FLORIDA DEPARTMENT OF HEALTH CHILDREN'S MEDICAL SERVICES MANAGED CARE PLAN Public Input Summary Report

March 2017



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SECTION 1 OVERVIEW

1.1 Background

The Florida Department of Health (Department, DOH), Children's Medical Services (CMS), Managed Care Plan (CMS Plan) is a Medicaid and KidCare health plan option for children with special health care needs (CSHCN). The DOH Office of the CMS Plan and Specialty Programs, is preparing to design and implement an improved service delivery model for children with special health care needs.

As part of this process, the Department hosted three sessions across the state of Florida to solicit public input related to serving families and children with medically complex, special health care needs.

The Department asked North Highland to facilitate public discussions with CMS Plan families, providers and other interested stakeholders to gather input. This input is intended to inform the evaluation of the feasibility of improved models for Title XIX, XXI or V funded delivery systems for Florida's medically complex CSHCN¹.

For general information on the CMS Plan, visit www.CMSPlanFlorida.gov.

1.2 Purpose of this Report

This report is a summary of the input received from CMS Plan families, providers and other interested stakeholders. North Highland assembled and categorized the public input and feedback collected through various forums including comment cards at public meetings, emails, and the CMS Plan public comment form which was available to the public to provide additional input through Friday, February 10th at 5:00 PM EST².

This report captures constraints and opportunities identified by the stakeholders mentioned above through the various forums. The information captured is structured by region (South, Central, and North Florida), in accordance with the public sessions and is summarized based on the three categories below which were discussed at the public forums:

- 1. Achieving Quality
- 2. Developing Provider Payments Incentives
- 3. Helping Families Navigate Health Care Landscape

The report then provides an overview of the key themes and opportunities identified across the regions.

¹ Children with Special Health Care Needs.

² Please refer to Section 5.3 of the Appendix for the raw input. The raw input includes a detailed account of all public input. It is unfiltered and captured exactly as recorded by the public.



1.3 Public Meetings

The public meetings were held to solicit public input regarding how the CMS Plan can better serve Florida's children with medically complex, special health care needs. CMS recognizes public feedback (CMS Plan families, provides, stakeholders, general public) is important input when looking at the health plan service delivery model.

The public meetings were held between Wednesday, February 1, 2017 and Friday, February 3, 2017 and were available to the general public at locations in Fort Lauderdale, Orlando, and Tallahassee³.

A Public Meeting Notice was posted by the Department on the Florida Administrative Register (FAR) 12 days prior to the February 1, 2017 meeting⁴. An email invitation containing a survey was sent to stakeholder interested parties providing them an opportunity to submit questions in advance of the facilitated sessions⁵.

³ Please refer to Section 5.1 of the Appendix for the Public Input Meetings Presentation.

⁴ Please refer to Section 5.2 of the Appendix for the Public Meeting Noticed posted by the Department.

⁵ Please refer to Section 5.2 of the Appendix for the email invitation sent to stakeholder interested parties.

SECTION 2 PUBLIC INPUT

Below is a summary of input from South Florida capturing the key take-aways with a primary focus on driving improvement through *Achieving Quality, Developing Provider Payments Incentives,* and *Helping Families Navigate Health Care Landscape.* This section incorporates both oral and written public input.

South Florida ⁶		
Key Take-Aways		
1 Achieving Quality	 Focus on incremental implementation of meeting value-based care initiatives as it is difficult for providers to maintain so many measures Improve coordination and communication between Nurse Care Coordinators and families 	
2 Developing Provider Payments Incentives	 Improve credentialing process, specifically: Reduce time to credential and re-credential therapy providers that serve infants and toddlers in the Early Steps Program Notify Early Steps providers about re-credentialing process Credential therapists individually so they can then be linked to other groups quickly and easily 	
3 Helping Families Navigate Healthcare Landscape	 Improve transition services for youth aging out of the CMS Plan Inform families of key changes Combine care for families with more than one child with special medical needs Provide greater support for ESL (English as a Second Language) families Maintain home-visits for families 	
4 Other	 Incorporate components of the other state models A true Medical Home Model (Texas) Specialty Area Care Coordinators (New York) One-Stop Multidisciplinary Clinics (Arizona) Maintain the components of the CMS Plan which are going well, specifically: Timely authorizations Broad provider network Comprehensive coverage Ensure children with PKU condition receive complete services to meet all medical needs 	

⁶ Please refer to Section 5.3.1 of the Appendix for the raw input from South Florida.



Below is a summary of input from Central Florida capturing the key take-aways with a primary focus on driving improvement through *Achieving Quality, Developing Provider Payments Incentives,* and *Helping Families Navigate Health Care Landscape.*

Central Florida ⁷		
Key Take-Aways		
1 Achieving Quality	 Improve processing of authorization for low protein foods Shift more authority to Nurse Care Coordinators and recognize them for their good work Maintain Partners In Care Identify an alternative to HEDIS⁸ measures and develop measurements specific to the class and conditions of the children the CMS Plan serves 	
2 Developing Provider Payments Incentives	 Increase reimbursement for special services such as private duty nursing Involve providers in risk and cost savings tied to value based outcomes Consider establishing/expanding pediatric networks close to children's hospitals Institute value-based contracts with providers - for example: Care management incentives tied to fewer ER visits, hospital readmission reductions and patient satisfaction Shared savings models or other alternative payment options Established pediatric network for the CMS eligible population Quality dashboard or performance data that provides accountability to the plan and to the providers Improve low protein food coverage and remove the monthly cap Establish competitive reimbursements to attract and retain specialty physicians and home health providers 	
3 Helping Families Navigate Healthcare Landscape	 Improve process and communication to parents transitioning off the CMS Plan Maintain quick medical approvals that currently occur Consider age eligibility to be increased to at least age 22 Maintain the flexibility for parents to be able to select the primary care and specialist providers Improve enrollment and eligibility process Expand coverage to families who do not financially qualify for the CMS program and provide parents the option to self-pay for CMS coverage if not financially qualified Improve newborn screening coordination Assist families with navigating financial eligibility 	

⁷ Please refer to Section 5.3.2 of the Appendix for the raw input from Central Florida.

