at one time. This is an important element in terms of support, case management, communication and, education.

Benefits:

- Better access to subspecialty care, such as neurology or orthopedics
- Greater expertise at family's disposal
- Increased support for families
- Children/youth can stay in their own community
- Comfort level of staying in own hometown with providers they know and trust
- Advances family-centered medical home concept
- Enhances community –based services for rural and underserved children/youth
- Decreases fragmented care
- Focuses on whole child
- Minimizes cost factor for parents in terms of travel: parking, overnight stays, meals, gas, and childcare expenses
- Distinct difficulties traveling for children/youth with mobility issues
- Families no longer have to miss work or school
- Easier for parents
- Don't have to deal with poor travel conditions and terrain
- Some families wouldn't get services otherwise
- It is less distracting for the child
- Child doesn't get tired and fussy because it's not an all-day affair
- Eliminate the need for children/youth with multiple disabilities to make many trips
- Parents don't have to repeat child's medical history over and over
- Needs are met in a timely fashion
- Family has continuity and consistent relationship
- Complexity of a tertiary hospital or medical system is intimidating and confusing to some families. Some would rather avoid it. Extended family/teachers/anyone who interacts with child would more likely come to community site than distant hospital site
- Ability to communicate with all of caregivers at once in local community and tertiary site; community providers and subspecialists simultaneously
- Interdisciplinary evaluations and follow-up care/planning can better be achieved through telemedicine. Because of the complex nature of problems facing children/youth with special health care needs, collaboration between professionals across the medical and non/medical spectrum makes a lot of sense and provides opportunity for EVERYONE to learn and share and plan effectively.
- Clinical feedback is generally timelier because everyone is there at one time.
- Services are implemented more quickly.
- Little lapse time for interpretation and reports
- Kids are enthralled with being on TV and speaking with distance providers over TV

- Can make some diagnoses as though the doctor was in the person's home

Detriments:

- Doesn't completely replace the need for face-to-face consultation.
- Not as personal
- Limited to sight and sound
- First time jitters of being on TV and talking to TV
- Fear of the unknown
- Family Doctor is usually not involved: Usually only a nurse at rural site
- Technical difficulties
 - difficulty being able to communicate,
 - difficulty hearing others and seeing others.
 - camera angles/locations might not be appropriately set
 - camera jerking and blurring
 - failing audio/and or video

However, good telemedicine gives patients attention. Doctors have to focus with their eyes. You have to focus in. Patients get a huge sense of satisfaction that they've been listened to.

***Touch isn't as important as sense of attention –Mark Carroll**

4. What are the advantages of telemedicine for doctors/health care professionals? Are there any disadvantages?

Advantages:

Telemedicine advances the belief that all providers and health professionals can, with the parents, create an effective plan and continuum of care for a child with special health care needs. The interactivity, the real-time ability and the collaborative focus that telemedicine affords is exciting, makes good clinical sense and benefits not just the family, but the practitioners as well. (Many answers to this question regarding benefits and detriments of telemedicine are similar to the previous question, raising similar concerns but, also, reinforcing the potential of this medium.)

- Better access to care; not possible for specialists to travel to rural sites on a regular basis
- Eliminates travel/costs for traveling subspecialists
- Limited number of specialists would travel to rural sites, because of distance and lack of volume. Telemedicine overcomes this obstacle.
- Bringing access to the community is very beneficial.
- A real benefit to maintaining health care team in the community.
- Increase of quality of care
- Improve primary/specialty care interactions
- Range of information you would never receive in a regular visit

- All providers' benefit from sharing information
- You see more family members in a community setting
- Collaboration and coordination increase
- Answers, clarifications, and mutual planning efforts on the spot make for timelier implementation.
- Video clips allow for reviewing a fixed image over again and picking up some things possibly not seen during videoconference, particularly child behavior issues
- Decreases isolation for local providers
- Increases the local providers knowledge base and can improve their skills
- Better case management and quality care because of collaborative planning.
- Leverages resources
- Care is more concentrated, coordinated, collaborative, and comprehensive
- The focus is more on the child and the family when the TEAM treats/plans/evaluates rather than what an individual therapist can do for him/her.
- Allows group interaction among health care providers, social services, educators etc.
- There is better rapport when everyone is assembled together
- Community and parents coupled with tertiary staff can raise issues, problem solve, and share expertise together and at once, taking a more holistic approach to the overall care of the children/youth.
- More referrals are being made now that distance is not an issue
- More appointments are being kept- decreases "no show" rates
- Can complement the care local docs give-can connect you, not take you out of loop.

Disadvantages:

- Projects think telemedicine is threatening to some clinicians and/or local providers
- Lack of face-to-face contact
- Affect issues, especially in psychiatry
- Family doctor is usually not involved
- Not touching patients is not a natural interaction
- Lack of technical expertise on part of practitioners
- Barriers to technology:
 - it doesn't always work
 - camera angles/locations might not be appropriately set
 - camera jerking and blurring
 - failing audio/and or video
- Hard to develop trust in quality of other physicians' expertise
- Reimbursement and licensure issues
- Never as good as being there
- Have to fill in the gaps with assumptions
- You have to rely on the interpretations of others during physical exam.
- Negative perceptions on part of physicians: reluctance to adopt it as a health care delivery adjunct or option and resistance to change is commonplace
- Challenges in scheduling

5. What is your environment/room like? Technology? Is it child friendly? Are parents allowed to be present at all times? How do you protect privacy and confidentiality within the setting?

- Good connectivity, high quality equipment, real-time full-motion video and audio, in addition to technical aptitude or, at the very least, basic technical understanding on the part of the presenter, all enhance a telemedicine session. Not all of the interviewed programs utilize the same technology but all strive for accurate presentation, clarity and resolution.
- There was a consensus that even though the equipment might not be child-friendly, kids are accustomed to technology, they like being on TV, they think it's cool, that it's not a big deal, that it doesn't present a barrier in any way. Children/youth were very comfortable in contrast to their parents who might have been uneasy.
- Technology ranges from high quality, fully interactive audio and video to a standard home telephone and TV set.
- Most programs utilized TVs on rollaway carts. Some cameras were on top of TV, some were ceiling or wall-mounted, and others were tripod based and moveable. There was even an example of an entire system on an IV pole.
- Settings ranged from consultation suites and conference rooms to regular exam rooms, from the Neonatal Intensive Care Unit to school nurses offices.
- Hookups included TI and ISDN technology, TCP/IP and Internet based systems, a state's own proprietary fiber optics network to a standard telephone line.
- Parents are allowed and, in fact, encouraged, to be present at all times. It is actually mandatory in most programs. Exceptions exist as in a clinician who might see a child alone for mental health services. Another might be school-based programs where parents cannot be reached or cannot be present. But, in most situations, parents are there.

