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# How Massachusetts Health Plans Make Coverage Decisions:

A Report on Interviews with Nine  
Massachusetts Health Plans

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**Prepared by:**



**Medical Coverage Decision-Making  
Work Group**

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This report describes the findings of health plan interviews conducted in 2004 and early 2005 by the Medical Coverage Decision-Making Work Group of the **Massachusetts Consortium for Children with Special Health Care Needs**.

The Work Group is focused on enhancing the understanding of families and providers about how health plans in Massachusetts make coverage and benefit decisions. Work Group members include representatives from commercial and Medicaid health plans, other purchasers, families and providers.

The findings in this report will be used to develop materials for families and providers that elucidate: the types of coverage decisions health plans make, the criteria used in making those decisions, and the avenues that exist for influencing the outcomes of coverage decisions.

We believe this to be an important step toward realizing in Massachusetts one of the national goals contained in the 10-year Action Plan to Achieve Community-Based Service Systems for Children & Youth with Special Health Care Needs and Their Families (U.S. Dept. of Health & Human Services, 2001): *All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.*

James H. Glauber, MD, MPH

Nancy C. Turnbull

*Co-Chairs, Medical Coverage Decision-Making Work Group*

*Massachusetts Consortium for Children with Special Health Care Needs*

*A Program of New England SERVE*

For further information, please contact:



101 Tremont Street, Suite 812, Boston MA 02108

Tel. 617-574-9493 ♦ Fax 617-574-9608

[www.neserve.org](http://www.neserve.org) ♦ [info@neserve.org](mailto:info@neserve.org)

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## **BACKGROUND**

The Medical Coverage Decision-Making Work Group began its work in 2003 with support from the Maternal and Child Health Bureau within the Health Services and Resources Administration, U.S. Department of Health & Human Services. It is one of several work groups of the Massachusetts Consortium for Children with Special Health Care Needs, a program of New England SERVE.

Our goal: to broaden understanding about the processes health plans use to decide whether or not to cover requested medical services. How is it determined, for example, if a treatment option is “medically necessary”? Are there specific circumstances that might allow a “benefit exception” or “experimental” procedure? With greater understanding of the different types of coverage decisions and the criteria used to make them, those who directly care for children with special health care needs (CSHCN) will also have a greater understanding of the avenues for reconsideration, influence and appeal.

To accomplish this goal, we first designed a set of case vignettes to highlight specific issues and service needs of CSHCN. We then used these vignettes in structured interviews with health plan decision-makers to discuss how coverage decisions would proceed in each example. Currently, we are using the interview findings to develop educational materials for families and health care providers.

We have also identified several areas that hold promise for building on our work to date. These suggested opportunities for further collaboration are included in this report, and may be of interest to a variety of stakeholders in addition to the Consortium.

## **APPROACH**

Our approach to examining medical coverage decision-making has been to hold discussions with health plans about a set of seven case vignettes.

### **Developing the Case Vignettes**

The case vignettes were developed by an ad hoc consultative group comprising parents, health plans, medical providers, and New England SERVE staff. Our intention was to identify realistic issues health plans face that could be used to clarify the medical coverage decision-making process. For that reason, the cases were intentionally designed to raise issues that are often in the “gray areas” of medical coverage.

The cases involved coverage for a range of services, including:

1. Fresh muscle biopsy to diagnose a possible metabolic disorder
2. A new reconstructive surgery technique for Crouzan’s Syndrome
3. Acupuncture and biofeedback therapy for inflammatory bowel disease
4. Durable medical equipment (DME) that exceeds the standard DME benefit
5. Outpatient mental health services
6. An innovative physical therapy treatment for cerebral palsy
7. Synagis, a costly monoclonal antibody used to prevent severe respiratory infection in very young children.

The vignettes are included in *Appendix 1*.

### **Interviewing the Health Plans**

We contacted eleven health plans operating in Massachusetts to request an interview with staff involved in making coverage decisions. Using the case vignettes as a starting point, our goal was to gain insight into the *approach* and *process* health plans use for decision-making, not to get a commitment about the outcome of a specific benefit request for a specific child. As part of the solicitation of health plan participation, we promised not to attribute any information to specific health plans, although we did get permission to identify the health plans we interviewed.

Nine health plans agreed to participate:

- Blue Cross Blue Shield of Massachusetts
- Boston Medical Center HealthNet Plan

- Fallon Community Health Plan
- Harvard Pilgrim Health Care
- Health New England
- Neighborhood Health Plan
- Network Health (an affiliate of Cambridge Health Alliance)
- Primary Care Clinician Plan (a plan operated by MassHealth, the state's Medicaid program)
- Tufts Health Plan

The case vignettes were sent to the health plans in advance of the interviews.