⁸ The Healthcare Effectiveness Data and Information Set.



	• Consider a model wherein the CMS Plan would take care of all of Florida's medically complex children and the other MMA ⁹ plans would pay the CMS Plan a fee for overseeing the needs of that plan's medically complex infants and children
	 Preserve the program regardless of federal changes
4 Other	 Most important aspects to CMS/Ped-I-Care:
	 Nurse Care Coordinator – familiar with children's cases and able to navigate the system and help find the right services and providers Quick approval of IV and injectable medicines Great customer service at Ped-I-Care Freedom to choose physicians Medical home model PIC-TFK program with hospice (social worker, nurse care)

⁹ Managed Medical Assistance.



Below is a summary of input from North Florida capturing the key take-aways with a primary focus on driving improvement through Achieving Quality, Developing Provider Payments Incentives, and Helping Families Navigate Health Care Landscape.

North Florida ¹⁰		
Key Take-Aways		
1 Achieving Quality	 Continue care coordination provided by nurses as they are the foundation of the CMS Plan Expand access to care through telemedicine and field clinics Establish a new model that is a coordinated system of care where a child could go anywhere in the state and receive the same kind of service without interruption Preserve social services coordinators for this population Establish a system which offers the administrator flexibility to cover items that are medically necessary for a child's care when they have very specialized needs 	
2 Developing Provider Payments Incentives	 Remove obstacles like low reimbursement for providers Provide flexibility for the administrator of the plan to offer providers in their network a competitive reimbursement within the market place Change payment structure now. Use Purchased Client Services 	
3 Helping Families Navigate Healthcare Landscape	 Remove obstacles like low salaries, low morale and competition from the private sector to attract and retain Nurse Care Coordinators Improve screening process for eligibility Expand CMS Plan and provide a private pay option Establish transition efforts for children and families that fall off of the plan due to becoming over the income limits – consider a high risk pool for them to join and pay a premium but still have access to CMS services of care coordination and follow up 	
4 Other	 Continue coverage for medically modified low protein foods for PTS inborn errors of metabolism (identified through state newborn screening) Leverage the current CMS MMA¹¹ Program to better reflect and utilize the resources and talent available within the current CMS system: Fully utilize the CMS Medical Directors, including involvement in the retooling Make care coordinators more prominent Provide CMS Medical Directors with the authority to enhance provider payments to further assure that CSHCN¹² can access needed services Seek the necessary contract, legislative, and waiver changes to allow enhanced payment rates for providers without the necessity of adopting a full-risk model 	

¹⁰ Please refer to Section 5.3.3 of the Appendix for the raw input from North Florida.
 ¹¹ Managed Medical Assistance.
 ¹² Children with Special Health Care Needs.



SECTION 3 NEXT STEPS

CMS will be facilitating Small Group Community Chats with families across the State. DOH will be providing more information in the near future surrounding these Chats.

Based off key findings, CMS team to post the report and keep the members and the public informed via the website, **CMSPIanFlorida.gov**.

Comments may be submitted to CMS at any time by emailing <u>cmsplan@flhealth.gov</u>.



SECTION 4 APPENDIX

4.1 Public Input Meetings Presentation

Below is a copy of the presentation from the public input meetings. Please double-click on the image to open and view the full presentation.



4.2 Public Notice/Communications

Below is a copy of the Public Meeting Notice posted by the Department on the FAR¹³. The posting was followed with an email which was distributed to stakeholder interested parties.

Mission: To protect, promote & improve the health of all people in Florida through integrated state, countly & community efforts.		Rick Scott Governor Celeste Philip, MD, MPH Surgeon General and Secretary
	Vision: To be the Healthiest State in the N	Vation
DEPARTMENT OF HEALTH Office of Children's Medical Service:	s Managed Care Plan	
The Florida Department of Health ar	nnounces a public meeting t	o which all persons are invited.
DATES AND TIMES: February 1, 2,	and 3, 2017 from 9 a.m. to	11 a.m. ET each day
LOCATIONS: Ansin Building, 1300 Department of Health—Orange Cou Office Complex, 4052 Bald Cypress order of meeting dates)	inty, 6101 Lake Ellenor Drive	e, Orlando, Florida 32809; Capital Circle
GENERAL SUBJECT MATTER TO	BE CONSIDERED:	
	h care needs and is offered	a Medicaid and KidCare health plan by the Florida Department of Health ww.CMSPlanFlorida.gov.
families, providers and stakeholders evaluation of the feasibility of improv Florida's medically complex children include a presentation on factors im	entatives of the Department s and the general public to g ved models for Title XIX, XX n with special health care ne pacting the CMS Plan mode tion to serve children with sp	will facilitate discussions with CMS Plar ather public input intended to inform the I or V funded delivery systems for eds (CSHCN). While the meeting will I and information on other service becial health care needs, the goal is to
Public participation in this meeting is Plan. Participation is also solicited w disability or family status. Persons w Disabilities Act (ADA) or require tran (Leda.Kelly@NorthHighland.com) at	vithout regard to race, color, vho require special accomm nslation services (free of cha	odations under the Americans with irge) should contact: Leda Kelly
Individuals may also submit written Leda.Kelly@NorthHighland.com.	comments or exhibits by 5 p	.m. ET on Friday, February 10 to
A copy of the agenda may be obtain	ned by contacting: Leda Kell	y (Leda.Kelly@NorthHighland.com).
CONTACT PERSON: Leda Kelly, N	orth Highland Consulting, Le	eda.Kelly@NorthHighland.com.
Florida Department of Health Office of Children's Medical Services Managed Care Plan Programs 4052 Bald Cypress Way, Bin A-06, Tallahassee, FL 32393		Accredited Health Department

