

Navigating the Affordable Care Act

Help for Families of Children with Special Health Care Needs

July 20, 2015

A webinar co-hosted the National Center for Medical Home
Implementation and the Catalyst Center

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LETICIA: Morning and afternoon greetings to you all. Welcome to today's webinar, "Navigating the Affordable Care Act—Help for Families of Children with Special Health Care Needs."

This webinar is presented by the Catalyst Center, the Health Insurance and Financing National Center and the National Center for Medical Home Implementation; both centers are cooperative agreements with the Maternal and Child Health Bureau of the Health Resources and Services Administration.

Webinar Overview

2

- Welcome from the moderator
 - LT Leticia Manning, MPH - HRSA
- What can you expect to learn from today's webinar?
- Who are today's speakers?
 - Stephanie Mucha, MPH - National Center for Medical Home Implementation
 - Meg Comeau, MHA - Catalyst Center

LETICIA: My name is LT Leticia Manning and I am the Project Officer for the Catalyst Center. With me on the webinar today is Dr. Marie Mann, who is the Project Officer for the NCMHI. We both work in the Division of Services for Children with Special Health Needs at the Maternal and Child Health Bureau. I am ecstatic about serving as a moderator for today's important webinar on ACA and Children and Youth with Special Health Care Needs or CYSHCN.

•The Affordable Care Act or "ACA" was upheld once again last month by the Supreme Court. As you all know, this is an extremely important piece of legislation for the CYSHCN population. There are many provisions in the legislation that are beneficial to this population including the removal of annual and lifetime dollar caps for insurance coverage, guarantee of insurance for children and adults with pre-existing conditions, the extension of coverage for young adults to age 26 under their parent's private insurance, the extension of Medicaid coverage to young adults aging out of the foster care system, limits to the amount of out of pocket expenditures and many more; some of which will be discussed on this webinar. I encourage you to refer to www.healthcare.gov for more information and updates to the ACA.

•Meg Comeau from the Catalyst Center at Boston University and Stephanie Mucha from the National Center for Medical Home Implementation at the American Academy of Pediatrics will be our presenters today. The agenda for this webinar includes:

*An introduction to both of the National Centers involved in the creation of the ACA fact sheets

*An overview of the "ACA Fact Sheets for Families" project

*Review of four targeted provisions in the ACA specifically relevant to families of CYSHCN and pediatric providers

*An opportunity for Questions and Answers

•At the end of the webinar, attendees will be able to:

*Summarize technical assistance resources available from both the National Center for Medical Home Implementation and the Catalyst Center, including the ACA Fact Sheets for Families

*Describe four specific provisions in the ACA and their implications for CYSHCN, their families and providers

*Identify other health insurance and ACA-related resources It's now my pleasure to turn the webinar over to Stephanie Mucha, from the NCMHI.