The interviews were conducted in person. In most cases, a plan medical director participated in the interview, and in several plans, other staff were involved, generally from the case management or clinical affairs department. During the interview, we discussed how the plan would approach the situation described in each vignette, based on the following questions:

- Is the service in question a covered benefit in the health plan's products? If so, does the health plan impose any limits on the benefit?
- What criteria and process would the health plan use to determine if the child is appropriate for the service described in the vignette?
- In particular, how would the health plan decide if the service is medically necessary?
- What processes exist for families and providers to request benefit exceptions or to appeal coverage decisions? What criteria does the health plan use for reviewing these requests and appeals?
- Who are the key decision-makers about coverage decisions at the plan?
- What role do purchasers, such as employers, play in making coverage decisions?

One health plan was not willing to discuss each specific case vignette in detail but instead outlined its general process for making benefit and coverage decisions. From the other eight, although we did not attempt to get definitive decisions about whether coverage would be approved in each case, we could often get a general sense of the *likelihood* of coverage. *Appendix 2* summarizes our general sense of those probable outcomes.

## **FINDINGS**

### **Overview**

All of the health plans we interviewed report a very similar approach to medical coverage decision-making. In general, each health plan has medical policies, which it uses as the basis for most coverage decisions. These case vignettes were deliberately designed to raise issues in the “gray areas” of medical policy, however, and coverage decisions in these cases would most often be made based on a review of the facts, including the specific medical situation and history of the member. All of the health plans further explained that as members, children similar to those in the vignettes would likely already be receiving the health plan’s case management services, which would facilitate the review of such coverage requests.

Although not a strictly linear process, the key questions and steps that are usually involved in making a decision are:

1. Is the service a covered benefit?
2. Does the member meet the “medical policy” for the service?
3. Is the service “medically necessary” for the specific member?
4. Is the benefit for the service subject to any limits (e.g., number of visits, annual dollar maximum)?
5. Is the provider acceptable (e.g., a provider who contracts with the health plan or an out-of-network provider likely to be approved by the plan)?
6. Is there any basis for a “benefit exception”?
7. Are there any special regulatory or legal requirements that apply to the coverage decision?

Each of these steps, and some of the key considerations that may arise at each step, are described below.

### **Key Decision-Making Steps and Considerations**

#### **1. Is the requested service a *covered* benefit?**

A service can be: *clearly covered*, *clearly not covered*, or *perhaps covered*. *Clearly covered* or *clearly not covered* means the service is explicitly included or explicitly excluded, respectively, in the member’s evidence of coverage. *Perhaps covered* means

coverage depends on the plan's determination of whether or not the service is "experimental," "investigational" or not "generally accepted."

A few of the services in the case vignettes were *clearly not covered* by most of the plans. In most cases the health plan believed it was unlikely that benefit exceptions would be made for these services, which included over-the-counter vitamins, acupuncture and expenses to travel to an out-of-state provider.

However, by deliberate design, many of the services in the case vignettes fell into the *perhaps covered* category. These included a number of innovative treatments, such as a new surgical procedure and a Canadian physical therapy program. The health plans reported that they would undertake a review of the service in question, which would likely include at least some of the following:

- **Review of the literature.** In reviewing available information about a service, health plans are looking for high-quality evidence of its effectiveness. Although plans seem willing to look at studies from a wide range of sources, including case reports from providers, articles in peer-reviewed journals that are based on well-designed studies are given the most weight. Several plans also mentioned using information from The Cochrane Collaboration, an international organization that produces systematic reviews of health care services and interventions.<sup>1</sup>
- **Technology assessments by external organizations.** The health plans rely heavily on assessments of new medical services that are conducted by three outside organizations likely not well known to consumers: Hayes, Inc., the Blue Cross Blue Shield Technology Evaluation Center (TEC), and ECRI (formerly the Emergency Care Research Institute).<sup>2,3,4</sup> Medicare's policies are also influential in health plan coverage decisions.
- **Discussions with "experts."** Health plans regularly consult with physician experts about their opinions of new or innovative services. The experts include

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<sup>1</sup> The Cochrane Collaboration (<http://www.cochrane.org>) is an international non-profit and independent organization that produces and disseminates systematic reviews of healthcare interventions and promotes the search for evidence in the form of clinical trials and other studies of interventions. It publishes the quarterly *Cochrane Database of Systematic Reviews*.