¹³ Florida Administrative Register.



Below is the invitation email distributed to identified interested parties. A survey was included to enable stakeholder interested party invitees the opportunity to submit questions in advance of the facilitated sessions.

----- Original message ------

From: Leda Kelly
Sent: Wednesday, January 25, 2017 12:59 PM
To: Leda Kelly Leda Kelly@northhighland.com
Subject: YOU'RE INVITED: Children's Medical Services Managed Care Plan - Public Meetings

Dear Friend,

You are invited to attend the below public meetings regarding the Children's Medical Services Managed Care Plan.

February 1, 2017 9:00 a.m. -11:00 a.m. Ansin Building 1300 South Andrews Avenue, Ft. Lauderdale, Florida 33316 February 2, 2017 9:00 a.m. -11:00 a.m. Florida Department of Health—Orange County 6101 Lake Ellenor Drive, Orlando, Florida 32809 February 3, 2017 9:00 a.m. -11:00 a.m. Capital Circle Office Complex 4052 Bald Cypress Way, Room 301, Tallahassee, Florida 32399

Please RSVP and provide optional input HERE.

Background

The Children's Medical Services Managed Care Plan (CMS Plan) is a Medicaid and KidCare health plan option for children with special health care needs and is offered by the Florida Department of Health (Department). For general information on the CMS Plan, visit www.CMSPlanFlorida.gov.

The public meeting is solely focused on the CMS Plan service delivery model administered by the Florida Department of Health. A facilitated discussion will be held with CMS Plan families, providers and stakeholders and the general public to gather public input intended to inform the evaluation of the feasibility of improved models for Title XIX and XXI funded delivery systems for Florida's medically complex children with special health care needs (CSHCN). While the meeting will include a presentation on factors impacting the CMS Plan model and information on other service delivery models used around the nation to serve children with special health care needs, the goal is to solicit input from the public related to serving families and children with medically complex, special health care needs.

Public participation in this meeting is solicited without regard for affiliation with the Department or CMS Plan. Participation is also solicited without regard to race, color, national origin, age, sex, religion, disability, or family status. Persons who require special accommodations under the Americans with Disabilities Act (ADA) or require translation services (free of charge) should contact: Leda Kelly (Leda.Kelly@NorthHighland.com) at least seven (7) days prior to the public meeting.

If you are unable to attend, or have additional feedback to provide, you may send your comments and additional documentation HERE or directly to Leda.Kelly@NorthHighland.com by 5 p.m. ET on Friday, February 10, 2017.

A copy of the agenda may be obtained by contacting Leda Kelly at Leda.Kelly@NorthHighland.com.

4.3 Raw Input

This section incorporates both oral and written public input.

4.3.1 SOUTH FLORIDA

Comment	Organization Type
Family care management perspective: CMS has been better of the MMA ¹⁴ plans, timely authorizations, broad provider network, comprehensive cover, etc. – Make sure to keep what is going well	Other ¹⁶
Quality: prefer incremental demonstration of meeting value-based core initiatives. Each managed care plan - in addition to HEDIS ¹⁵ , MU, PCMH – all have their own performance requirements with only some overlap – very overwhelming to be accountable to them all	
Transitioning: youth aging out of eligibility for the CMS Plan have difficulty accessing providers after 18 years old even though there is coverage	
Care coordinator unable to contact	Parent
Combine care for families with more than one special needs child	
Transitioning from an MMA plan to CMS. Can effective dates be retroactive or are they prospective?	Health Care Provider
I have a lot of bilingual patient Creole and Spanish - patients don't know where to go or what to do…can we help?	Health Care Provider
Wanting my son to receive his complete medical needs (low protein foods) for his PKU condition	Patient/Parent
For information and clarification, CMS provides low protein food coverage via the CMS SafetyNet Program.	
I am writing to support for clinics in Fort Lauderdale that have been closed to be reopened.	Health Care Provider
It is an unnecessary burden for the family of severely disabled children to have to go to multiple physician and vendors to get the care that they require.	
At the Wheelchair clinic we were able to address their wheelchairs and make simple repairs and adjustments to allow them to be more comfortable and order the appropriate modification to allow them to be maintained correctly in a fast concise manner.	
Not only did we address wheelchairs but necessary equipment for their safety in their home environment.	

¹⁴ Managed Medical Assistance.
 ¹⁵ The Healthcare Effectiveness Data and Information Set.

¹⁶ Other encompasses all additional stakeholders not affiliated with one of the listed Organization Types. When completing a comment form online or in-person, stakeholders were asked to provide the following information: Name, Email and Organization Type: Business Owner, Health Care Provider, Elected Official, Parent, Patient, Other and Prefer Not To Say.