Two privacy and confidentiality issues were considered paramount by programs:

a) Privacy in the setting.

b) Privacy regarding the technology.

a.) To protect privacy in the setting, standard procedures relating to the physical setup of the rooms include:

1. Closed doors
2. No windows on doors
3. Very private rooms set off from rest of area
4. Appropriate signage displayed i.e. "clinical consult in progress"
5. Blackout of all viewing by audio/video technicians
6. Extra soundproofing because of speakers

b.) To protect privacy using videoconferencing and Web-based technology, several approaches exist and vary by program.

1. Secure computer programs (these are not available to others, and are protected by password)
2. Dedicated, secure fax and phone lines (access limited to participants)
3. Point-to-point connection (private as a phone line)

4. Intranet use only (works only within one setting such as a hospital)
5. Firewalls (specific safety programs to limit access to information)
6. Leased encryption lines (security feature where information is decipherable only to participants)
7. Signal scramblers and de-scramblers (Images are clear only at the two sites, but scrambled when traveling)
8. Signal is digitized
9. Some programs don't use Internet
10. Proprietary network
11. Some programs taped the encounter; others didn't save anything for security reasons.

6. Which types of health and educational professionals participate in telehealth sessions? Who runs the sessions? If you use different models within your program, we are also interested in understanding them-for example, some programs provide telemedicine sessions where there are teams present on both sites as well as a more traditional session where there is a specialist on one end and the child, family and telemedicine presenter on the rural end.

Linking children/youth and parents with specialists outside of their community has the potential to involve many different kinds of service providers. At the remote site and at the hospital/medical center site, opportunities abound for health care, educational and community professionals to be uniquely situated together to provide multidisciplinary care or, alternatively, to provide services in more of a 1:1 arrangement, making it a win-win situation.

The different professionals that participate in telemedicine encounters can include all or some of the following:

1. Primary care physicians
2. Specialty physicians i.e. psychiatrists, cardiologists, developmental pediatricians
3. RN's
4. Nurse practitioners
5. Residents
6. Community aides
7. Psychologists
8. Social workers
9. Family therapists
10. Speech and language pathologists
11. Occupational and physical therapists
12. Special education teachers
13. Nutritionists
14. Child care personnel
15. Interpreter/translator
16. Case managers

The different people who might run a telemedicine session include:

1. Nurse presenter, local liaison, clinic/site coordinator, school nurses and mental health professionals at remote site.
2. Health care providers/subspecialist physicians on tertiary end
3. Designated team leaders at both sites for multidisciplinary discussions

Telemedicine service delivery occurs within several different models:

- **Hub and spoke model:** a specialist or many specialists at a tertiary medical facility connect with presenters and/or providers at another site.
- **A matrix network or integrated lattice:** Connections can be made with all spokes and facilities sharing expertise and experience across a given geographic area.
- While a hub would most likely be a hospital or medical center, spokes and subspokes might include; rural hospitals, rural clinics, health departments, mental health centers, homes, long-term care facilities, school health clinics, school nurse's office, sites across reservations, developmental centers and early intervention programs.

Janet Farmer, PhD., Assoc. Professor at the Department of Physical Medicine and Rehabilitation at the University of Missouri describes service delivery models in these terms:

...” traditional medical model: Pediatric tertiary care specialists are linked to community-based hospitals and primary care clinics.”...higher education model: pediatric specialists in hospitals are linked to community-based professional training centers such as nursing schools”...School-linked model: ...School linked model connects pediatric specialists to public education systems through school based health clinics...” Home-based model:...home-based services link pediatric specialists directly to child's home. “(4)

7. Do you have any advisory committees related to your telehealth project? Who comprises this committee? (Physicians, Ancillary service providers, Community agencies, parents)

At this juncture in time, several telehealth projects have advisory boards dedicated solely to telemedicine. The ones that do have experts in the field of technology innovation, looking at ways to improve the telehealth environment and to explore new applications. Other advisory committees fit into hospital hierarchies or their agendas fit into medical board meetings. In other situations, ideas and suggestions are shared informally between hubs and spoke providers. Parents are not participants in any of these forums.

In terms of parent involvement as to telemedicine policy, some programs have had focus groups prior to commencing their initiatives. These focus groups comprised parents of children/youth with special health care needs. Some programs had a series of informational meetings and Open Houses in the communities prior to setup coupled with question and answer sessions. Where there are school based telehealth programs, community members do have a say through their school board. In one innovative program, parents have an advisory role on their telehealth website.

Parent Involvement in Telehealth: A web-based parent advisory group in North Carolina

TelAbility (www.TelAbility.org), a comprehensive e-health program in North Carolina utilizes telecommunication technologies including videoconferencing, a website, interest-based chat rooms for parents and professionals and a monthly newsletter focusing on improving the lives of children/youth with special health care needs and their families.

Their Parent Advisory Group focuses mainly on guiding program content and delivery style of their website, which is meant to complement their videoconferencing programming. The website portion of TelAbility is extremely family-friendly thanks to major input from families, starting with focus groups early on in the planning, to inception and development, to ongoing operations.

They have a parent expert who is available to answer questions posed in their website's Expert Answers area and are in the process of enlisting parents from across North Carolina to serve as resources in their Expertise Directory.

The parent advisory group coordinator, a mother of a child with special health care needs, is also their interpreter/translator and strives to make sure all of the e-health facets including medical care are culturally competent.

As of yet, this parent advisory group has had no input into the videoconferencing elements of TelAbility, but that will hopefully be forthcoming. Although the parent advisory group hasn't advised the program on videoconferences, parents who have participated in video clinics are asked to complete a questionnaire to rate their program.

Based on the success of the TelAbility website and all of its many components, and the fact that it is meeting the needs of families with special health care needs in their geographic area, it behooves other projects to consider the value of a parental involvement role into all areas of telemedicine, from support to program to policy.

8. How do you prepare kids/parents for a telehealth visit? Do you have any program for preparation? How far ahead? Do they meet staff? Are they given materials? Is there a website? When they come for appointments, do the children/youth/parents understand the protocols?

This is an area that varied widely program to program. Preparation, an important area in terms of family comfort, is a part of telemedicine that, acknowledged by most programs, is underdeveloped. Most agreed that family orientation and pre-planning was a significant issue and most programs had not developed it fully or formally. And most were very willing to entertain suggestions.

Some projects have brochures that describe the definition and role of telemedicine, phone contacts, what to wear, services provided, locations served, what happens at a telemedicine

session.