<sup>2</sup> Hayes, Inc. (<http://www.hayesinc.com>) tracks new and emerging healthcare technologies and produces information for health plans and others to offer guidance in coverage policy development.

<sup>3</sup> The Technology Evaluation Center (TEC) (<http://www.bcbs.com/tec>), which is operated by the national Blue Cross Blue Shield Association and has a close collaboration with Kaiser Permanente, creates assessments of medical technologies based on "a comprehensive evaluation of the clinical effectiveness and appropriateness of a given medical technology." TEC's work is guided by a Medical Advisory Panel (MAP), which is composed of independent physician experts.

<sup>4</sup> ECRI (<http://www.ecri.org>) is an independent and nonprofit health services research agency that works to improve the safety, quality, and cost-effectiveness of healthcare, both in the United States and around the world. Its funders and collaborators include the U.S. Agency for Healthcare, Research and Quality (AHRQ) and the World Health Organization. Among its activities is a Health Technology Assessment Information Service that conducts unbiased, objective technical assessments on how well drugs, devices, and medical procedures work. It also works to make information available in a patient-friendly format.

local, regional and often national providers. The more innovative the service, the more likely it is that health plans will consult with experts outside of the state.

- **Consultation with the member's physicians.** The member's physician(s) and other providers are a critical source of information for the health plan. Every health plan noted that a member's treating providers know the member the best, and can most effectively explain, support and advocate for the member.

## **2. Is the service appropriate based on *medical policy*? Is the service *medically necessary* for the member?**

Even when a service is a covered benefit, it may or may not be covered for a specific member in a specific situation. A plan may have a *medical policy* that defines when a particular type of service is covered and any specific coverage requirements (e.g., age, condition or diagnosis).

In addition, not all covered services or services that meet *medical policy* may be *medically necessary* for all members at all times.

We did not attempt to compare the definitions of *medical necessity* used by each health plan, partly because it is likely that each plan uses a slightly different definition but also because it was clear from our interviews that *medical necessity* determinations are often complicated and difficult to make. However, it appears that plans use the same general principles in determining *medical necessity*, including:

- Is the service "reasonable and necessary" for diagnosis or treatment?
- Is the service "appropriate" in light of the medical needs and condition of the member?
- Will the service help improve treatment?
- Will the service likely help improve function, maintain ability, and/or prevent deterioration?
- Is there an equally effective, less costly alternative that would achieve the same outcome?

In answering these questions, health plans may review a range of information, such as: clinical details in the member's medical history (e.g., signs and symptoms); results of previous diagnostic tests and previous treatments; and alternative treatments that have already been tried or that could be furnished instead of the requested service.

In certain cases, a health plan may apply a *clinical guideline* to determine whether a covered benefit is appropriate for a particular member. These guidelines, which are most commonly developed by external organizations and then adopted by health plans, are

based on surveys of scientific literature and the best available evidence for the treatment of specific health conditions or the use of certain services. For example, in the case vignette about Synagis, almost all of the health plans reported that they generally use the *clinical guideline* developed by the American Academy of Pediatrics to determine whether or not to cover Synagis for individual members.

In some cases, cost can play a factor in the coverage decision-making process. In particular, plans will consider a less costly, equally effective service before a more costly one in making a coverage decision.

### **3. Is the benefit subject to any limits?**

Even if a service is covered and medically necessary, coverage may be restricted by explicit benefit limits (e.g., number of visits, annual dollar maximums). In the case vignettes, the service most likely to be limited was durable medical equipment. Although very mindful of the problems that these limits can cause for members, the prevailing view of health plans toward these limits was expressed as some variant of “The benefit is the benefit” or “The purchaser bought a benefit.” In other words, the health plans see themselves as administering and enforcing the benefit limits developed and imposed, or at least agreed upon, by employers and other purchasers.

### **4. Does the provider contract with the health plan? If not, is there a strong basis for approving the use of an out-of-network provider?**

Three of the case vignettes involved requests for services from providers who did not contract with the health plan. In general, health plans strongly prefer to have members obtain care from network providers, for both quality and cost reasons. However, all of the plans regularly review, and often approve, requests for out-of-network services, and they reported similar issues and processes for making coverage decisions in such cases:

- Is there a provider in the health plan’s network who could provide the service?
- Is the out-of-network provider being requested by the member or by his or her physician? If the request is from the member, does his or her physician agree that the out-of-network provider is a better choice than any network provider?
- Does the non-network provider have unique expertise that is not available within the network (e.g., language, culture, experience with a particular procedure)?
- Would there be an unacceptable delay in obtaining services if care were redirected to a network provider?
- Would the non-network provider agree to meet the health plan’s quality standards, such as credentialing requirements, or submission of information for utilization review?