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We als service accomp children availab		
Thank	you for this opportunity to send public comment.	Other ¹⁸
1)	Lengthy time to credential and re-credential therapy providers that serve infants and toddlers in the Early Steps Program.	
2)	Some providers are not notified about re-credentialing and are being taken out of the network without notice.	
3)	Therapists should be credentialed individually so they can then be linked to other groups quickly and easily.	
4)	CMS specialty clinics have historically been of great value to the families. Broward recently closed the wheelchair clinic and there is concern that children will not get the care they need.	
5)	Parent comment that CMS care coordination is challenging, feeling like they are getting the run around at times.	
6)	Need to keep a strong family focus with CMS and the CMS MMA ¹⁷ .	
7)	CMS staff need to attend the NICU discharge meetings to provide information and assist families with a smooth transition home (this is not marketing).	
8)	Agree with components of the other state models that were very quickly shared: promoting a true Medical Home Model (Texas), specialty area care coordinators (NY), One-Stop Multidisciplinary Clinics (Arizona). We really did not have enough time to study the other state models and provide informed/thoughtful comments.	
9)	Recommend that CMS MMA be the designation specialty plan for all Early Steps children that meet the income criteria. Use the Sunshine model – IFSP is the authorizing document for services, uses the Early Steps provider network.	
l also n peers i		
I am ha	appy to answer any F/U questions you may have related to these comments.	
Nothing but positive things to say about the staff at Henderson Behavioral Health (Henderson) and their commitment to helping families navigate the emotional complexities involved when children are fighting their own emotional battles. From the moment I was referred to them, I was treated with the utmost respect and felt the genuine desire of the staff assigned to my family to help us. The staff has repeatedly gone above and beyond any expectations I had in their efforts to let my daughter know she's not alone and to help us design a plan to implement the right tools to		Parent

¹⁷ Managed Medical Assistance.

 ¹⁸ Other encompasses all additional stakeholders not affiliated with one of the listed Organization Types. When completing a comment form online or in-person, stakeholders were asked to provide the following information: Name, Email and Organization Type: Business Owner, Health Care Provider, Elected Official, Parent, Patient, Other and Prefer Not To Say.



successfully communicate with our children and raise our very blended family. The	
home visits are vital for my family as our schedule would otherwise prohibit the	
frequent visits. The staff is always available to listen to me and my daughter	
absolutely loves them. It's not easy for her to open up and express her feelings, but	
she's made great improvements in the time she's been involved with Henderson.	

4.3.2 CENTRAL FLORIDA

Comment	Organization Type
Highly recommend looking for options to institute value-based contracts with providers. This could include:	Health Care Provider
 Care management incentives tied to reducing emergency room encounters, hospital readmissions and patient satisfaction 	
 Shared savings models or other alternative payment options 	
 Established pediatric network for the CMS eligible population 	
 Quality dashboard or performance data that provides accountability to the plan and to the providers 	
We need to think about if we change delivery models, how this will impact care and coordination for inborn errors of metabolism. Need nurse care coordinators who will help and understand provision of services. Under our current model, we need further assistance with prior authorizations and low protein foods. Currently, low protein foods are approved for a specific age based monthly amount; however, for those 1-3 years of age, it is impossible to provide cold based foods such as cheese and bread. We need to provide these foods in 2-3 month amounts in order for patients to coordinate proper provision of low protein foods.	
Also, we need to address the surveys sent to patients which are not always approved.	
Some of our families were screened out of CMS without knowledge. It can take up to one month for families to find out and determine that the Medicaid have been switched. When it comes to issues such as private duty nursing, we need to have a better reimbursement for these services. Some of our very complex patient struggle with insurance coverage because they needed skilled service from a different MMA ¹⁹ and we now have to fight harder to get other services and medications covered.	
As the parent of three children with autism and Executive Director of Outreach Autism Services Network, I am incredibly grateful for CMS. I would like to see more authority being put into the hands of nurse care coordinators and more recognition for the amazing work they do. I also want to make sure parents of children with special needs are being heard in regards to keeping this program available regardless of federal changes. It would be great to see the program age eligibility to be increased to at least age 22 as in the public school system. We would also like to make sure that parents continue to have the freedom of choice to be able to choose primary care and specialist providers.	Parent/ Other ²⁰
CMS/Ped-I-Care has been the rock that has helped my son have a childhood. The most important aspects to us have been:	Parent
 Nurse Care Coordinator – knowing my sons case and helping find services and providers 	

¹⁹ Managed Medical Assistance.

²⁰ Other encompasses all additional stakeholders not affiliated with one of the listed Organization Types. When completing a comment form online or in-person, stakeholders were asked to provide the following information: Name, Email and Organization Type: Business Owner, Health Care Provider, Elected Official, Parent, Patient, Other and Prefer Not To Say.