National Center for Medical Home Implementation

3

Stephanie Mucha, MPH
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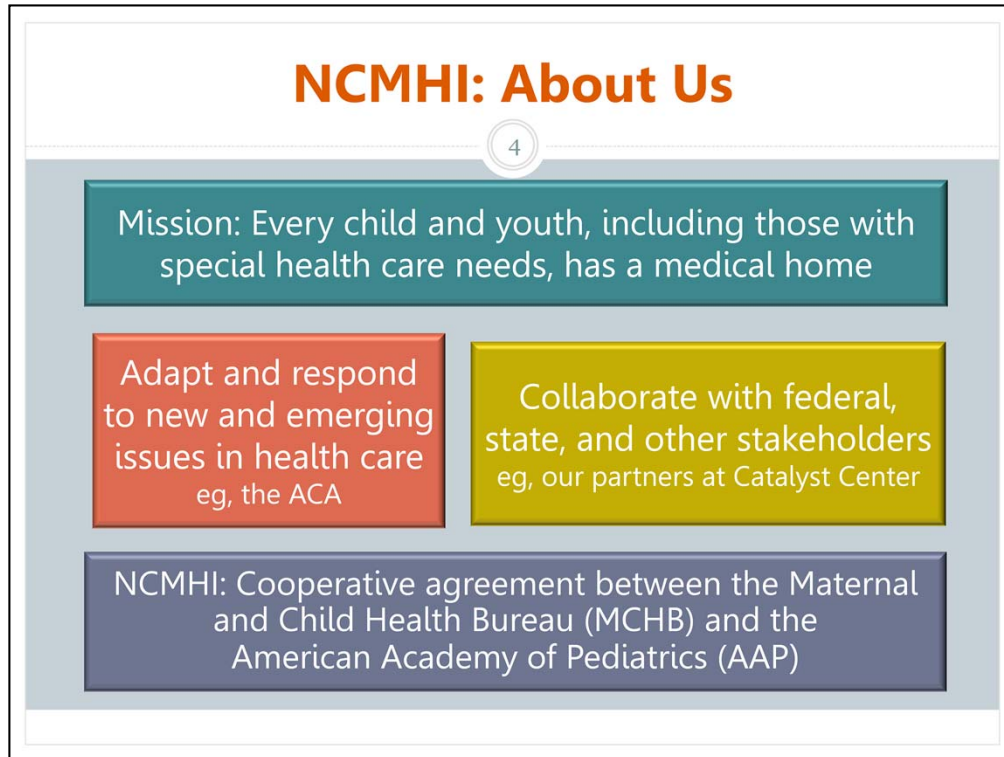
American Academy
of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™

STEPHANIE: Hello. My name is Stephanie Mucha and I'm happy to be speaking with you all today.

As Leticia mentioned, I'm with the National Center for Medical Home Implementation – a cooperative agreement between MCHB and American Academy of Pediatrics (AAP). I think most of you may be familiar with the AAP, but I think it's important to note that it is a distinct and separate organization from the National Center. However, the National Center and the AAP collaborate on many, many medical home-specific activities of importance to the pediatric population and their families.

I have the distinct pleasure to work with both the National Center and the AAP. For the Academy, I work on initiatives focused on the clinical care for children with disabilities, including autism, and their families. For the National Center, I work on the more system-based aspects of the world of pediatric disabilities – like how the ACA would affect this population and their families. I think of myself as the center of the Venn diagram, which is fitting, I think, because we all know that care for children and youth with special needs is multi-faceted, with multiple layers and multiple players.

I'm here today to briefly highlight the National Center offerings and resources and at the end of the presentation, AAP resources will also be listed for your information and use.



STEPHANIE:

- Our goal, our mission, the reason we do what we do, along with federal agencies, particularly the MCHB, and so many of our partners – is working to ensure that all children and youth, including children with special needs, have access to the medical home approach to care. New focus on health disparities, working with populations who are at-risk and vulnerable, based on evidence that these populations do not have access or understanding of medical home.
- We continuously work to stay up-to-date on new and emerging issues not just in health care –like the ACA and its impact and effect-- but also in technology, policy, and culture.
- Use of emerging technology and social media to communicate our message

NCMHI: Offerings & Resources

5

We offer:

- Training & education opportunities
- Individualized technical assistance
- State specific medical home information
- Connections to pediatric medical home experts

Our resources include:

- "Care Notebook for Parents and Families"
- "Building Your Medical Home" online resource guide
- *Medical Homes @ Work* e-Newsletter
- Instructional videos
- Family-friendly information

www.medicalhomeinfo.org

Your complete source for pediatric medical home information and support

STEPHANIE:

This is to be read, as is, with some additional examples, but leading participants to all offerings – housed on the www.medicalhomeinfo.org website.

Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs

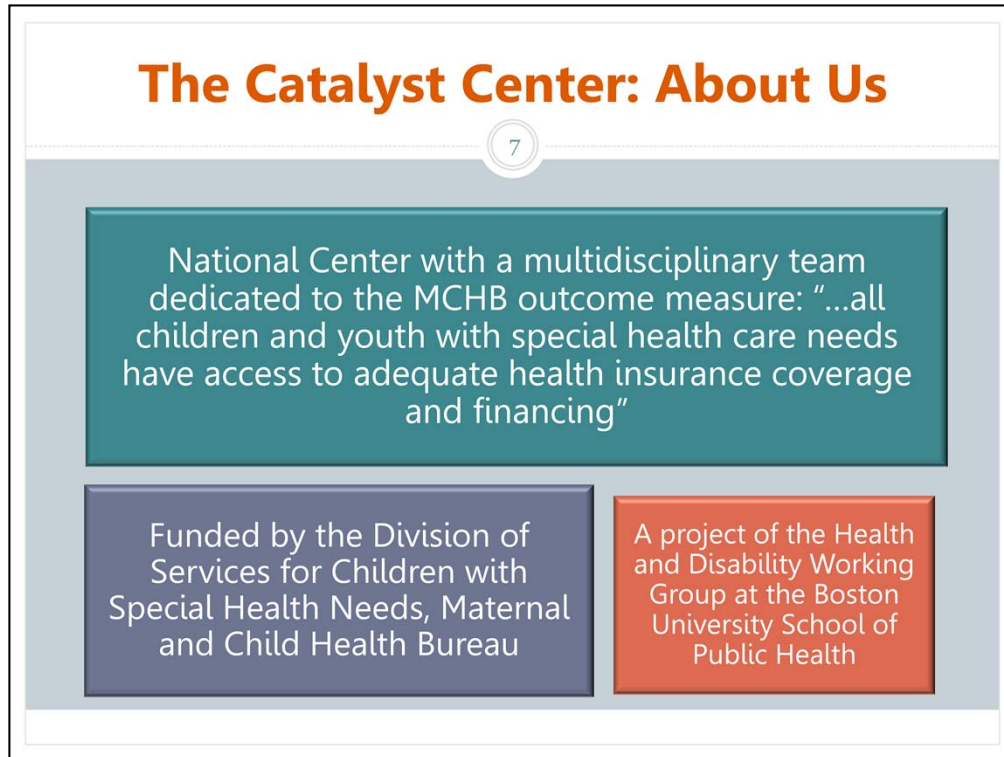
6

Meg Comeau, MHA **Co-Principal Investigator**

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MEG: Thank you Stephanie and thanks to today's webinar participants from a wide range of stakeholder groups who've taken time out of their busy schedules to join us today. My name is Meg Comeau and I'm the co-principal investigator for the Catalyst Center.



MEG: For those of you who are not familiar with the Catalyst Center, let me take a moment to share a quick overview of who we are and what we do....

- The federal Maternal and Child Health Bureau has six core outcome measures for CYSHCN and there is a national technical assistance center dedicated to each. The Catalyst Center is the one dedicated to working with States and stakeholder groups on achieving the outcome measure that: "...all children and youth with special health care needs have access to adequate health insurance coverage and financing for the care they need". Our partners in the work we'll discuss today, the National Center for Medical Home Implementation is the one dedicated to, you guessed it, medical home.
- Because health insurance coverage and financing is influenced by a wide variety of factors, we have assembled a multidisciplinary team which includes expertise in health policy research and analysis, economics, epidemiology, social work and more. Our work is funded by the Division of Services for Children with Special Health Needs under the Maternal and Child Health Bureau (MCHB) and we're located at the Health and Disability Working Group at the Boston University School of Public Health.

The Catalyst Center: What Do We Do?

8

- **Provide technical assistance** about health care financing policy, practice, and the ACA to states and stakeholders
- **Conduct policy research** to identify and evaluate coverage and financing strategies
- **Create resources:** examples include our [State-at-a-Glance Chartbook](#), [ACA fact sheets](#), other [health care reform](#) briefs, [tutorials](#), [family resources](#), and more
- **Connect those interested in working together** to address complex financing issues



•MEG: We provide technical assistance to states and stakeholder groups, conduct policy research on financing strategies, create educational resources and connect stakeholder groups to one another. Let me give you an example of how all these activities can work together to improve coverage and financing of care for CYSHCN: a state Medicaid program contacted us and said they'd heard from family leaders and pediatricians in their state that kids with disabilities whose families were just over the income limit for Medicaid needed help getting better coverage and access to care. Through TA, we helped them think through what strategies for expanding coverage were available, like state plan options, waivers and buy-in programs, and we drew on our policy research to give them more details on how these different strategies were working in other states. We shared educational resources we'd created with their staff and the advocacy community and helped convene a meeting so that everyone could ask better questions of one another and make informed decisions together. This is just one example of the kinds of activities we lead.

