

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 think about. 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 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 visit?
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 appropriate for this than an office visit?

Useful Websites

Office for the Advancement of Telehealth (OAT)

<http://telehealth.hrsa.gov>

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

Medical Home: <http://www.medicalhomeinfo.org>

Family Voices is a non-profit grassroots organization of families and friends speaking on behalf of children and youth with special health care needs.

www.familyvoices.org

The Family Voices in SCHIP Telemedicine Report to Families

Bridges Not Boundaries



The Value and Use of Telemedicine for Children and Youth with Special Health Care Needs

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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. Parents and children/youth need to 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. A description of program services, either by website, brochure or videotape demonstrating a videoconferencing session should be made available to families. Families should be given a checklist of questions beforehand to ask as the visit approaches and takes place. Children/youth should also be given the opportunity to ask questions and see the setting beforehand. A child-life specialist might be useful for that purpose. Worries about equipment should be addressed as well as any other fears and concerns.

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 for 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** and **Family Satisfaction Questionnaire**.)

7. Neonatal Intensive Care Unit (NICU) is worthwhile for families in terms of and education. It is also valuable for consultative just physician to physician. This could be the Because these parents, whether they have had a child with special health care needs and show necessary services, data and support. After baby enters a wonderful complement to help parents gain learn to care for their recently discharged newborn issues.



The Family Voices in SCHIP Telemedicine Report to Families

Bridges, Not Boundaries, The Value and Use of Telemedicine for Children and Youth with Special Needs, Karen Albus, Barbara Popper, and Lois Wainstock. April 2003

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Recommendations

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.** Children/youth with special health care needs must have access to a Medical Home, a place where they get regular, ongoing care. 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, families should be involved in developing and promoting its use.
- 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 gaps, 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. Telecommunication technologies can improve access to care for rural populations and for other groups as well including children/youth who live in urban areas, in proximity to major medical centers, with rare conditions. This broadens the definition of underserved to 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.** The contributions of families cannot be underestimated. Parents, as experienced health care consumers, can make a huge contribution to discussions of planning, policy, delivery, evaluation, types of services, marketing to families, brochure and other materials. Considering the family perspective is important because parents of children/youth with special health care needs utilize health care services more than other pediatrics 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 telehealth and telemedicine. Technical staff, who offer technical support, ensure connectivity, set up equipment and troubleshoot

Family Voices in SCHIP (State Children's Health Insurance Program) Telemedicine Report to Families

Report Summary
Family Checklist of Questions to Ask
Family Satisfaction Questionnaire
Recommendations of Family Voices
Present and Future Questions

"Telemedicine is an exciting new way to achieve quality medical care through the use of television, telephone and other communication equipment. Experts who are not in the immediate area are able to share their knowledge and skills using this advanced technology. The result is that quality health care is more available without the extensive travel that is often necessary and which can be risky or even life-threatening to the patient. In addition telemedicine is often less costly."

-Jerry Overson, Family Voices

Report Summary

Telemedicine

Telemedicine refers to the use of electronic communication and information technologies to provide or support clinical care at a distance. (*Telemedicine Report to Congress, U.S. Department of Commerce 1997*)

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. (Ibid.)

This is telemedicine...

My daughter has a very rare neurological disorder. Her pediatrician is wonderful but doesn't have experience in this area of disability. We used to have to travel 200 miles to see her specialist, a specialist with enormous experience in her condition. Now, with telemedicine, we can go to our local clinic, and, with our physician, hook up to the hospital where this neurologist is located. With basically a camera, a video screen and a fast telephone hookup we can have the benefit of a world renowned doctor's medical opinions while in the comfort of our community.

This is telemedicine...

My son needed to have a developmental evaluation to figure out what services would be appropriate for his new pre-school to give him. Because we don't live near a major medical center it would have meant traveling a great distance at great cost to have many appointments with an awful lot of specialists. With telemedicine, we were able to take our child to one clinic site, close by, and through a video and audio hookup have an occupational therapist, speech pathologist, psychologist and developmental educator talk directly with me, my child, my child's physician and my child's early intervention provider. We felt that because of this evaluation they were able to look at my son as a whole child in one visit and start to determine how his needs could be met.

48. What other sources of support did you have on these topics?
49. Have you any suggestions for others setting up telemedicine 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 consult for:
 Diagnosis
 Treatment
 Medication management
- 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 telemedicine programs for schools or child care programs?

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

33a. In what ways has telemedicine been effective for your child?

b. 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 interacted with only through telemedicine?

37. Do your local providers have a good relationship with the telemedicine 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, were you satisfied 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?

And this is telemedicine...

....a child with attention deficit hyperactivity disorder is assessed and treated in his own community because of a video/computer hookup at his middle school . He can "see" an expert child psychologist from the comfort of the school nurse's office even though this doctor might be miles away and the parent/parents can be there to participate in this electronic visit without missing too much work or having added transportation hassles.

Through telemedicine, using video cameras, audio equipment and other electronic media, all eyes focus on the child, at one time, across many miles. Health care providers and non-medical providers, through various means of communications can provide services to patients at remote sites or between two or more sites. At its best, telemedicine helps develop true partnership between the family, the primary care physician/and or nurse, the community and the specialists.