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Quick approval of IV and injectable medicines Great customer service at Ped-I-Care • Freedom to choose physicians Medical home model Concerns: 1) Some therapy providers are reluctant to take CMS children because of the Medicaid rate and I have even been told by one they must have 2 private pay patients to offset one CMS/Medicaid 2) Is there a way to make CMS have a private pay option? There is no care purchasable which cares for medically complex kids with compassion and care like CMS/Ped-I-Care I am incredibly grateful to CMS. I work as a nurse care coordinator at the Chronic-Complex Clinic at St. Joseph's Hospital Health Care Provider in Tampa. I started working for the Children's Hospital 2 years ago and before then I was a CMS care coordinator for over 21 years in the Tampa office. This gives me a unique perspective as a former CMS employee and now as a provider. The Chronic-Complex Clinic has a longstanding partnership with CMS and we feel very strong that CMS is an important program for our most vulnerable patients. In fact, through a federal Centers for Medicare and Medicaid Services grant, we have been able to collaborate with Florida's CMS to enhance care coordination about and beyond what CMS does for our patients. Our clinic provides primary care for the most medically complex children in our region over 600 medically complex children. I work every day with these families and have detailed knowledge of how well the various plans meet or don't meet their needs. The vast majority of our patients are covered through Florida Medicaid either in the CMS specialty plan or in one of the MMA²¹ plans. Since we only provide care to children with complex and chronic conditions, they all meet the medical criteria to be CMS eligible. At this time roughly half of our Medicaid patients are enrolled in CMS, which presents a downward trend. Before the mandate of enrolling all eligible children in a managed care program, almost all of our Medicaid patients were part of CMS (T19, T21/Florida KidCare or Safety Net). We came up with 3 main reasons for decline in enrolling children in CMS: 1) It is more challenging for parents to enroll their eligible children and to continue on the plan. Initial enrollment is a 2 step process: either requires a parent to contact CMS and get screened eligible, at which point the information gets forwarded to Medicaid. Once that information shows up in Medicaid screen, family has to contact the Medicaid choice line and ask to be assigned to the plan and then they should be effective the first of the following month. The other option is to have a physician complete an attestation form confirming the child meets medical criteria, faxing that to the CMS and once they agree, family gets notified and then can contact

²¹ Managed Medical Assistance.



the choice line to choose CMS as their plan. The attestation form has a list of diagnoses with associated ICD10 codes to choose from, and most recently an option has been added to write in diagnosis.

- Before these new enrollment procedures were put into place, a parent could just contact their local CMS office, talk with a nurse on the intake team and the nurse could use her nursing judgement to decide if the child met criteria and would benefit from CMS services. Then CMS would fax form to Medicaid and the child was enrolled.
- 2) Once enrolled, CMS requires a yearly redetermination to make sure child still meets criteria. The family gets contacted and asked 5 general questions which determine if the child continues or gets disenrolled from the program. The questions are very general and some patients were screened out that should not have been. (we had patients screened out with DiGeorge syndrome and tetralogy of Fallot) Also if unable to contact parent within a predetermined timeframe, (within 30 days of anniversary date) child gets disenrolled, even if medical records support ongoing eligibility. Our Families are very busy juggling taking care of their special child while maintain a job and taking care of other family obligations. Returning one more phone call is not always a priority. Also some of our patients move and change phone numbers frequently, which adds to the difficulty reaching them by phone or mail. Previously, the nurse care coordinator who was familiar with the patient was able to make decision by speaking with the caregiver at any time and reviewing medical records.
- 3) The biggest challenge is becoming evident: the reimbursement rate for skilled nursing and home health aides through CMS is lower than other Medicaid plans. This has led to families being steered to opt out of CMS by nursing agencies to choose other plans that have higher reimbursement rates. Our families are heavily reliant on skilled nurses and home health aides to assist them in the care of their children, ultimately preventing or reducing hospitalizations and allowing the parents to continue working, get rest and care for the rest of their family.

One the other hand, DME, and Therapy providers prefer CMS as it provides better coverage when it comes to supplies, equipment and PT, OT and ST. One example is customized wheelchairs and special needs car seats. Under CMS the child is more likely to get the needed equipment as recommended by physician and therapist. We feel the parents should not have to choose between nursing coverage and better equipment.

To my knowledge, the MMA's²² only provide a case manager if the child receives services from a nursing agency, skilled nursing facility or PPEC (prescribed pediatric extended care).

We encourage our families to enroll in CMS since this is the specialty plan for kid with special health care needs and it provides a more individualized approach to healthcare. Every child in CMS gets assigned a care coordinator and has access to social workers and family advocates to help them navigate the healthcare system and other community programs. This access to social workers and

²² Managed Medical Assistance.

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resources is important since taking care of a child with special needs often comes along with psychosocial challenges.	
CMS is the only program that offers PIC (partners in care) which gives extra support and resources for children and their families requiring palliative care.	
Taking care of a special needs child requires a team and CMS has always been up to the challenge.	
Thank you for the opportunity to speak here today.	
I received the info below from a Facebook group I am in. My five-year-old daughter has DiGeorge Syndrome, a genetic mutation that causes a range of issues - heart defects, low tone, developmental delay, Autism - each person with DiGeorge is affected differently.	Parent
If it weren't for the CMS program, I would not be able to care for Clara. She receives weekly speech, PT, and OT therapies at school and outside of school, and is followed by a range of specialists including cardiology, immunology, and genetics, and is currently being evaluated for admission into a developmental pediatrics program at All Children's Hospital.	
We rely COMPLETELY on CMS for Clara's care - including the two cans a day of PediaSure she needs to drink to gain weight. Our CMS nurse has been so helpful, as have all of our providers. I am a single mom of two kids, and taking care of Clara means I have little time to work in my business, a small writing and resume business. I could not afford health insurance for Clara, even on the exchange.	
Please do not take funds away from the CMS program. So many little ones rely on it.	
Express Care of Belleview has been doing business with Pedicare for a number of years. Pedicare is always available to answer questions and are accurate in the processing of our medical claims. The staff is also courteous and knowledgeable. Overall, we enjoy doing business with Pedicare and intend to continue our relationship for the foreseeable future.	Health Care Provider
I am an administrator for a home health care agency named Integrity Health Services, located in Winter Park, Fl. I have worked with CMS closely for approximately 5 years now in both Jacksonville and Winter Park. My experience has been outstanding and I find that they are very pleasant to work with. If you require any additional information, please let me know.	Other ²³
CMS provides complete coverage to meet the medical and mental health needs of children with complex medical conditions. They provide services that commercial insurance policies do not. My family's greatest need is for our son to be able to access CMS coverage even when he is eligible for coverage under another policy. Due to my husband's work, we sometimes qualify for CMS and other times do not. We frequently change between policies and it creates inconsistency in our son's health care coverage. I would like to see the option to self-pay for CMS coverage if we do not financially qualify. That would allow our son to get much needed medical services that he doesn't get from traditional insurance policies.	Parent