In making these determinations, health plans seek information from a wide range of sources, including published literature, outside experts, and the member's physicians. If a request for care from a non-network provider is approved, health plans generally try to negotiate a variety of terms and conditions with the provider, including rates of payment and agreement to hold members harmless from any additional fees.

## **5. Is there any basis for a benefit exception?**

In some cases, health plans will approve a non-covered benefit as an exception. The standards used by health plans to make such benefit exceptions are quite strict. In general, the substitute benefit must provide a clear, predictable, documentable, and contemporaneous savings for the health plan.

For example, in the case vignette involving a limit of coverage for durable medical equipment, the child's family argues for a benefit exception based on the theory that approval of the requested equipment might avoid the need for surgery, which would be a covered benefit. Most of the health plans reported that they would likely not approve a benefit exception in this situation because any savings were highly speculative. In the case vignette involving a request for coverage of acupuncture, the lack of peer-reviewed literature or other robust evidence was regarded as a major barrier to approving an exception. However, health plans seemed somewhat more willing to consider benefit exceptions in cases where the member had exhausted other available and generally accepted treatment options. One example mentioned by several plans was end-of-life treatment for children.

Health plans also noted that they often do not have the contractual authority to make benefit exceptions. This is most commonly the case for members who are covered by "self-insured" or "self-funded" health plans. (An employer-sponsored health plan is "insured" if the employer purchases health insurance from a health plan, but "self-insured" or "self-funded" if the employer pays for the health care costs of its employees directly. Most self-funded employers contract with a health plan to administer their benefits, even though they do not purchase health coverage.) In self-insured plans, the employer group, rather than the health plan, generally has the contractual obligation to make decisions about benefit exceptions.

An additional issue raised by several health plans in the discussion of benefit exceptions is the need to determine an "end-point" for treatment when reviewing non-traditional therapies. For example, in the acupuncture case, several health plans said that they would clearly outline the desired treatment expectations and outcomes and a set number of treatments as part of any benefit exception.

## **6. Are there any special state regulatory or legal requirements that apply to the coverage decision?**

In Massachusetts, as in most other states, members of health plans are entitled to certain legal protections, including requirements governing health plan internal grievance procedures and independent external reviews. These protections are overseen by the state Office of Patient Protection, which is part of the Massachusetts Department of Public Health (<http://www.state.mass/dph/opp>). Health plans noted that their health coverage decisions and decision-making processes must comply with these legal requirements for members whose health plans are governed by these rules. (Members covered by insured plans are subject to state law; these state rules do not apply to members of self-funded plans.<sup>5</sup>) In most cases, these rules govern process rather than the clinical factors that underlie a coverage decision.

## **OPPORTUNITIES**

We were impressed by the careful and thoughtful approach of the health plans to each of the case vignettes. It is clear that medical coverage decisions are complicated and often not clear-cut. Based on our interviews, there appear to be a number of issues that might be pursued further by the Consortium, through the Work Group or otherwise, and by a variety of other stakeholders to make use of these findings.

Four of the most interesting are:

1. Help improve the ability of physicians and other providers to support requests for coverage;
2. Develop a better understanding of the major external organizations that produce technology assessments and clinical guidelines;
3. Explore the potential to increase benefits for durable medical equipment; and
4. Continue efforts to ensure that health plans are knowledgeable about other financial resources and supports for CSHCN and their families.

Each of these opportunities is discussed below.

### **1. Help improve the ability of physicians and other providers to support requests for coverage.**

The discussions with the health plans made clear the critical role of physicians and other providers in supplying the information health plans need to make coverage decisions. Yet health plans reported that physicians often provide inadequate information to support

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<sup>5</sup> The federal ERISA (Employer Retirement Income Security Act) law also provides members of employer-sponsored plans (both self-funded and insured) with certain legal rights regarding grievances and appeals.

coverage requests. Acknowledging that physicians are very busy, and often resent the “administrative hassle” of seeking health plan approval for services, health plans believe that physicians and other providers could do a much better job supporting members in seeking coverage. In the words of one medical director:

*“I have only ever seen a few ‘ideal’ letters of support from a physician. Such a letter should accompany any request for non-standard care. Physicians ought not to expect that their requests will be approved simply because they are ordering a service and put one or two lines down on paper. Sometimes it’s clear that a physician is just sending a letter because the family asked for one but the physician really doesn’t support the request. Or sometimes the physician ‘floats’ a request, not really expecting it will be approved but giving it a shot. But often it’s really hard to tell. I would love to tell physicians to send in requests that tell me: what the literature and other evidence says; what you’re proposing to do; what the expected outcome is; what treatments you’ve tried; what treatment alternatives you’ve considered and why they aren’t suitable; and why you think the requested service is important for this patient and why it’s good quality care...I hope we eventually get this information anyway but the process could be a lot simpler, quicker and easier for everyone, particularly the member, if physicians more often provided better information at the beginning....”*

There may be a useful role for the Consortium or others to play in helping to develop educational material that physicians, medical students and residents, other providers and families could use to support their coverage requests.

## **2. Develop a better understanding of the major external organizations that produce technology assessments and clinical guidelines.**

As noted earlier, health plans often use research and technology assessments conducted by one of the major external organizations (Hayes, Inc., Blue Cross Blue Shield’s TEC, or ECRI) to help inform their medical coverage decision-making. Despite the importance of these organizations, it’s likely that most health plan members have never heard of them, let alone have any understanding of what they do and how they operate. An opportunity exists to develop a better understanding of these organizations, including whether there are ways for families to help inform or participate in their work.

The Institute for Clinical Systems Improvement (ICSI), a Minnesota-based quality improvement organization that produces clinical guidelines and technology assessments for its member health plans and providers, might also be an interesting organization to explore. ICSI has produced more “consumer friendly” versions of some of its health care guidelines, which are designed to “define or provide descriptions of medical terms for the benefit of patients and family members who are well educated but may otherwise be

unfamiliar. The Health Care Guidelines for Patients and Families are not intended to replace traditional patient education materials currently in use, but rather to be used as a tool to assist patients in partnering with their physician in their care.”<sup>6</sup>

ECRI has long articulated a vision of producing information that is useful for patients and families, including creating a “National Patient Library,” although its efforts in this area seem to have moved slowly because of lack of funding.<sup>7</sup>

### **3. Explore the potential to increase benefits for durable medical equipment.**

In discussing the case vignette on durable medical equipment (DME), it was obvious that the typical limit on this benefit not only creates financial hardship for many families but also creates angst for health plans. The Medicaid health plans were an exception because the Medicaid DME benefit has no cap.

Several health plans noted that there are other large purchasers in the state who do not cap the DME benefit (although at least one of these purchasers imposes a 20% coinsurance for DME). The health plans that contract with these purchasers report that the per-member cost of an uncapped DME benefit is very similar to a capped benefit, principally because so few members have the need for DME that exceeds the cap. But these plans are unwilling to change their DME benefit because they fear that they would then be susceptible to “adverse selection,” in which a disproportionate number of people with a need for significant DME would join the health plans with better benefits, giving those plans a disproportionate share of the cost.

The only way to redress this situation would be to require all health plans to provide an unlimited DME benefit. Because of the federal ERISA law, the state could impose such a requirement only on insured plans, not on self-insured plans. Although this would limit the applicability of such a mandate significantly, the Consortium might evaluate whether it might be worthwhile to take some action in this area, given the enormous challenges that the DME limit creates for many families caring for CSHCN.

### **4. Continue efforts to ensure that health plans are knowledgeable about other financial resources and supports for CSHCN and their families.**

All the health plans noted repeatedly their desire and need to know about other sources of financial support for members who have the need for services and supports that are not covered by the health plan. For example, one nurse case manager reported, “The Family TIES Resource Directory is our bible.”<sup>8</sup> Among other important resources named by

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<sup>6</sup> For more information, see <http://www.icsi.org>.

<sup>7</sup> See [http://www.ecri.org/Patient\\_Information/NationalPatientLibrary.aspx](http://www.ecri.org/Patient_Information/NationalPatientLibrary.aspx).

<sup>8</sup> This directory was developed by Family TIES of Massachusetts to help parents and providers locate services and resources for children and youths with special needs. See <http://www.massfamilyties.org/directory/html>.

health plans were the Department of Public Health's *Directions* resource guide and the Catastrophic Illness in Children Relief Fund.<sup>9, 10</sup> These conversations validated from the health plan perspective the important work that the Consortium has done and reaffirm the need to continue to work with health plans in this important area.