•I noted on the previous slide that we are a multidisciplinary team; in addition to our professional expertise, two members of our senior leadership are parents of now young adults with complex medical needs. Our team is very aware, from our personal experience and from the family leaders we've been privileged to work with, how challenging it can be to get the coverage and care kids need to learn, grow and thrive and how frustrating it can be to find the right resources to help. I want to mention here, so as not to disappoint anyone later, that the Catalyst Center provides research and technical assistance on the policy level; we can't advocate or lobby for either groups or individuals and we cannot provide coverage or benefits counseling to individuals. The State Family-to-Family Health Information Centers and the health insurance navigators and consumer assisters available through Healthcare.gov can help individual families through support and information and I'll share ways to contact them and other resources at the end of the webinar.

ACA Fact Sheets for Families Project

9

- Educational materials on **ACA** that are relevant to **families of CYSHCN and pediatric providers**
- Written in **plain language**
- 4 topics:
 - **Wrap-around coverage**
 - **Concurrent care**
 - **Habilitative benefits**
 - **Section 2703 health homes**



•MEG: So now that you have a sense of what the NCMHI and the Catalyst Center are and what we do as individual national TA centers, we'd like to tell you about a educational project we worked on together.

•In the years since the ACA was passed, we learned from national polls and surveys as well as what we were hearing from our stakeholders that while there were many provisions in the ACA that could benefit CYSHCN, their families and pediatricians, people just weren't hearing about them, or they were hearing things that were inaccurate. Together, we did an environmental scan to see what kinds of educational materials on the provisions of the ACA were available to families and pediatricians. We learned that while there were many excellent organizations producing high quality materials on the ACA, few were focused on individual provisions relevant to the needs of CYSHCN or written specifically in plain language for use by families and pediatricians.

•We decided to work together to produce four fact sheets targeted on the following: wrap around coverage in the Marketplaces, concurrent care, habilitative benefits and Section 2703 health homes. We worked with an outside consulting firm specializing in health literacy to help ensure that the fact sheets were indeed in plain language. This was a great learning experience for me; I am used to writing for policy makers and other "wonky" types like myself and I learned a lot from this process about writing more clearly and more concisely, while still making sure the material is meaningful. We welcome your feedback, through the survey at the end of the webinar or via direct e-mail to either Stephanie or myself, on whether we met this goal. Let's take the next several minutes to review each of the fact sheets, and then we'll open up to answering any questions you may have asked.

Health Insurance Marketplace and Medicaid Coverage for Children with Disabilities