Some projects have websites that parents can access. Only a few interviewees considered their websites family-friendly. One program has a parent-involved website and, besides providing information on telemedicine visits, has chat rooms and newsletters for parent use. (above)

Preparation takes many forms and includes:

1. Community coordinators/local liaisons/ site coordinators, nurses, nursing students, physicians or telemedicine project directors are the links to telemedicine scheduling, preparation, facilitation and services.
2. Orientations can occur on the phone while scheduling patients, at the time a patient and/or provider decides a telemedicine visit is appropriate, during phone conversations within a week of visit, advance site visits, or in the reception area immediately prior to the visit. Sometimes, there is no preparation at all.
3. Preparation can include informational phone calls with telemedicine coordinators, taking family members into the room ahead of time to see equipment and talking about how to communicate via the technology, handouts, i.e. brochures, introductions to key personnel, information regarding confidentiality, filling out parent consent forms, review of procedures and protocols, conversations about what to expect.

9. How has telehealth affected the accuracy and efficacy of diagnosis and treatment?

There was a consensus amongst the interviewees that more research needed to be done into this vital area. Some programs have completed preliminary studies and evaluations, in others, outcome data is being collected and measured by research analysts. Some said it was too early to tell and others said much more research needed to be completed.

Here are a few comments by some of the projects:

1. After several years, an evaluation has shown that quality of care has not been compromised and, in fact, access to care has actually improved.
2. Very preliminary data shows that we are catching problems earlier, especially in chronic health and decreasing recidivism.
3. Patients are getting diagnosed quicker because of access (not necessarily more accurately)
4. Based on studies, outcomes are generally the same. Telemedicine hasn't really affected the efficacy of diagnosis and treatment that we can measure.
5. Not as good as face-to-face care, but it does allow a medical visit to occur where one might not occur because of geographic, monetary or time constraints.
6. More evaluation studies are needed to demonstrate how telehealth has and can improve health care.

10. What is the level of satisfaction among parents? Is it surveyed? If not, what is your estimate?

We asked projects if they evaluated satisfaction levels of parents and what were the results. All projects agreed that family/patient satisfaction with telemedicine visits was an important area to evaluate. Many of the reports on satisfaction were anecdotal in nature and recounted success stories. Some projects did phone interviews with families following telemedicine consults while others utilized written questionnaires. Several projects used different types of scales to gauge responses, with a range of agree to strongly disagree, positive/negative or yes/no responses. Because of confidentiality concerns in addition to the fact that data collection was, for some, in preliminary stages, most projects could not share specific details. However, some projects did share general information about levels of satisfaction.

As an overall general response, all projects said that patient satisfaction was very high. Projects reported that patients think the services are great, parents are delighted, and families are very receptive. The projects that could give a more in-depth report on their evaluations, (through our interviews, by way of websites and perusal of project reports) offered the following information. Because this does not purport to be a quantitative report, we chose not to give evaluation figures. We have also not specified their figures as some mixed adult and child patients and the ratings systems were varied.

1. One university based health system's surveyed these points: Patient satisfaction assessments were collected in five key areas. Patients evaluated a) whether they felt staff were properly trained using telemedicine technology, b) were their medical needs met during the telemedicine consult? c) were they able to talk freely during the consult and d) would you use telemedicine in the future? (5)

2. In a university affiliated project the following information was asked of parents: a) is your current view of the telemedicine experience the same or more positive as face to face direct clinical consultation; b) the quality of care of the telemedicine experience; c) the current quality of provider concern during telemedicine consultations and following telemedicine consultation; d) parents evaluation of the technical aspects of telemedicine consultation. (6)

3. In a statewide telemedicine project the findings included: Overall, both children/youth and their caregivers were very positive and satisfied with the services received via telemedicine. In general, they believed that the quality of services was very good, they received the kind of service they wanted, their needs were met, they would choose this type of service again and they would recommend this service to others. (7)

4. Phone surveys done through a telemedicine health network recorded responses to (agree-disagree) to the following type of questions: a) I found the telehealth equipment easy to use; 2) I think telehealth is a good way to provide medical care; 3) It was easy to communicate with the other person during the telehealth visit; 4) The care that I received during the telehealth visit was as good as a regular in-person visit; 5) I believe that the telehealth equipment increases my access to health care; 6) I felt telehealth limited my privacy. (8)

5. A telemedicine network at a children/youth's hospital asked the following types of questions:
 - a. Rate your ability to see the specialist over the television screen and your ability to understand the specialist's recommendations.
 - b. Rate your overall satisfaction with the visit.
 - c. Tell us whether telemedicine made it easier for your child to see a specialist.
 - d. Agree or disagree with the statement "I feel less confident about the specialist's recommendations because he was not in the same room."
 - e. Rate your priorities in determining whether to see a specialist by telemedicine instead of traveling a distance, i.e. wait time, inconvenience, monetary factors, missed work (9)

Again, some of these projects are in incipient phases of their initiatives and either cannot share data or can only offer small study samples. However, without giving numbers, the results were reported to be overwhelmingly positive with several caveats for both the consumer and the provider, namely privacy and technology.

11. How do you see the caregiver-patient-family relationship being affected?

Does telemedicine compromise the relationship between patient, family and provider? Does it sacrifice the benefits of direct care provider-patient collaboration? Does telemedicine offer an acceptable, appropriate or merely adequate way of initiating, developing and nurturing this relationship? As you'll see in providers' comments, their answers are directly tied to why telemedicine is utilized and what the benefits of this medium can bring to a relationship and basically, that a relationship could not exist at all if the access is not there.

1. It actually provides the family with an opportunity to see the caregiver more often than one or two times a year, which they like.
2. Sessions are held in real time. When talking to someone in a distant community, it's actually them we're speaking with face-to-face.
3. Teams can come to a consensus and treatment plan for the child with the parent's input right then and there. Parents can ask questions, get feedback, be part of the solution, and get information right at hand.
4. Access makes up for not being hands-on. Families truly appreciate the care coordination.
5. Families like the attention.
6. Families like being part of cutting-edge health care.
7. Whatever negatives there are, are overcome by the benefits of decrease in travel, decrease in cost and tremendous access to specialists.
8. Better communication and collaboration can be facilitated between team members
9. Many families feel more supported and reassured with the link to a tertiary specialty care

center.

10. Parents know that the network built between local clinicians and specialist can only help them in terms of enhancing their own community provider's skills and knowledge.

11. Pretty similar relationship between provider and patient in psychiatry in person as compared with telemedicine, but something is possibly lost with other types of visits.

12. Not better or worse, it's just different.

What Parents are Saying

"We just traveled 230 miles (one way) for 3 follow-up visits with various specialists. Each visit lasted approximately 15 minutes, provided no new information for my child, or me as the parent and we were told to come back in 3-6 months (depending on the specialist). I understand my child has a very rare disorder... but I am tired and need other options." Parent of a child with a disability from Nevada.