²³ Other encompasses all additional stakeholders not affiliated with one of the listed Organization Types. When completing a comment form online or in-person, stakeholders were asked to provide the following information: Name, Email and Organization Type: Business Owner, Health Care Provider, Elected Official, Parent, Patient, Other and Prefer Not To Say.

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Accepted into CMS in Jan 2017 would like to request pamphlets/list of providers.	Parent
To Whom it May Concern, As DOH CMS prepares to design an improved service delivery model for infants and children with special and complex health care needs, we at ChildrenFirst Home Health Care Services, respectfully request that the following comments be considered: It is evident that CMS Plan families are having access to care issues for their medically fragile children. Most notably, many speciality physicians and home health providers have dropped out of the CMS Plan network due to lack of competitive reimbursement. ChildrenFirst Home Health Care Services is a large provider of private duty nursing and therapy services in the greater Orlando area. We have partnered with all of the CMS locations in our region for more than 20 years. It has become increasing difficult to admit new CMS PDN referrals because we cannot pay competitively based on CMS reimbursement. While we are not closed to CMS admissions, nor have we quit the network, we mainly focus on staffing the CMS cases that are on service with us and infrequently admit new patients because, in most instances, payment is dramatically higher than FFS ²⁵ Medicaid and CMS. ChildrenFirst is in favor of a service delivery model which will untie the hands of CMS and allow the plan to move away from FFS, thereby attracting and retaining specialty providers who are experts in serving medically complex infants and children and deeply understand this population. We encourage CMS to find an alternative to HEDIS ²⁶ measures. HEDIS measures are mainly geared toward well care and preventative care. While HEDIS measures focus on preventative health and well visits for children and adults, HEDIS is not enough for medically complex children and the other MMA plans would take care of all of Florida's medically complex children and the other MMA plans would pay the CMS Plan a fee for overseeing the needs of that plan's medically complex infants and children. This would allow the CMS Plan to have a robust, child focused network of specialty physicians, home health and anc	Health Care Provider

²⁴ Managed Medical Assistance.
²⁵ Fee-for-Service.
²⁶ The Healthcare Effectiveness Data and Information Set.



4.3.3 NORTH FLORIDA

Comment		
Agree that the foundation of CMS are the nurse care coordinators. CMS has trouble hiring because of low reimbursement salaries, low morale, and competition from the private sector whose salaries have vastly increased while ours have been stagnant. We need to improve the numbers and quality of our care coordinators. I don't see how we can do it without major salary increases unless you only want recent grads who want the state to pay for their Master's degree.	Other ²⁷	
Access to medically modified foods for treatment of inborn errors of metabolism. Create a better screen for eligibility for CMS/Medicaid. Education level tends to be low and forms (current) need improvement out of the program.	Parent	
 My concerns 1) PTS inborn errors of metabolism (identified through state newborn screening) are not able to get medically modified low protein foods covered through Medicaid. CMS has picked up this coverage and urge this coverage to continue to prevent cognitive impairment 	Other	
 2) Access – few centers to provide care – need telemedicine or outreach clinics to cover children and inborn errors of care 3) Need to continue care coordination 		
When I think of the care my son receives from CMS, what comes to mind first and foremost are the words "family" and "community". This is the heart of CMS, and has been reflected in my experience with the District One office here in Pensacola. I see those very words written in the CMS goal statement where "family-centered" and "community-based" are used to describe the CMS system of care.	Parent	
Throughout the years, whether it was my son's first caseworker or his current caseworker, we have been assisted kindly and with compassion by nurses who truly love children and strive for the best outcomes in every health challenge faced. It is my firm conviction that the tone of an organization is set by those at the top. CMS staff have been tireless advocates for my son. I've never met the CMS leadership in Tallahassee, but thank you. It is your leadership that gives the CMS organization its compassionate heart for the children and families you serve.		
With CMS I have never felt that we were just a number, or that somehow, my child didn't matter. A CMS caseworker has always been available to personally assist our family when needed. They know my son, are familiar with his diagnosis and his health needs. Relationships are so important. This is part of what it means to be a community, and the community-based care component of CMS is vital to its success. Please don't ever lose this. Community is one of the reasons why I have deep concerns over the utilization of mail-order pharmacy services for CMS kids. When you lose the local community-based care link, you lose a part of the very heart of CMS. Furthermore, restricting specialty		

²⁷ Other encompasses all additional stakeholders not affiliated with one of the listed Organization Types. When completing a comment form online or in-person, stakeholders were asked to provide the following information: Name, Email and Organization Type: Business Owner, Health Care Provider, Elected Official, Parent, Patient, Other and Prefer Not To Say.