10

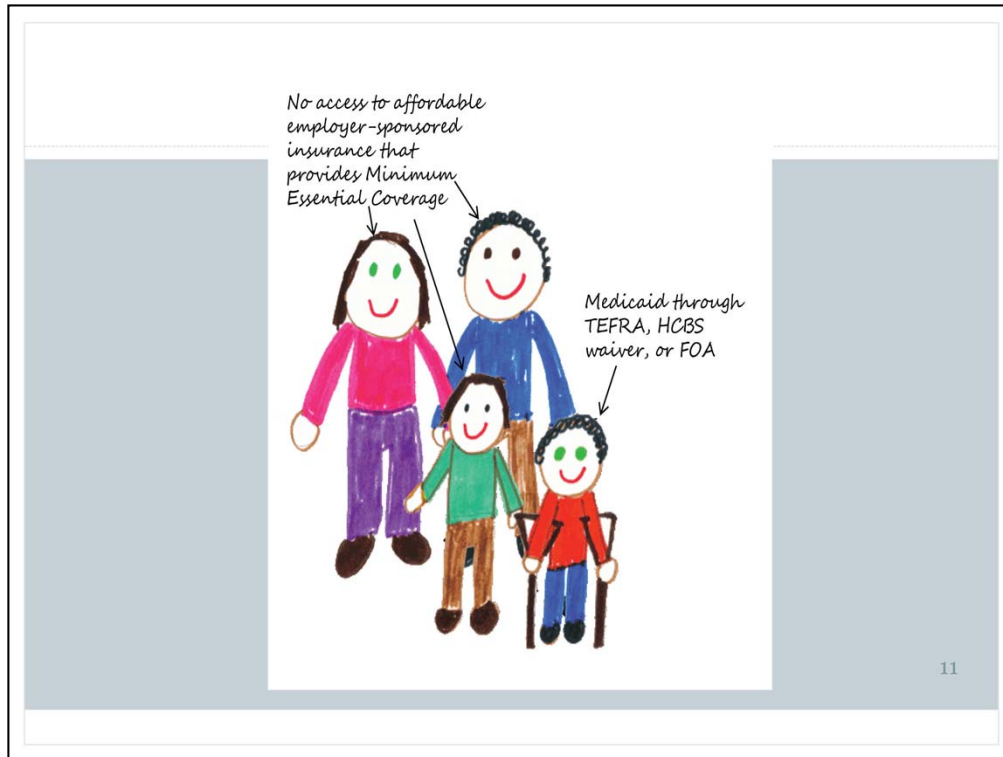
- The State Health Insurance Marketplaces
 - Qualified Health Plans (QHPs)
- The Individual Mandate and Minimum Essential Coverage (MEC)
- What is “wrap” or dual coverage? Who qualifies?
- Is dual coverage allowed along with a QHP?
 - Coverage = yes
 - Subsidies = no, but just for the child with dual coverage



•MEG: Our first fact sheet on dual coverage under the Marketplace and Medicaid is based on one of the most consistent and pressing questions we get asked at the Catalyst Center and it involves a compilation of several provisions in the ACA. Let me start with some background. Each state has a Health Insurance Marketplace, some of which are run by the state, some by the federal government and some as a partnership between the two. The Health Insurance Marketplaces give consumers who don't have access to large employer sponsored insurance access to information about what individual or small group coverage options they're eligible for, help in choosing a plan, and several ways to sign up for their choice. The plans available through the Marketplace are called Qualified Health Plans or QHPs, because they've met certain requirements for affordability and adequacy under the ACA. In addition, individuals and families whose income is between 100% and 400% of the Federal Poverty Level qualify for subsidies to help them afford their QHP premium. The State Health Insurance Marketplaces were not designed to replace other kinds of coverage, but to instead fill in the gaps for people who do not have access to affordable and adequate insurance.

•As I'm sure you know, everyone who can afford it is required to have health insurance under the ACA. This is called the 'individual mandate'. The health insurance that "counts" under the individual mandate has to meet certain standards for adequacy – insurance that meets these standards is called "Minimum Essential Coverage". Among other types of coverage like most employer-sponsored private insurance, Medicaid coverage is automatically considered minimum essential coverage or "MEC".

•This posed a challenging question for families who are eligible for and want coverage through their state Marketplace but whose children with disabilities have Medicaid coverage through a buy-in program, a state plan option or a waiver. Would they be allowed to have both, because Medicaid is minimum essential coverage? Medicaid rules allow enrollees to have private insurance as their primary source of coverage, with Medicaid picking up co-pays, deductibles and other uncovered services – sometimes this is called “wrap” or “dual” coverage. According to the National Survey of Children with Special Health Care Needs (2009/10 – found at www.childhealthdata.org), a little over 8% of kids with special health care needs have dual coverage. So Medicaid allows dual coverage. But it sounded at first as if the Marketplaces would not, because Medicaid is MEC and the Marketplaces were not designed to replace existing insurance that was affordable and adequate. Would families whose children have dual coverage have to give up their child's Medicaid in order to get family coverage through the Marketplace? We consulted with the folks at the IRS who wrote the MEC rules as well as folks at CMS and learned that dual coverage is allowed – the issue of MEC comes into play with regard to the subsidies but only for the child with dual coverage. Let me give you a specific example of how this might look for a family.