Over a similar six-month period we attempted to send out parent questionnaires to the telemedicine projects we were speaking with. We had also asked programs, if they couldn't distribute our questionnaires, whether they had satisfaction questionnaires of their own to share with us. The returns were disappointing; however, the reasons were understandable. Confidentiality and privacy concerns governed this area as well as the channels of hospital bureaucracy that we encountered trying to receive replies. In addition, because of the newness of some of these projects, different stages of data collection were in process, and most were not available for public usage.

We tried other methods of getting parent feedback, including our own brainstorming survey that we distributed to parents who have utilized telemedicine services as well as those that had not, but, nonetheless, have had considerable experience with health care services. We posted messages on pertinent websites, retrieved comments from projects' websites and project reports as well as accessed Family Voices channels to invite parents to participate.

Here are some parents' responses:

Positives of Telemedicine Experience

- Getting the information needed from knowledgeable sources.
- Didn't have to wait in a busy office.
- Didn't have to travel.
- Saves a lot of time
- Little or no missed work
- Everyone is less tired
- Child was not frightened.
- Child was fascinated by equipment
- Trusted sophistication of equipment

- Very quick with results and reports to all parties
- The feeling that the people who set up the telehealth programs went to great lengths to make it a Positive experience for all.
- Ability of telemedicine to involve all professionals at once
- Services are implemented more quickly.
- We don't have to repeat medical information over and over

Negatives of Telemedicine Experience

- Teleconference not always available when actually needed
- Couldn't be used for emergency visits
- Not as personable
- Frustrated by lack of personal contact
- Doctor can't do hands on exam
- In person it is easier to talk back and forth

Preparation for Visit:

- Clinic coordinator called in advance to explain how it visit would work
- Appointment sent by mail

Here are some thoughts that parents shared with us as to important considerations when they thought about deciding to use telemedicine:

Considerations:

- what the type and purpose of the visit would be
- (i.e. medical, evaluation, assessment, follow-up)
- type of technology to be used
- cost of the visit
- source of payment for the visit
- ability to stay within own community
- purpose of using telehealth rather than other methods to get the same information
- Setting of the visit:
 1. What is an acceptable setting?
(school, home, hospital, clinic, doctor's office?)
 2. Who are health professionals involved?
 3. Can entire team of health professionals, teachers, therapists, and family be available and able to participate?
 4. How will privacy and confidentiality are protected?
- Can the telephone still be considered as part of telemedicine? It saves time, travel, and allows for familiar people to hear of progress and make recommendations.

What type of preparation would you want to have?

- Videotape preparation
- Pictures of equipment

- Advice on preparing my child
- Written materials explaining how the visit will go
- An advance site visit
- Discussion with a health professional or clinic coordinator about the visit
- explanations of all technology
- discussion with other parents who have had the experience
- talking to another child about their experience

Parent Role:

Families would like to be heard in different ways

1. providing feedback on their telemedicine visit to projects/providers
2. mentoring/advising other parents before their telemedicine experience
3. serving in an advisory capacity to the Telehealth projects

“Everyone knows what to do with her.” - Iowa parents of child with special health care needs

One Parent’s Story

Having a son with a rare eye anomaly and living in a city with one of the most renowned hospitals focusing on ophthalmology seemed like a true blessing. But even in such a medical Mecca, when he needed complex surgery, it was nearly impossible to find a surgeon specialized enough and comfortable enough to perform it. In the best medical interests of my child, I knew where I needed to go, and it wasn’t to the next town, the next city or even the next state. After much research and a strong referral, I found the perfect pediatric surgeon about 300 miles away. Before we could have the surgery, however, we needed, of course, to have a consultation. We needed to travel; we needed to find a hotel; and he needed to miss school. Could this consultation have been performed via telemedicine? Would it have been an appropriate use of videoconferencing technology for this surgeon to “examine” my son? Could I have asked a local eye surgeon or our wonderful eye doctor to be our patient presenter and offer her experience as well? In an ideal world (assuming both local and remote sites had the equipment and the doctors had the desire and knowledge to use videoconferencing) what would have been the advantages and limitations of this scenario?

Advantages

Time savings

money savings (hotel, meals, train)

very little missed school/work

access to qualified subspecialist

our (both my son and I) comfort level with specialist’s experience

our comfort level with our own doctor being present

collaboration between two experienced ophthalmology professionals

Making sure this specialist is the right physician for this surgery without having to travel.

Nothing is lost, much is gained.

Limitations

Lack of hands-on and face-to-face contact can be disconcerting

Question of whether technology is accurate enough to allow for a clear and distinguishable examination of his eye.

If local eye doctor isn't presenting, how experienced will another presenter be who doesn't know my son, doesn't know about his condition, and can't process what remote specialist is requesting him/her to do.

Concern whether the specialist will get all the information he needs to proceed to surgery.

I think making optimal use of telemedicine is directly connected to the type of health condition/disability/syndrome of one's child. If a videoconferencing consult were offered to me, I would have to weigh whether this technology, despite the many advantages, could offer an examination similar or better than an office visit. I would have to ascertain whether, given the complexity of his condition and given the intricate anatomy of the eye, whether this was even possible. I would also have to consider what outcomes I could expect in respect to this option.

As things stand now, based on my son's unusual eye problem, this probably would not have been worth pursuing. But, it's good to think that in the future, as technology becomes more state of the art, as physicians become more versed in using the equipment, that it might offer possibilities for me. For a child with different health care needs, in a rural area or not, telemedicine does offer incredible potential for providing access, collaboration and an excellent source of support for parents. But the caveat remains, a parent and not only a physician has to be part of that judgment call, whether telemedicine is right for their child. *Parent advisor to Family Voices*

Special Situations

- Emergency Rooms
- Day Care
- Neonatal Intensive Care Units

Telemedicine and the ER

In the metropolitan Boston area, an innovative application of telemedicine has emerged and with it has brought another level of support for parents of acutely ill children/youth.

Three hospitals, with a focus on children/youth, are collaborating together to provide critical services at a distance. North Shore Children's Hospital, a dedicated children's hospital north of Boston and Newton Wellesley Hospital, a comprehensive medical center in Boston's western suburbs with expanding services for children/youth have teamed up with Massachusetts General Hospital, a world-renowned medical center and the largest hospital in New England. Since the latter hospital is the only one among the three that has a Pediatric Intensive Care unit, while the others have acute care and emergency services, an association between them made good medical sense. Given the possibilities available through telemedicine channels, opportunities abound to provide clinical and consultative videoconferencing services by pediatric intense visits to emergency personnel at the other two hospitals. Videoconferencing hookups allow the child and

family to be seen by all the health care professionals involved at both sites. The child is in his/her own community or locally while being able to access the expertise of critical care physicians. So, instead of just having a team at one hospital, many professionals are looking after the child.