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<sup>9</sup> *Directions: Resources for Your Child's Care*, Second Edition, 2004, Massachusetts Department of Public Health. *Directions* is an organizing notebook and a resource guide for families of children with special health care needs. See <http://www.mass.gov/dph/fch/directions>.

<sup>10</sup> The Catastrophic Illness in Children Relief Fund (CICRF) was established by legislation in 2000 to help eligible Massachusetts families pay for services needed to care for children with special health care needs and disabilities. See <http://www.mass.gov/cicrf>.

## **APPENDIX 1. CASE VIGNETTES**

### **Vignette #1: Claire and the Fresh Muscle Biopsy for Metabolic Disorder**

Claire, an almost two-year-old, has seizures and episodes of clumsiness when she seems to lose her balance. She also has a number of developmental delays: she is cruising, but not walking, her fine motor skills are delayed, but improving; her speech is quite delayed. She only babbles, but she used to use some words such as "book" and "dog." Her receptive language is normal.

Claire has undergone extensive blood and urine testing, an MRI, and karyotype and mitochondrial DNA tests—all with normal results. Despite the normal test results, Claire's specialist suggests she has mitochondrial disease, which can be difficult to diagnose. The doctor has recommended that Claire have a muscle biopsy to determine if she does have mitochondrial disease. Because he believes the results from frozen or fixed tissue samples are not reliable, he believes better results would be obtained if Claire has a fresh muscle biopsy. This procedure can only be performed at a few centers in the US, and so the physician has referred Claire to a non-participating provider in Atlanta for the test. Claire will be able to travel there safely by commercial airline. Claire's doctor has also recommended that she take a variety of vitamins and cofactors, including Coenzyme Q10, Vitamin E and B50 Complex, and have a comprehensive nutritional evaluation.

Claire's family is requesting coverage for the cost of the fresh muscle biopsy, vitamins and cofactors, and a complete nutritional evaluation.

## **Vignette #2: Sarah and Reconstructive Plastic Surgery**

Sarah is an 11-year old born with Crouzon's Syndrome, a rare genetic condition that inhibits normal growth of the skull and facial bones. Poorly formed eye sockets and ear canals result in vision and hearing loss; obstruction of the nasal passages create breathing, eating and speech problems; and often there is severe malocclusion between the upper and lower jaws. These physical complications are often compounded by the emotional effects of growing up looking different.

Since birth, Sarah has required multiple surgical procedures to expand her skull to accommodate brain growth and allow normal functional development. Because of severe nasal obstruction, she had a tracheotomy from birth to age 6. A shunt was inserted due to hydrocephalus, with several revisions until age 3. At age 8, Sarah had a reconstructive facial surgery, which had multiple complications and was largely unsuccessful.

In the last few years, a new technique has been pioneered called distraction osteogenesis using the Rigid External Device or RED. There are only a few surgical teams experienced in this technique. Sarah's surgeon in the Boston area does not perform this surgery but her parents found out about this procedure independently and sought consultation with the NYU team. She has been approved as a candidate for the surgery, but the reconstructive team at NYU does not participate with her health plan. The doctors have also recommended that prior to the surgery, she receive a palate expander to relieve the severe overcrowding of her upper jaw teeth. This procedure could take place at an in-network provider.

There have been two publications in peer-reviewed medical journals describing favorable short-term outcomes (one year) involving fewer than 20 patients from one of the institutions performing this procedure.

Sarah is tired of looking different and being stared at where ever she goes. In addition, her speech is not clear and she now wears a hearing aid. She recently started middle school and has experienced some teasing. While she wants to have the surgery, she is extremely anxious, especially given the poor outcome of her last surgery.

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### **Vignette #3: Michaela and Acupuncture for Inflammatory Bowel Disease**

Michaela is a 17-year-old high school senior forced to interrupt her studies due to a recent severe onset of inflammatory bowel disease. The condition is now so serious that she has become malnourished to the point of losing her periods. Michaela has been treated with a range of anti-inflammatory drugs, steroids and immunosuppressant agents, all with only intermittent and modest relief.

After some research, she and her family have become interested in acupuncture as a possible means of minimizing the symptoms of her disease. Claire's gastroenterologist has encouraged her to pursue these therapies, and has written a letter of support on her behalf to the health plan. There is published literature on acupuncture therapy for IBD in the *Journal of Acupuncture* but not in peer-reviewed medical literature.

#### **Vignette #4: Alexander and the Electric Wheelchair**

Alexander is an almost 16-year-old who has cerebral palsy. A sophomore in high school, Alexander is, according to his family, in wonderful “shape,” in their view due in no small part due to the various therapeutic interventions and durable medical equipment in his life. For example, he has never required any orthopedic surgeries.