•MEG: This is the Jones family; mom, dad and two children. As a family, they don't have access to affordable employer sponsored coverage that is considered MEC and their income is between 100-400% of FPL. So they qualify for both Marketplace coverage and subsidies. But one of their children has a disability and gets Medicaid under a state plan option, a buy-in program or a waiver, which is MEC. They can get coverage for their entire family of four under a Marketplace QHP and they'll be charged a premium for their whole family of four. But their premium subsidy will be calculated for a family of three – the child with MEC is not eligible for it. What they lose in the subsidy for one individual is more than likely offset by the savings in co-pays, deductibles and uncovered services they get through dual coverage for their child with a disability who has greater health care needs than typically healthy children do. Each family will have to decide if this is a good choice for them but the option is there.

Concurrent Care (Section 2302)

12

- What is concurrent care?
 - Curative care
 - Hospice care
- Who qualifies?
- What does this mean for children, families and providers?



•MEG: Our next fact sheet covers Section 2302 of the ACA; concurrent care for Medicaid-enrolled children with life-limiting conditions. I'm not sure if she's with us today, but I'd like to give a shout-out to our friend and colleague at the Indiana F2F HIC, Rylin Rogers, whose idea this particular fact sheet was. Again, let's start with some background:

•When very sick children qualify for concurrent care, it means they can get 2 different kinds of care at the same time: **Curative treatment** focuses on curing a health condition. Examples of curative treatment can range from medicine to fight an infection to chemotherapy to fight cancer. **Hospice care** (end-of-life care) helps patients who aren't expected to live longer than 6 months stay as comfortable as possible. Hospice care can include many different kinds of services — for example, pain management and family counseling.

•Before the ACA became law, children and youth with life-threatening health problems usually couldn't get both hospice care and curative treatment at the same time. For a child to get hospice care, the child's family had to agree to stop all curative treatment first. Now, there were a few programs that existed before the ACA that offered concurrent care, and the Catalyst Center has a policy brief on our website that describes one of them, along with other options for financing pediatric palliative and hospice care (<http://hdwg.org/sites/default/files/palliativecare.pdf>) but in general, this required "switch" between curative treatment and hospice care was a significant challenge.

•In many cases, this meant that families were forced to choose between treatments that might help their child's life-threatening condition and care that would help their child feel as comfortable and supported as possible at the end of his or her life. This was a very painful and difficult choice for patients, families, and doctors.

•Now, under the ACA, state Medicaid programs have to allow enrolled children who qualify for hospice care to get both curative treatment services and hospice care at the same time — if their family and doctors agree it's the right choice for them. This provision also applies in states that operate a separate Children's Health Insurance Program (CHIP) program which offers hospice care. This part of the ACA is called Concurrent Care for Children or Section 2302. The ACA does NOT require concurrent care if families and/or their child's doctors do not want it.

- If you are a parent of a Medicaid-enrolled child with a life-limiting condition who might benefit from concurrent care, talk with your child's doctors for more information. Parents and pediatricians can contact their state Medicaid program to learn more about what coverage and benefit options are available for children with life-limiting conditions.

Habilitative Services (Section 1302)

13

- What are habilitative services?
- What are the Essential Health Benefits (EHBs)?
- How are habilitative services defined under the EHBs?
- Who qualifies?



MEG:

•Habilitative services help people of all ages develop new skills needed for everyday life. They include things like occupational, physical, or speech therapy; and hearing and vision services, too. Habilitative services may also help people build mental, behavioral, or social skills. Certain devices, like hearing aids, may also be considered habilitative.

•Habilitative services are very important for children and youth with disabilities who need help from therapists and other professionals to learn to communicate, get around, or take care of themselves.