What are the advantages of telemedicine in this instance?

As Dr. Noviski, Chief of Pediatric Critical Care Medicine at MGH has said, “It’s another pair of eyes specifically trained to care for critically ill children.” That cannot be underestimated in a critical situation.

- It can prevent the ER doctors from acting in an aggressive way (i.e. to intubate).
- It can prevent the ER doctors from treating in an overly invasive way (e.g. intubation and others).
- It can prevent the ER from transferring the patient to another hospital and assist in stabilization of the patient and keeping the child in his/her own community hospital.
- A telemed consult calms things down.
- If the family has to transfer to MCH, they already know the staff. Because of the continuity of care, they’re more comfortable.
- The doctors in outside ER’s learn the way the ICU doctors work and eventually might need them less.
- If there is the need to transport the child, there is also potential for having a video hookup in the ambulance transport.
- A possible future innovation might be using a video hookup in the ambulance transport of these children.

Everyone gains in a situation like this. The doctors are able to share their areas of expertise with one another; the child benefits from a collaborative TEAM approach of different specialists; the parents are reassured knowing that there are specialists “on site” to offer consultation, and the potential for continuity of care is there.

Day Care Based Telemedicine

According to Dr. Ken McConnochie, Project Director of the Child Care Telehealth Access Network at the University of Rochester, most families would choose a day care center with telemedicine services over one without them. Why is that? In their inner-city day care environments, families cannot afford to miss too much work; parents might delay a visit, or make no doctor visit at all. And, while a telemedicine visit from a school facility might not be perfect, research conducted by Dr. McConnochie and colleagues indicates that accuracy of diagnosis made by telemedicine for common childhood illness is as good as accuracy made in person.

Telemedicine meets the need of getting the child seen, possibly avoiding spread of an infectious disease, or reducing the need for an emergency room visit.

Telemedicine equipment is hooked up to physicians and nurse practitioners at the Golisano Children's Hospital at the University of Rochester Medical Center and equipment is monitored by trained day care staff. Different people present the child's case including LPNs, nurse's aides and trained administrators with little or no medical background. Parents are encouraged to attend sessions but have only done so in 15-20 % of visits due to scheduling and distance.

Children's illnesses and issues include ear infections, sore throats, fever, asthma, behavioral concerns, pneumonia and, according to Dr. McConnochie, because of these timely visits, and virtually immediate dispensation of prescriptions, almost no children/youth have been out of childcare this year. The outcomes have been outstanding and the patient satisfaction has been overwhelming.

"Clinicians involved find they're able to make observations that are as accurate as being there," Dr. McConnochie said, noting that a child's regular doctor is notified of each course of treatment. (10)

What the NICUs are saying and doing: Valuable applications of telemedicine in the area of neonatology

Telemedicine offers many opportunities for families, neonatologists, primary care practitioners and other staff to care for a newborn baby in the neonatal intensive care unit. When baby (ies) arrive with new and very immediate special health care needs, it is important for providers to give the parents tools to learn about their baby (ies), bond with their baby (ies), care for their baby (ies) and eventually, take their baby (ies) home with some measure of continuous care. It is equally important for a provider/s to learn from the parents as to what their needs and questions are.

Family Voices has spoken with five NICU programs nationwide shared their innovations, expertise and challenges with us. Each has a different type of usage but all have the same interests and goals: to make connections for parents, who are very new to this world of neonates and maybe new to parenting.

The forms that telemedicine/telehealth have taken and, in some cases, still take are utilization of videoconferencing to meet family needs rather than to conduct medical consultations, web-based Internet systems and videophones? And the usage is primarily from a family service viewpoint, not clinical visits.

The range of purposes includes:

- Baby bonding from rural hospital to a University NICU when a mom/family is either in the hospital or at a distance
- Interaction with staff caring for their babies including nurses and neonatologists
- Family therapists providing support and counseling
- Virtual case reviews and other communication between physicians as well as between primary care providers and the neonatologist.

- Discharge planning
- Information regarding specific baby care, pertinent information on prematurity and general wellness issues accessible through the World Wide Web

Telemedicine technologies, in one case, offered parents in a case trial, the opportunity to view their babies and have virtual visits with hospital staff from their homes. At Boston's *Beth Israel Hospital*, both videoconferencing and web-based capabilities allowed parents the opportunity to check in with their babies from home, utilize distance-learning opportunities and have the continuity of remote monitoring of their babies by neonatal staff after discharge. The provision of medical, informational and emotional support to these families during and after baby came home were an important aspect of fully integrative care utilizing telemedicine as an adjunct. It is important to note that families still visited the NICU as much and made just short of an equal number of daily phone calls. In addition, through this model, called **BabyCareLink**, parents had access to a wealth of information in a secure venue on the Web, about their baby including clinical updates, a daily picture journal and supports and services available to the parents. The video conferencing equipment is no longer available for home use for parents of *Beth Israel's* NICU babies, but the Web-based portion still exists and offers tremendous benefits to families.

Another fascinating application comes from *Marquette General Health System* in Marquette Michigan from a very enthusiastic clinic coordinator:

"My favorite story was one Labor Day I was called at home to coordinate a neonatal bonding. The mom and a set of grandparents were at their local hospital 2 hours away. The dad and his parents were here with the baby. The baby was not expected to live and was going to be transferred from us to the University of Michigan Health System for further care. We called the chaplain as the parents wanted the baby baptized. Because of video conferencing, the mom and grandparents in the home community were able to take an active part in the baptism. Then the flight team from UMHS arrived. I was able to introduce them to the mom and she was able to ask questions. The good news is-the baby lived! She had surgery at the UM and her surgeon did his follow up via telemedicine to the home community." (11)

Advantages and Potential for Telemedicine, Telehealth and Web based technologies in the NICU

- 1) Visual connection/Entire family visitation irregardless of locations
- 2) Emotional support
- 3) Continuity of care
- 4) Care management
- 5) Bonding support
- 6) Family-paced learning including:
- 7) Able to monitor progress of premature infant physical and developmental growth pattern daily, over a period of time.
 - b) Able to visualize size of infant and recognize infants needs.
 - c) Able to gain improved comfort in managing a small premature infant.
 - d) More awareness of feeding, routine care of premature infant
- 8) orientation to available services

- 9) coordination of transition
- 10) post-discharge support
- 11) decreased anxiety and relief of stress on part of parents
- 12) siblings can play an increased role (one child even sang a lullaby to his baby brother during the night via video hookup)

Family Voices' Recommendations for families and telemedicine projects:

1. Medical Home

Well-designed Telemedicine programs, as part of an integrated health services delivery system, can help create Medical Homes for children/youth with special health care needs.