Alexander is in the midst of a tremendous growth spurt, which is having significant consequences for the equipment he uses. He is far too tall for his manual wheelchair and needs a new one immediately. The Boston Jacket (upper body brace) that was made for him just six months ago is already too small. (He is being measured for a new one next week. As an example of what a positive difference this has made, his spine curvature has been reduced from over 40% to virtually negligible when he is in the jacket. Without this, he would need back surgery).

In addition, the powered wheelchair that Alexander uses is also in need of replacement. There are two issues with his current wheelchair --- he is too tall for it so a larger frame and seat cushions are necessary. Also, the chair is in very poor condition; the motors need replacement. The DME supplier has told his family that repairs to the motor and new cushions alone would come to over \$2000. If the frame is enlarged, which is needed, this would add further cost. In sum, repairs to the current wheelchair that are immediately necessary would be well over \$2000 on a chair that probably doesn't have much life left. (It is over 4 years old.)

A new Invacare power wheelchair costs \$8000. The needed Jay cushions (for seat and back) add another \$1200. A new manual wheelchair with the necessary cushions would cost about \$4000. The new body brace will run about \$1500. Alexander also needs a piece of equipment, called a prone stander, to help him be upright on a daily basis, to further strengthen his leg muscles, improve posture, and help with overall health. The Leckey Freestander, the equipment of choice, costs somewhere in the neighborhood of \$1200. (It was recommended by the orthopedist and physical therapist at the orthopedic hospital at which Alexander was evaluated late April of this year.)

In total, Alexander and his family are facing durable medical expenditures of over \$16,000 in the next couple of months. Their current health plan has an annual limit on durable medical equipment of \$1,500. They have no other medical insurance.

Alexander and his family would like their health plan to consider an exception to pay some or all of the cost of the necessary DME. They argue that there is a substantial benefit to these outlays for DME for the health plan because Alexander avoids surgery.

## **Vignette #5: Sidney and Major Depressive Disorder<sup>11</sup>**

Only a month into his sophomore year of high school, Sidney was feeling anxious and alone. He was not sleeping well at night, often going several nights at a time without sleep. His appetite was significantly decreased, and he complained frequently of headaches and stomachaches. Though he had always been a good student, Sidney was unable to concentrate and his school performance declined steadily. Eventually, he missed 8 full days of school and withdrew from sports, social activities and friendships. His parents had tried to get him into therapy but he refused. By spring, Sidney had attempted suicide and his parents had taken him to the emergency room. There is a history of depressive illness in Sidney's family; his father suffered a serious depressive episode 10 years ago and was hospitalized, though he never attempted suicide.

Sidney was admitted to the hospital's psychiatric unit, where he was treated for several days. With assistance from the hospital social worker, his parents arranged for him to see a psychiatrist after his discharge. After several sessions, the psychiatrist referred Sidney to a psychologist for on-going treatment, including cognitive behavioral therapy and family therapy. The psychiatrist has maintained contact with Sidney to oversee his medication. However, Sidney's family found another psychologist who does not contract with the family's health plan, and Sidney has already seen this provider twice and has bonded well. His parents are now requesting that the health plan cover ongoing psychotherapy with this provider. They are afraid that if he has to establish a relationship with another provider that he will refuse to continue therapy.

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<sup>11</sup> This vignette is adapted from Harriette B. Fox et al., *The Strengths and Weaknesses of Private Health Insurance Coverage for Children With Special Health Care Needs*, (MCH Policy Research Center, Washington DC, 2002,) p. 23.

## Vignette #6: Francesca and the Spider

Francesca is an 11-year-old girl with cerebral palsy. Her parents have requested that the family's health plan authorize a stay for Francesca at The Intensive Rehabilitation Center in Toronto, an international therapeutic clinic using a new method of rehabilitation for children, teenagers and adults with CP and other neuromuscular disorders. The new method involves an intensive physical therapy program, including the use of a system named the "Spider" to help patients gain the ability to walk independently.

The "Spider" consists of a number of elastic cords of different elasticity attached to certain points on the patient's body at one end and to the different points on the surrounding construction on the other one. This unique suspension device enables independent and controlled movement as well as strengthening of the affected parts of the body. The equipment enables the practitioner to create a unique "Spider's" web prescribed individually for each patient. The flexible connectors allow changes to help the patient improve balance and posture as well as to develop voluntary movements with greater precision and ease of movement. The "Spider" promotes independence with security and sometimes motivates reluctant patients to participate in therapy.