•Before the ACA became law, many individual and small employer health insurance plans didn't cover habilitative services. Now, these services are included in the ACA under Section 1302(b), also known as the Essential Health Benefits (EHBs). The Essential Health Benefits are a list of 10 categories of services that individual and small group health insurance plans, both those sold within the State Health Insurance Marketplaces and outside, have to cover. You may recall I mentioned earlier that the Qualified Health Plans (QHPs) must be "adequate" – the Essential Health Benefits are the requirement under the ACA that helps ensure they are.

•The ACA described the EHBs via a list of broad categories – like prescription drugs, maternity services and **rehabilitative and habilitative services**. It did not include details on exactly what must be covered, how much or for how long. The details were determined by using what is called a "benchmark" plan, to be used as a model or example for creating the EHBs and each state has its own. States either chose a benchmark plan from a short list of options or, if the state didn't make a choice, the benchmark plan automatically defaulted to the largest small group plan in the state. When a benefit or service listed in the ACA under the EHBs was not part of the benchmark plan, states were given flexibility in how to fill in the gap. This was particularly true with regard to habilitative benefits, since many benchmark plans didn't already include them. There was some discussion of how habilitative services should even be defined. States could determine themselves what would be covered under habilitative services, how much and for how long or, if it chose not to, insurers could decide for themselves.

•This approach has changed somewhat for the 2016 plan year, which is the next one coming up. The changes do not impact our fact sheet, but so many people are interested in this topic I thought I would share some of the details with you now. Starting in 2016, the US Dept. of Health and Human Services (HHS) has adopted a uniform definition of habilitative services. Here's how that uniform definition impacts the benchmark approach:

- If the benchmark plan doesn't include hab services and devices, states can still define the benefit themselves, using the uniform definition as the standard by which they measure their definition.
- If the benchmark plan does include hab services and devices, states will compare them to the HHS uniform standard to ensure they're adequate.
- If the state doesn't define the benefit, the uniform standard will apply
- Insurers can no longer define hab services and devices for themselves.
- In 2016, rehab services and hab services must be offered at parity with one another - meaning they have to be equal. This is just one example of how the ACA continues to evolve as it's implemented.

Health Home Programs and Coordinated Care (Section 2703)

14

- What is a Section 2703 health home? Who qualifies?
- What is covered?
 - Comprehensive Care Management
 - Care coordination
 - Health promotion
 - Comprehensive transitional care from inpatient to other settings
 - Individual and family support
 - Referral to community and social support services
 - Use of health information technology, as feasible and appropriate
- How can I find out if my state has a Section 2703 program?



•MEG: Our last fact sheet is on Section 2703 health home programs. Just about everyone agrees that care coordination is an important way to make sure a child's family and all his or her care providers are working together as a team. But funding sources for care coordination can be difficult to find. Since the ACA became law, **states have the option to set up a new kind of program that pays health care providers to coordinate care for people with chronic illnesses who are enrolled in Medicaid.** This part of the ACA is called Health Homes (or Section 2703). The federal government provides 90% of the funds for the program for the first two years.

A few things to know about Section 2703 Health Home programs:

- States can choose to start a Medicaid Health Home program, but they don't have to. To date, 19 states have done so, with a handful having more than one.
- 2703 Health Home programs can be very different from state to state. Some states might choose to have a Health Home program for one specific condition — for example, a state could choose to create a program only for people with HIV/AIDS, or for those needing substance use treatment. Some choose to concentrate on a specific geographic area. So just knowing your state has a 2703 program isn't the end of the story; you also need to know the target population, the geographic area and more.
- In states with a health home program, children and youth (and adults) who are enrolled in Medicaid qualify for Health Home services if they have:
 - 2 chronic conditions (which the state can propose)
 - 1 chronic condition and the risk of developing another one
 - A serious mental illness

To find out if your state has a Section 2703 Health Home program:

- Contact your state's Medicaid program member services department

- Go to the Medicaid website ([medicaid.gov](https://www.medicaid.gov)) and search for “states with health homes”
- Contact the Catalyst Center – we keep track of Section 2703 programs and we’d be happy to answer your questions.