Starting in the community and building out the network from the primary care practitioner's office, Medical Homes can naturally be created and expanded with telemedicine as a catalyst for the integration of services. It is vital that all children/youth with special health care needs have access to a Medical Home where care is accessible, coordinated, ongoing and comprehensive. And, since, one of the barriers to comprehensive health care is, indeed, access, then telemedicine can overcome that barrier. Families of children/youth with special needs should have access not only to a primary care team in the community, but the availability of pediatric subspecialists and pediatric surgical specialists, wherever they may be located.

In addition, because of the potential of telemedicine to bring together many professionals, including child health, psychology, therapies, education, social services, community workers, all in support of the best interest of the child, this is an area that needs to be looked at, developed and implemented. Some telemedicine programs are already providing health care partnering in this manner. New projects need to be made aware of the remarkable ability that telemedicine offers to help establish create Medical Homes for this special population. For this reason, families should be actively involved in development and promotion of telemedicine.

Telemedicine and Medical Home:

The medical home model advocates a comprehensive system of child health care that is accessible, collaborative, family-centered, community-based, and culturally competent. Telecommunications systems have the potential to advance this agenda for children/youth with special health care needs by increasing partnerships between primary and specialty health care providers, improving continuity of care, and enhancing the capacity of the community to meet child and family needs. Janet Farmer (4)

.... What you will be saying is vital in helping us make telemedicine a very important venue for communications between families and the primary care pediatrician, the pediatric subspecialists and pediatric surgical specialists, and all related services in education, health, and family support, public and private! It will help bridge family centered, community based care in a more friendly way. It should empower families towards better understanding of the entire integrated

system of care beginning with the Medical Home! Cal Sia, M.D (13)

The American Academy of Pediatrics has prepared a policy statement that details the desirable characteristics of a Medical Home. Several of the features would also relate to the importance of telehealth and telemedicine so that children/youth in remote locations or in difficult circumstances in urban areas will have the full opportunity of having a Medical Home. For example:

1. "Care is provided in the child or youth's community;
2. A plan of care is developed by the child or youth and family and is shared with other providers, agencies and organizations involved with the care of the patient.
3. Care among multiple providers is coordinated through the Medical home.
4. The Medical home physician shares information about the child or youth, family or consultant, and provides specific reason for referral to appropriate pediatric medical subspecialists, surgical specialists, and mental health/developmental professionals:" (12)

Access, partnering, coordination, collaboration and community based care can all be helped along by some form of telecommunications as one component in the achievement of Medical Homes for children with special health care needs. Other features of the Medical Home relate to the availability of care for special needs that include medical, psychological, educational, behavioral, developmental and functional characteristics.

2. Access for Everyone

Telemedicine eliminates barriers and brings together subspecialists with unique expertise with children/youth with special health care needs and their primary care team.

Telemedicine can bridge the gap, overcome the obstacles and level the field to insure that more children/youth get the appropriate care they need despite distance, money and time constraints. We chose to focus, primarily, on telemedicine for children/youth with special health care needs who live in rural, underserved areas and, therefore, have limited or no access to subspecialty care. But as we have talked to parents and providers as well as examined our own personal interest in telemedicine, it has become increasingly clear that the use of telecommunication technologies can improve access to care for rural populations and for other groups as well. It could also serve children/youth who live in urban areas, in proximity to major medical centers, but who have such rare conditions or syndromes that there may only be several doctors nationwide that could address their needs. This population, then, too, would have the same obstacles to overcome, the same boundaries to traverse as the rural group of children/youth. This is an area that must be explored as it broadens the definition of underserved to now include children/youth with special health care needs who have access to specialty care, but, perhaps, not quite specialized enough.

3. Family Advisory Roles

As telemedicine projects become more fully realized and funded, and as they become a more recognized part of an integrated health care delivery system, folded into the every

day care of patients and not just a stand- alone service, the role of families will be crucial. Family advisory committees will need to be formed, if not already in existence. Most programs did not have a dedicated telemedicine family advisory committee comprising individuals connected in some way to telemedicine. NONE had parent members, except one that was related to its website rather than to a program (see page 15). The contributions of families cannot be underestimated. From the planning stages of new programs to the implementation phase to evaluation and expansion, parents have knowledgeable points of view, have resources, have tapped into networks, and, most importantly, are excellent care coordinators. Parents, as experienced health care consumers, can make a huge contribution to discussions of protocol, planning, policy, delivery, evaluation, types of services rendered, marketing to families, brochures and other materials, etc. Programs must examine and consider the family perspective as parents of children/youth with special health care needs utilize health care services more than other pediatric patients, are active and well-informed and have a major interest in what is being provided.

4. Privacy and Confidentiality

Families require guarantees of privacy and confidentiality protections in these new settings from all professionals. These are key issues for families and all providers involved in telemedicine. In our findings we spoke about privacy and confidentiality regarding the videoconferencing itself and the setting it takes place in. Another aspect that is vitally important is that staff be aware of privacy and confidentiality issues and that some training go on around that. Moreover, in the context of a health care delivery mechanism, there are new personnel who might be present to deal with the technical aspect of telemedicine. Families need to be prepared for these extra individuals who will be involved. These people, who offer technical support, ensure connectivity, set up equipment and troubleshoot among other things, have to be trained and oriented to elements of privacy, confidentiality and security. This is as important as being well versed in the technology. In addition, it is vital that parents and children/youth feel comfortable with this non-clinical person, as he/she is not a direct participant in the telemedicine visit.

5. Preparation of Family

The more information and preparation families and children/youth have, the better and more comfortable the visit, and, possibly, the more accurate the results. This was an area that was, admittedly, under-examined by most projects and an area in which parent participation would be quite useful. Several suggestions were made in the parent section regarding advance preparation. Others might include a description and demonstration of program services made available to families through either a website, brochure or videotape demonstrating a videoconferencing session. Families should be given a checklist of questions beforehand to ask as the visit approaches and takes place. (see Appendix) Children/youth, along with their families, should also be given the opportunity to ask questions and see the setting beforehand. A child-life specialist might be utilized for that purpose. Accommodations for equipment should be

addressed as well as fears and concerns about the technology, the staff and/or the visit itself.

6. Technology

Because technology is at the center of a telemedicine visit, providers and families alike need to look at and understand the ways that telecommunication technologies can both enhance and hinder a visit. Are there ways for a technical person to prepare the visit in advance in terms of hookup, camera setup etc.? Has the equipment been adapted appropriately for the child or the parent? Is the technology good enough for diagnostic purposes? Consultative/evaluation purposes? Do image quality, clarity and resolution meet the needs of your particular visit? How can you ensure connectivity through the phone lines? Can more enhanced technology improve the quality of a visit? (see **Family Checklist & Family Satisfaction Instrument**)

With the advent of new and more state of the art interactive equipment and diagnostic tools, telemedicine can become a more accurate and effective means of providing care. But practitioners and families are still limited to sight and sound. Despite this fact, practitioners can professionals, their careful reports, listening to families and the incredible focus and attention on the child provided by this medium.