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pharmacy services to a single mail-order provider is antithetical to CMS's stated objective which is to provide members with access to a wide-range of primary, specialty and facility providers.	
Thank you for the help that CMS has provided in caring for my son. CMS is a first-class organization and a genuine asset to our state.	
As a pediatric nurse for more than 35 years, I have worked the majority of that time with children with special health care needs. This vulnerable population in our community has a very difficult time accessing services and the family often experiences heavy burdens of care and coordination that may take a toll on family dynamics and daily lifestyle.	Health Care Provider
Children with special needs require a large number of specialty services that include medical care, therapies, medications, treatments, and counseling not to mention ongoing education regarding their specific needs.	
People who work with this population must have skills related to an in-depth understanding and appreciation of the activities of daily living that impact the child and family. This includes knowledge of the disease processes and conditions and the management of those that the children in their care require.	
Staff who work in a health plan that provide services to this population must have these same skills. They must have an intimate appreciation of the special situations and needs of these children and their families in order to make decisions that are effective and efficient with the best interest of the child or member at stake. When serving this population time and navigation tot eh right services at the right time is paramount to achieving good outcomes. It is not easy to maintain a budget when serving this population. We all know that services for members or children who have special needs will be costly but these children are in the middle of their one and only chance for optimal growth and development.	
It would be irresponsible for us to allow them to be cared for by people who may have experience and understanding of adult care as these children are not just "little adults". They need professional member services staff and administrators and medical directors who know these children's possible course of treatment and the dire consequences if appropriate care is not provided in a timely manner.	
It is my greatest hope that this group of persons in our society can be respected enough to provide them with knowledgeable and culturally sensitive persons who will care for, advocate for and support them in these very important years of their lives.	
In my personal and professional experience with CMS and Ped-I-Care, we had a great partnership. All of the situations were handled with the question of what is the best for the care of the child. The nurses, doctors, and administrative staff all understood the daily lives of children with special health care needs.	
I do have the following recommendations when creating an even better plan for Florida's children:	
 It must be a coordinated system of care meaning that a child could go anywhere in the state and receive the same kind of service without interruption. Care Coordination provided by nurse must be a major feature for the plan. Nurses know the pathophysiology and the normal growth and development needs of children. They also understand the family dynamics and the mental health issues related caring for this population. 	

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	3)	Social services coordinators are a must for this population. Children with special needs have an increased rate of behavioral health issues either co-morbidly or directly related to the health issues.			
	4)	The administrator of the plan must have flexibility to offer providers in their network a competitive reimbursement within the market place. Restricting the administrator to only Medicaid rates is not a good thing for children with more complex issues as it restricts their access to care.			
	5)	There must be greater transition efforts for children and families that fall off of the plan due to becoming over the income limits. A high risk pool could be created for them to join and pay a premium but still have access to the CMs services of care coordination and follow up.			
	6)	Special consideration needs to be made regarding the items that are needed for a child's care when they have very specialized needs. Some of these items are not covered by Medicaid or have limitations. There needs to be a system to offer the administrator flexibility to cover these when they are medically necessary.			
		you for the opportunity to offer my comments on this program and the children that eply concerned about.			
wei con	At the public hearing, overseen by staff from the consulting firm North Highland, attendees were asked to provide oral comments and were also encouraged to submit written Provider Comments, including any additional thoughts, by 5 p.m. EST on Friday, February 10, 2017 to Leda.Kelly@NorthHighland.com.				
the	What follows are questions I posed in advance of this hearing, comments that I made at the hearing, as well as additional comments that have occurred upon reflection on the events of the day.				
1)					
	a)	Could you send me an updated table of organization for DOH, the CMS Network, etc.? The DOH table of organization that I have does not show where the CMS Medical Directors fit into the network, what components are in the MCH bureau in DOH, where Healthy Start fits, where metabolic screening is located, and the names of the individuals currently filling the various positions.			
	b)	When are parents allowed to speak at the hearing?			
	c)	There was some mention of parent focus groups. What is that about?			
	d)	How have parents been notified of the meetings?			
	e)	When are CMS individuals, like Medical Directors, to give their input? The notice (copy attached) says that "participation is invited without regard to affiliation with the Department or CMS", yet I understand that CMS Medical Directors have been asked not to attend these hearings.			
	f)	The notice has no date and no indication of who authored it. Where and when did it originate from?			
2)		at follows are comments I made at the hearing and comments generated psequently:			
	a)	None of the 4 state plans presented by the North Highland consultants as examples of alternative models for the care of Florida Children with Special			

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		Care Needs (CSHCN) fully encompass the features of Florida CMS as it at the start of the conversion of Florida CMS to an MMA ²⁸ program.		
	It should be noted that for several years prior to the 2011 Florida legislation and the subsequent 1115 Federal CMS Waiver approval, Florida CMS had already seen significant change within the CMS Program Office, with the unexpected departure of individuals with institutional memory, including the board certified pediatrician CMS Statewide Medical Director. All are extremely grateful that Dr. John Curran is temporarily filling the CMS Statewide Medical Director position, but it is essential that there be a full time board certified pediatrician in that position once Dr. Curran leaves.			
b)	progra	time of the Florida legislature's decision to adopt what is now the MMA m (2011) Florida CMS possessed the majority of the features presented by rth Highland consultants as desirable for a program caring for CSHCN ²⁹ :		
	i.	A network of primary care programs across the state assuring CMS children with a comprehensive medical home, including primary care case management.		
	ii.	Specially trained nurse care coordinators able to assist CSHCN and their families with navigating the health care system.		
	iii.	Assuring that area CMS offices had knowledge of and access to specialty and primary care physicians who could appropriately address the needs of CSHCN for whom the area offices were responsible. This function was carried out by the CMS Medical Director in conjunction with the Nursing Director in each area office.		
	iv.	The ability of the area office Medical Director to enhance payments above the published Medicaid rate by the use of PCS dollars in order to assure that CMS children have access to needed services. This is especially important in complex cases, such as cleft lip and palate.		
c)	Over til service	me, there has been a marked decrease in the availability of all of these		
	i.	All but two of the CMS primary care programs have been closed.		
	ii.	There has been a decrease in the availability of specially trained nurse care coordinators, and there is significant turnover in those who do exist.		
	iii.	The role of the CMS Medical Directors is not clear. I cannot find them on the table of organization that I have. CMS Medical Director quarterly meetings disappeared. CMS Medical Directors had little input in the development of the current CMS MMA structure.		
	iv.	The contract between AHCA ³⁰ and the CMS MMA does not allow CMS to pay above the published Medicaid rate, unlike the contracts between AHCA and the regular MMAs, which allows for enhanced payment at the Medicare level.		