Health Care Reform Resources

15

- www.HealthCare.gov
- The Catalyst Center
 - <http://www.hdwg.org/catalyst/news/2015-06-26/1>
(today's webinar landing page)
 - hdwg.org/catalyst/publications/aca
- The State Family-to-Family Health Information Centers fv-ncfpp.org/



•MEG: We've covered a lot of ground during our time today but before we start to wrap up, Stephanie and I wanted to share some additional resources with you. First and foremost is www.healthcare.gov, which is the central location to get more personalized information about coverage, benefits, premiums, cost-sharing and subsidies in the state Marketplaces, Medicaid and CHIP. You can also get access to local navigators and consumer assisters through www.healthcare.gov who can help you learn more about eligibility and enrollment. I know it was challenging when it first opened but it's gotten a lot better; I've tried it myself. Don't hesitate to check it out.

•The Catalyst Center has a wide variety of ACA-related materials on our website, including a landing page for today's webinar. We hope you'll visit.

•An outstanding resource for state-specific information and support are the F2F HICs. They are each directed and staffed by families of children with special health care needs so they know the lay of the land better than anyone. I strongly encourage you to visit the web address on the screen, click on your state and get to know the folks at the F2F and their many resources, if you don't already.

Health Insurance Resources

16



healthychildren.org
Powered by pediatricians. Trusted by parents.
from the American Academy of Pediatrics

AAP Family Resources Website

- The Affordable Care Act: What your family needs to know
- Reviewing your family's health insurance: Questions to ask
- Exclusions and Limitations: Reading the fine print
- Pediatric specialists: Coverage information
- Understanding Cost-sharing: Deductibles, co-pays and co-insurance
- More at www.healthychildren.org/English/family-life/health-management/health-insurance



AAP Division of State Government Affairs

www.aap.org/StateAdvocacy

- Resources and targeted assistance on ACA issues

•STEPHANIE:

In addition to the resources I mentioned earlier from the National Center and available on medicalhomeinfo.org, the Academy has a website, specifically for families. www.healthychildren.org. On that site, in addition to these fact sheets, we have a number of additional resources including topics listed here. All materials on www.healthychildren.org, written with families as the primary audience for this information.

•The Academy has a Division of State Government Affairs that can assist states, in collaboration with their AAP state chapters, on legislation and new initiatives that affect the populations you serve. www.aap.org/StateAdvocacy

Questions?

17

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MEG: let's see now if we have any questions – Leticia? **(Meg and Stephanie answer questions posed by Leticia from the chat box)**

LETICIA: **Closing Remarks:**

- Thank you so much for your questions and thank you again to today's speakers. This webinar series was presented by the National Center for Medical Home Implementation and the Catalyst Center, both cooperative agreements with the Maternal and Child Health Bureau of the Health Resources and Services Administration.
- The National Center for Medical Home Implementation houses a number of care coordination resources on their Web site and on the sites of their partners. These resources include clinical guidance, tools, videos, a comprehensive curriculum and a measurement tool. Visit the links on your screen for more information, and do not hesitate to reach out for individual technical assistance.
- The Catalyst Center offers states and stakeholder organizations technical assistance resources, policy analysis and applied research to help improve coverage and financing of care for children with special health care needs. Visit their Web site for more information or e-mail Meg to ask a specific question.
- To help the Catalyst Center assess the impact of its work, an evaluation survey will appear at the end of this webinar. Please take 10 minutes to provide feedback about whether this webinar was helpful in addressing coverage and financing of care for CYSHCN in your organization or state. Your responses will be completely anonymous.
- Many of the strategies for improving coverage and financing of care for CYSHCN are implemented over time, so in 2 weeks and again in 6 months you will receive follow-up surveys so the Catalyst Center can learn about any financing strategies, partnerships, or practices in your organization or state that were the result of the information shared today.
- The webinar slides, links to resources mentioned during the webinar, and a list of questions and answers will be posted on the Catalyst Center site within a few days. You will receive an email notification when they are available.
- Have a wonderful day and thank you again for joining us.