As a parent you may want to consider:

The purpose of using telemedicine for your child

What information you hope to learn from the visit

What your child's doctor recommends

What outcome you & your child's doctor expect

If telemedicine is equal to in person care

Family Voices members are interested in all health care policies that impact children/youth with special health care needs. Many families have become involved in assuring family-centered care at their hospitals, making sure they could be with their babies and children/youth while they were receiving needed medical attention. Some have also become active on committees within their state health programs, managed care plans, and state insurance planning. Since Telehealth/Telemedicine care can be covered by Medicaid and SCHIP in many states, Family Voices with support from the OAT set out to learn if families were being asked for their ideas about how to create telemedicine care for their children.

Benefits of Telemedicine:

- services in your own community
- collaboration among medical caregivers
- a means of improving communication and worthwhile partnerships between families, local providers and subspecialty providers
- increased access to medical specialists and pediatric subspecialists
- 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 lessen costs including travel and childcare expenses
- less missed work or school
- decreases the difficulty of traveling with children with disabilities and/or mobility issues

Uses of Telehealth:

Assessments	Developing Medical Home *(through
Evaluations	consultation and coordination
Consultations	between specialists, community
Follow-up Appointments	based care providers and the family)
Diagnosis and Treatment	Newborn Baby/Parent Contact
Patient Education	Discharge Planning
Distance Learning for Health Care Professionals	Family Support
Staff Development	Preventative Care
	Post Operative Care

*MEDICAL HOME refers to an approach to pediatric care that is provided by a physician in partnership with the family and is accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective.

..."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 specialist, 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. Chair, AAP PAC National Medical Home Initiatives for CSHCN, Hawaii

- Of the following people, which ones would you feel most comfortable presenting your case to a remote person? Check all that apply:
 - parent (yourself or another parent)
 - clinic coordinator
 - community person
 - nurse
 - nurse practitioner
 - doctor
 - spiritual advisor
 - other _____
- Did you understand the role played by each of the participants at both sites?
- What was your role in your telemedicine consult?
- Were you comfortable with that level of participation?
- Did you have enough opportunity to ask your questions and provide input?
- Did telemedicine provide a chance for you to have a discussion with many specialists at the same time?
- How difficult was it for you to access many specialists before telemedicine?
- Do you think telemedicine helps in the coordination of your c
- From your perspective, was your privacy and confidentiality respected and protected during your visit?
- How was this done? Please explain.
- Were there other ways for you to get quality services before telemedicine?
- What were some major obstacles in obtaining quality service?
 - Cost
 - Distance
 - Missed Work
 - Child Care
 - Large hospital is overwhelming
 - Other _____



8. How were you prepared for your telemedicine visit?

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

Family Checklist

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?

1. What is the purpose of using telemedicine for my child?
2. What will I learn from my visit?
3. What are the advantages of telemedicine to my child and to my family?

What are its benefits and disadvantages?

4. Will telemedicine meet my needs better or equal to going to a distant site?
5. Will telemedicine provide access to specialists we otherwise couldn't see?
6. Will the lack of direct contact affect my child's medical outcome?



Is it the right thing for my child?

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

8. What are my other concerns?

Making the decision

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

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

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

Setting up the visit

12. How do I schedule a visit?

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

Family Satisfaction

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)

Follow-up

Results

32. What is the timeframe of when I will get results/reports?
33. Can I get preliminary results right there since the whole team is present?
34. How will the results of the visit be communicated otherwise?

Follow-up Care

- 35a. What is involved with follow-up care?
- b. Will it be done as an onsite visit or through telemedicine?
- c. Who will work with me to coordinate follow-up care?

Parent Involvement

36. Do you have a satisfaction survey that I can fill out after my visit?
37. 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.

Talking with the other Parents

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

Telemedicine Visit Preparation Questions

Information

- 15a. Who will be my contact in terms of preparing for myself & my child's visit and asking questions later ?
- b. Will he/she advise me how to act and speak before the camera, what to wear, etc?
- c. Will someone explain to me how the videoconference will work including an explanation of the technology?
- d. Do you have a brochure or materials I can read? A website to look at?

The Set-up

16. Where will the visit take place?
17. Is the equipment child-friendly?
18. Will my child and I be able to see the room and equipment beforehand?



My Role

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

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

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

The People Involved

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

23. Which team member might help me prepare my child?

24a. Who is the person presenting my child's issues to the team?

b. What are their qualifications?

c. Are they trained in the use of telemedicine equipment?

25a. Is there a telemedicine technician?

b. What are his/her qualifications?

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

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

27. Who else might participate in our telemedicine visit?

Privacy Issues

28. Do all staff including technical staff have training in confidentiality and privacy standards?

29. Will the team members conducting the telemedicine visit be familiar with my child's records? Will this happen before the visit?

30. How do you insure privacy and confidentiality?

a. In the exam room?

b. Over the Internet?

c. Over the phone?

d. Over videoconferencing equipment?



Record Keeping

31a. Will the telemedicine session be videotaped?

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

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

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

e. For how long is the video kept?