7. The Neonatal Intensive Care Unit (NICU)

Use of telecommunications in the NICU is worthwhile for parents in terms of family contact, support, information and education. All of those interviewed concurred that telemedicine for NICU patients is not appropriate for diagnosis and/or treatment, but feel that different variants of telecommunications are useful for parents in terms of family contact, support, information and education. It is also valuable for consultations between many providers and families, not just physician to physician. And equally important, from the very beginning the child's pediatrician as well as early intervention staff, if needed, should be involved. This could be the start of a Medical Home for the child. Some of the professionals who have been or will be working with this child should be in place and linked as the child transitions home. This collaboration, facilitated early on through telemedicine, will allow families to feel more comfortable taking care of their newborns.

Because these parents, whether they have had other children or not, may be new to having a child with special health care needs, and should be helped and empowered to get the necessary services, data and support. Through a hospital connected website (i.e. BabyCareLink), parents can become prepared, learn about their child's specific diagnosis, and communicate by e-mail with medical providers. Family members such as grandparents and others could be given access to the Web for information to help keep them updated. It encourages parents to become more participatory and eases the transition back to home and the community. Chat rooms could become a part of a site like this as well as parent support groups.

According to staff from several projects, videoconferencing from home to NICU has not continued as a viable option, because of funding, infrastructure costs, problems with the technology in people's homes, plus it really isn't feasible for diagnosis and treatment. But there

is tremendous value is providing the less tangible services of bonding, after care for baby, and emotional support of families. And while it doesn't replace onsite visitation it can certainly enhance it and increase the times parents share with their babies, especially if they are still in hospital or far away. And, after baby comes home, videoconferencing presents a wonderful complement to help parents gain confidence from hospital staff as they learn to care for their recently discharged newborn who might come home with numerous issues and problems. If videoconferencing equipment costs are too expensive now, we expect that, like other technology costs, they will come down over time. Videophones are less expensive and can perform a similar duty, albeit less resolute and clear. This would not be for diagnostic purposes but family-centered support purposes. Perhaps, this is something for NICUs to look into and revisit. Some programs have tried videophones at home with some success and others use them between referring hospitals and NICUs. One project to keep families connected is in a Ronald McDonald House (video connectivity with the telemedicine programs at the University of Tennessee Medical Center in Knoxville).

Present and Future Questions:

Based on our findings and our discussions with telemedicine projects, providers and families, here are some questions that most projects have looked at, thought about and continue to ponder. We suggest families would do well to think about them carefully as well.

1. Are families achieving a level of involvement as advisors to telemedicine/telehealth projects to help accomplish family-centered, community based, coordinated, culturally competent care?
2. Can appropriate health care be delivered using telemedicine technologies? Are there any areas or specific diagnoses that wouldn't be appropriate for a telemedicine venue?
3. Is telemedicine equally effective for initial appointments, consultation/evaluations, and follow-up appointments?
4. Do medical outcomes differ between a telemedicine visit and an office visit? If they are not equal, how can they be improved? What barriers that limit a telemedicine visit can be overcome?
5. What about information-related outcomes? Are families getting the information they need from a visit? Is telemedicine more conducive for this than an office visit?

APPENDICES

FAMILY CHECKLIST

***Family Voices* Questions to Ask if Telemedicine is Offered to You and Your Family**

CHOOSING TELEMEDICINE FOR MY CHILD

A note to families: In trying to be aware of many families' different and unique needs, we have devised a long list of questions that might be worthwhile for you to consider when telemedicine is an option for your family. There are many questions, yes, and while it may be overwhelming for you, whether you have had prior telemedicine experience or not, it is merely meant as a guideline to help you make your decisions. You can use all of the questions to help you, some of the questions, or none of them. This list might inspire you to come up with your own questions or to even rephrase them and that would be great. Let us know of them! Use them as you wish and we hope that they will be helpful to you.

Why use telemedicine?

What is the purpose of using telemedicine for my child?

What will I learn from my visit?

What are the advantages of telemedicine to my child and my family?

What are its benefits and disadvantages?

Will telemedicine meet my needs better or equal to going to a distant site?

Will telemedicine provide access to specialists we otherwise couldn't see?

Will the lack of direct contact affect my child's medical outcome?

Is it the right thing for my child?

Is my child's condition /disability appropriate for a telemedicine visit?

What are my other concerns?

Making the decision

Who makes the decision whether telemedicine is appropriate at this time?

Can I request a telehealth visit or does the referral have to be made by my service provider?

Is my telemedicine visit reimbursable by any insurance? If not, will there be a cost to me?

Setting up a visit

How do I schedule a visit?

Is there a way to have visits scheduled when the need arises just as with an office visit?

Talking with other parents

Do you have parents that I can contact regarding their telemedicine experiences?

TELEMEDICINE VISIT PREPARATION

Information

Who will be my contact in terms of preparing for myself and my child's visit and asking questions later?

Will he/she advise me how to act and speak before the camera, what to wear, etc?

Will someone explain to me how the videoconference will work including an explanation of the technology?

Do you have a brochure or materials I can read? A website to look at?

The Set-up

Where will the visit take place?

Is the equipment child-friendly?

Will my child and I be able to see the room and equipment beforehand?

My Role

Who can I bring to my visit? Family, friends, teachers, therapists?

What shall I bring to my visit? Toys, food, snacks?

Will I be able to be with my child throughout the entire visit?

The People Involved

Will I be able to meet all the team members involved beforehand?

Which team member might help me prepare my child?

Who will be presenting my child's issues to the team?

What are their qualifications?

Are they trained in the use of telemedicine equipment?

Is there a telemedicine technician?

What are his/her qualifications?

Is he/she in the room at the time of the consult or just on the premises to troubleshoot a problem?

Who are the people at the distant site that will participate in our visit?

Who else might participate in our telemedicine visit?

Privacy Issues

Does all staff including technical staff have training in confidentiality and privacy standards?

Will the team members conducting the telemedicine visit be familiar with my child's records?

Will this happen before the visit?

How do you insure privacy and confidentiality?

In the exam room?

Over the Internet?

Over the phone?

Over videoconferencing equipment?

Record Keeping

Will the telemedicine session be videotaped?

What purposes will it serve? Training of family? Training of staff? Teaching?

Will I be able to have a copy of this video?

Will it be a part of my child's medical record?

For how long is the video kept?

FOLLOW-UP

Results

What is the timeframe of when I will get results/reports?