According to the Center, the Spider enables patients to:

- Implement a full course of recommended exercises in any chosen position
- Exercise selected parts of the body and/or selected muscles in a controlled manner.
- Attain vertical position of the body when this is not usually possible.
- Perform activities of daily living such as sitting, crawling, walking.
- Improve spatial awareness.
- Decrease the intensity of pathological movements and ataxia (lack of coordination).
- Improve stability and voluntary movements of the body.
- Improve balance and coordination of the body.
- Align the body in a way that stimulates proprioceptors in the muscles and the joints.
- Improve the performance of the vestibular system.

The Intensive Rehabilitation Center offers a 28-day-course of rehabilitation (six days of exercises in a week and one-day of rest). The patient is treated approximately 220 minutes a day, depending on the abilities of the patient. Individual therapy consists of massage, soft tissue and joint mobilization, stretching, strengthening, range of motion exercises, activities of daily living training, balance and coordination activities, gait

training, and 60 to 120 minutes of exercises in the "Spider" equipment. "Spider" can be combined with conventional physical therapy methods and with most rehabilitation and sports equipment. Practitioners argue that the "Spider" makes treatment more effective because it can substitute for the hands of two or three physical therapists and allows fuller use of the patient's strength and abilities.

Francesca's physician has written a letter expressing her support for the family's desire to have Francesca attend the Center's program, noting that there is some published information showing that the program is efficacious. This information, based on a small study from a similar program in Poland that was translated from a Polish physical therapy journal, is included with the doctor's letter.

## **Vignette #7: Courtney and Synagis**

Courtney is a 30-month-old girl with central hypopituitarism, cortical blindness, seizures, s/p (palate surgery) cleft palate repair, with gastroesophageal (GE) reflux and history of aspiration pneumonia. She is fed by G-tube. She was hospitalized last winter for pneumonia for 6 days. She was born at full term and did not have respiratory compromise in the newborn period.

She is cared for at home and has two older school age siblings.

Courtney's pediatrician has recommended that she receive Synagis throughout the winter. He says "if this kid got RSV [Respiratory Syncytial Virus] she'd definitely land in the hospital or it could kill her."

## APPENDIX 2. SUMMARY OF HEALTH PLAN RESPONSES

Note: Of the nine plans interviewed, one was not willing to discuss the specific case vignettes in detail. From the other eight, although we did not attempt to get definitive decisions about whether coverage would be approved in each case, we could often get a general sense of the *likelihood* of coverage. This table summarizes our general sense of those probable outcomes.

The frequency of the “It Depends” response highlights the significance of input from external organizations, medical journals, and the member’s own health care provider(s).

Case Vignette	Likely Would Cover	Likely Would Not Cover	It Depends	Most Common Issues/Questions
<b>#1 Fresh muscle biopsy at out-of-state provider</b>				
Biopsy	4 plans	0 plans	4 plans	-How would biopsy change treatment plan? -Is Atlanta the only place that can do it?
Travel	0 plans	7 plans	1 plan	-Would seek other resources for family
Vitamins and coenzymes	3 plans	2 plans	3 plans	-Not covered if available over the counter
Nutritional evaluation	8 plans			
<b>#2: Reconstructive Plastic Surgery at out-of-state provider</b>				
Rigid External Device			8 plans	-Is functional improvement expected? -What are alternatives? -Is there an appropriate in-network provider?
Palate expander			8 plans	-Are there sound medical reasons to do the procedure at the same provider that will do the RED?
<b>#3: Acupuncture for Inflammatory Bowel Disease</b>		6 plans	2 plans	-Excluded service for all plans -Some plans might cover depending on review of evidence and what other treatments have been tried
<b>#4: Electric Wheelchair and other DME</b>	2 (Medicaid plans, unlimited benefit)	6 plans		-Limited benefit -Not strong support for benefit exception
<b>#5: Out-of-network provider for treatment of major depressive disorder</b>		2 plans	6 plans	-2 visits is not compelling “relationship” -Decision would depend on understanding more about why the family wants to use the provider, if there are special circumstances and any issue of timely access in network
<b>#6: “The Spider,” an innovative treatment for cerebral palsy</b>		8 plans		-Weak evidence -Condition doesn’t require residential treatment -Other treatments available
<b>#7: Synagis</b>	1 plan	3 plans	4 plans	-Doesn’t meet AAP guidelines -But “if physician cares enough to make case, would likely approve it”