 ²⁸ Managed Medical Assistance.
 ²⁹ Children with Special Health Care Needs.
 ³⁰ The Agency for Health Care Administration.

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	V.	The ability of CMS Medical Directors to enhance payments above the published Medicaid rate on a case-by-case basis has disappeared.
	vi.	I cannot identify the Title V program, one of the underpinnings of the Florida CMS program since its inception, on the CMS MMA ³¹ table of organization that I have.
d)	d) In a November 7, 2016 letter to then-acting AHCA ³² Secretary FCAAP ³³ president requested that "DOH adopt a model that retains the current CMS structure, thereby retaining the nurse care coordination, social services, and primary and specialty physician networks already established in local communities" and further that "DOH seek approval from AHCA to use the enhanced payment fee schedule available to the MMAs caring for average Medicaid children to boost payments to those physicians seeing CMS children." Further, FCAAP president asked that "AHCA seek whatever waiver revisions with Federal CMS and whatever contractual changes between AHCA and CMS, such that CSHCN ³⁴ insured by Florida CMS truly have equal and prompt access to health and dental care to the same extent as do average Florida Medicaid children."	
system, Florida		mary, it is suggested that, rather than seeking an entirely new delivery , Florida CMS retool the current CMS MMA to better reflect and utilize the ces and talent available within the current CMS system:
	i.	Fully utilize the CMS Medical Directors and involve them in the retooling. As practicing physicians embedded in their communities, the CMS Medical Directors have a long history of serving as local "champions", assuring that CMS children receive needed services in the most efficient way possible.
	ii.	Provide CMS Medical Directors with the authority to enhance provider payments to further assure that CSHCN can access needed services
	iii.	Seek the necessary contract, legislative, and waiver changes to allow enhanced payment rates for providers without the necessity of adopting a full-risk model.
	iv.	As mentioned in the "Next Steps" portion of the North Highland presentation, please provide information on how and when families will be encouraged to provide input, as their comments are extremely important.

³¹ Managed Medical Assistance.
³² The Agency for Health Care Administration.
³³ Florida Chapter – American Academy of Pediatrics.
³⁴ Children with Special Health Care Needs.



4.3.4 OTHER - REGION NOT SPECIFIED

Comment	Organization Type
1) Don't lump these kids in with the MMA ³⁵ Plans - they don't receive the special care they need, and don't receive authorization for care timely.	Other ³⁷
2) CMS should be for ALL special needs children in FL - not just poor ones. Special Needs children in the other plans are not receiving the care they need. The CMS Plan should cover Special Needs CHIP children, Medicaid children and those children whose parents earn enough to pay. Have a sliding scale for 'insurance' payment. This will provide CMS with more money (non-federal/state funds) to allocate. The MMA Plans and other insurance companies currently covering Special Needs children would also have to pay CMS for caring for these children instead.	
3) CMS should simply supervise the "Plan", and subcontract out the ENTIRE structure. All aspects currently handled by CMS, EQ Health, and others (the eligibility, care coordination, payment) also should be handled by the subcontractor(s). The fragmentation makes it hard on the parents, the providers, and the subcontractors.	
4) AHCA ³⁶ should not restrict CMS from being able to subcontract out payment at higher than Medicaid rate. AHCA can fix this problem.	
5) Don't throw the baby out with the bath water! The presentation showed other plan types, but not the results. Why start over with something totally new, that we don't know. Keep what is good, and fix what isn't.	
I have 2 children who both have asthma and one of them also has rheumatoid arthritis. I wish there was a plan for my kids to be able to have access to CMS insurance that we can pay for. It would be nice for children with chronic, sometimes debilitating illness to have access to this program, not just children who of low income. We cannot afford insurance and our jobs do not provide them. We make more to qualify for Medicaid programs and the full pay options from KidCare do not cover the doctors' my daughter needs. When she was on CMS, she was able to have excellent care. It sad that those working hard families, who fall in that gap that cannot afford insurance and don't qualify for the help because we make a few hundred dollars too much, are not given access to care that others receive. There should be an option for parents to pay something towards CMS insurance for their child based on their illnesses not money.	Parent

 ³⁵ Managed Medical Assistance.
 ³⁶ The Agency for Health Care Administration.

³⁷ Other encompasses all additional stakeholders not affiliated with one of the listed Organization Types. When completing a comment form online or in-person, stakeholders were asked to provide the following information: Name, Email and Organization Type: Business Owner, Health Care Provider, Elected Official, Parent, Patient, Other and Prefer Not To Say.