Can I get preliminary results right there since the whole team is present?

How will the results of the visit be communicated otherwise?

Follow-up Care

What is involved with follow-up care?

Will it be done as an onsite visit or through telemedicine?

Who will work with me to coordinate follow-up care?

Parent Involvement

Do you have a satisfaction survey that I can fill out after my visit?

Are you interested in having parent advisors or starting a parent advisory committee?

Even with so many questions to choose from, you may have other questions you want answered. Make a list beforehand to take to your medical provider(s).

- 1.
- 2.
- 3.

Family Voices In SCHIP
Telemedicine Family Satisfaction Instrument

Many programs were generous enough to share their patient questionnaires being used with their patients, parents and families. We now propose sample satisfaction questions that we feel are family-friendly and family-centered, incorporating ideas from several projects as well as questions that we, ourselves, devised. We offer this as a working model for families of children/youth with special needs experiencing telemedicine visits. Projects could select questions to create their own questionnaires to distribute to families upon completion of their telemedicine visits. Families could also give this questionnaire to their telemedicine providers. In addition, families could select questions from this list to give feedback to a project about their own experience.

Sample Questionnaire

1. Age of Child _____
2. Nature of Disability _____
3. Setting of Visit _____
4. Test/Procedure/Consultation/Evaluation done at this telemedicine visit _____

5. Why did you consider a telemedicine visit? Was it an option you requested or was it presented to you by a health care provider?

6. Do you think the use of telemedicine was appropriate for your current needs?

7. Do you think telemedicine should be used for: (check all that apply)
___ initial consultation
___ interdisciplinary evaluation (where many providers are participating),
___ treatment
___ follow-up care
___ tests/procedures
___ educating me about my child's condition and care
___ school setting visits
___ other(specify)

8. How were you prepared for your telemedicine visit?

	None	In Advance	Day of Visit
Videotape was provided			
Brochure or other written materials			
Phone calls from clinic coordinator or other health professionals			
Site visit			
Demonstration of equipment technology			
Advice on how I could prepare my child			
Names of other parents utilizing telemedicine were given to me			
We could participate in a practice session			
Other			

9. How far in advance did you receive preparation?

10. Were staff properly trained in the use of telemedicine technology?
 onsite _____ remote site _____

11. Was equipment reliable?

12. Were the images clear?

13. Was the camera usually focused on the right person?

14. Was it ever difficult to hear?

15. Was the equipment bothersome, in any way, to you and/or your child? In what way?

16. Who presented your child's case?
 Title of Presenter _____

17. Were you comfortable with that person?
 Please explain.

18. Did anyone do a hands-on exam of your child?

19. Were you comfortable with that person?
 Please explain

20. Of the following people, which ones would you feel most comfortable presenting your child's case to a remote person? Check all that apply:

parent (yourself or another parent)_____

clinic coordinator_____

community person_____

nurse_____

nurse practitioner_____

doctor_____

spiritual adviser_____

other_____

21. Did you understand the role played by participants at both sites?

22. What was your role in your telemedicine consult?

23. Were you comfortable with that level of participation?

24. Did you have enough opportunity to ask questions and provide input?

25. Did telemedicine provide a chance for you to have a discussion with many specialists at the same time?

26. How difficult was it for you to access specialists before telemedicine?

27. Do you think telemedicine helps in the coordination of your child's care?

28. From your perspective, was your privacy and confidentiality respected and protected during your visit?

29. How was this done? Please explain.

30. Were there other ways for you to get quality services before telemedicine?

31. What were some major obstacles in obtaining quality services?

Cost_____

Distance_____

Missed Work _____

Child Care_____

Large hospital is overwhelming_____

Other_____

Comments:

32. Without this telemedicine session how would you have received health care for your child for this particular issue?

Would have traveled a distance to get appropriate care _____
Would have traveled up to _____ miles
Would have relied on my local provider _____
I would not have gotten the care I needed _____

33. In what ways has telemedicine been effective for your child?
In what ways was it not effective?
34. Would you choose telemedicine for your child again? In what capacity?
35. Would you rather have been seen in person than through telemedicine?
36. Could you place the same level of trust in a doctor you only interacted with through telemedicine?
37. Do your local providers have a good relationship with the telehealth providers and carry out most suggestions?
38. Would you recommend telemedicine to other families?
39. What, if anything, would have made your visit better?
40. Overall, what was your level of satisfaction with this visit?
41. Would you care to make any suggestions to others setting up telehealth programs?
42. Would you be interested in serving on an advisory committee related to telemedicine?

Neonatal Intensive Care Unit (NICU) Specific Questions

43. How were you invited to participate in a NICU telehealth experience?
44. If the post hospital care included home care by telemedicine, was this also offered as a choice?
45. Were you ever limited in your contact with your baby (ies) because of the technology?
46. Did the technology increase, decrease, or not affect the amount of visiting you did with your baby (ies)?
47. Were you able to get support for infant care, breastfeeding, family contact, etc. through the telehealth system?
48. What other sources of support did you have on these topics?
49. Have you any suggestions for others setting up telehealth programs for NICU programs?

School or Child Care Programs Specific Questions

50. Were you notified before your child saw the nurse for a telemedicine visit?
51. Had you previously signed a consent form to allow this visit?
52. Were you invited to be present at the school/child care facility for the visit or given the option of going to the medical site if closer?
53. Was your child's primary care provider notified before the telemedicine visit?
54. What was the consult for:
 Diagnosis
 Treatment
 Medication management
- b. What was the type of condition:
 Ear infection/strep/cold
 Asthma
 Diabetes
 Rashes
 Behavioral/psychological
 Other
55. Was it a scheduled visit or due to sudden illness?
56. Did the results of the visit meet your needs?
57. Was your primary care provider notified of treatment/medication decided by the telemedicine visit?
58. Who described your child's symptoms to the doctor?
 School nurse
 Child care worker
 Teacher
 Social worker
 Your child
 Other
59. Did you feel this person was well trained to describe your child's symptoms and assist the doctor, i.e. using instruments to examine ears, throat, etc?
60. Have you any suggestions for others setting up telehealth programs for schools or childcare programs?

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Websites to help you learn more about telemedicine

<http://www.atasp.org/>

- Association of Telehealth Service Providers

<http://telehealth.hrsa.gov>

-Office for the Advancement of Telehealth

<http://trc.telemed.org/telemedicine/primer.asp>

<http://tie2.telemed.org/AboutTheTIE.asp>

Insurance

<http://www.hcfa.gov/medicaid/telemed.htm>

<http://telehealth.hrsa.gov/pubs/report2001/pay.htm>

Medical Home

<http://www.medicalhomeinfo.org>

Telehealth Applications

www.babycarelink.org

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