Children’s Hospice International
15th ChiPACC Conference
With technical assistance from
Centers for Medicare & Medicaid Services
Hosted by
Arnold & Porter, LLP
September 14, 2018
WELCOME!

Mahnu Davar, Partner
Arnold & Porter, LLP
Children’s Program for All-inclusive Coordinated Care (ChiPACC)
Ann Armstrong-Dailey
Founding Director
Children’s Hospice International
“CHI’s ultimate goal is to so ingrain the hospice concept into pediatrics that it is considered an integral part of health care for children and adolescents rather than a separate specialty…”

1983, American Academy of Pediatrics
Ann Armstrong-Dailey
CHI paving the way since 1983:

- Definition/Standards/Glossary of Terms
- Education and Training
- World Congresses
- International Resource
- Technical Assistance
- Advocacy
- Special Programs including ChiPACC
POPULATION USA: 296 Million

**Adult Deaths**
- 2.5 Million
- 36% died under hospice care

**Child Deaths**
- 53,526 children 0 - 19 years
- 2.2% died under hospice care

**Children Diagnosed with Life-threatening Condition**
- 1.2 Million
## Causes of Death

### Children 1 – 19 Years

<table>
<thead>
<tr>
<th>All Children 1 - 19</th>
<th>All Children 1 – 19 w CCC</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Accidents</td>
<td>• Malignancy 48%</td>
</tr>
<tr>
<td>• Assault</td>
<td>• Neuromuscular 23%</td>
</tr>
<tr>
<td>• Malignancy</td>
<td>• Cardiovascular 17%</td>
</tr>
<tr>
<td>• Suicide</td>
<td></td>
</tr>
<tr>
<td>• Congenital malformations, deformations</td>
<td></td>
</tr>
<tr>
<td>• Chromosomal anomalies</td>
<td></td>
</tr>
<tr>
<td>• Heart disease</td>
<td></td>
</tr>
<tr>
<td>• Cerebrovascular diseases</td>
<td></td>
</tr>
</tbody>
</table>
Causes of Death
Infants

<table>
<thead>
<tr>
<th>All Infants</th>
<th>Infants with CCC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congenital Malformations</td>
<td>Cardiovascular</td>
</tr>
<tr>
<td>19.5%</td>
<td>32%</td>
</tr>
<tr>
<td>Short gestation/LBW</td>
<td>Congenital/genetic</td>
</tr>
<tr>
<td>16.5%</td>
<td>26%</td>
</tr>
<tr>
<td>Sudden Infant Death Syndrome</td>
<td>Respiratory</td>
</tr>
<tr>
<td>7.4%</td>
<td>17%</td>
</tr>
<tr>
<td>Maternal complications</td>
<td>Neuromuscular</td>
</tr>
<tr>
<td>6.3%</td>
<td>14%</td>
</tr>
<tr>
<td>Complication of placenta,</td>
<td></td>
</tr>
<tr>
<td>cord or membranes</td>
<td></td>
</tr>
<tr>
<td>4%</td>
<td></td>
</tr>
<tr>
<td>Accidents/unintentional</td>
<td></td>
</tr>
<tr>
<td>4%</td>
<td></td>
</tr>
</tbody>
</table>
Children with chronic illness and complex health care needs are living longer and require creative approaches to delivery of care coordination and PP/HC (HHS)

10.2 Million children (13.9% of US children ages 0-17) have special health care needs. This number is increasing slightly every year. (HHS)

CHI and ChiPACC are addressing this urgent need!
As Governments debate changes & reforms to their nation's healthcare programs

ChiPACC considered:
Cost-effective solution,
Step in the right direction,
Improved care for less cost!
Current models of care do not adequately address needs of children with life-threatening conditions and their families.
A parent should never have to choose between hospice care and hope for a cure.

ChiPACC: Comprehensive compassionate coordinated care for children with life-threatening conditions and their families

From time of diagnosis
Alongside Curative Care
Most appropriate setting based on Family Choice – rather than funding stream
Reimbursement dollars, and support, follow the child and family throughout the continuum of care.

ChiPACC increases quality of care *AND* saves money!
ChiPACC

Successful “partnership” since 1997

Congress + CMS + CHI

A growing number of states beginning with

✓ Florida! 1st in the NATION 2005!
✓ Colorado! 1st 1915 (c) waiver 2006!
✓ California waiver approved 2010!
✓ New York waiver approved 2010!
✓ North Dakota waiver approved 2010!

Additional states exploring

A growing number of countries exploring
"I am approving this new Medicaid program in Florida because I believe we must do everything possible to lighten the heavy burden on families of children...

This is a step beyond traditional hospice rules, and the right thing to do for these most vulnerable children and their families"
NEXT STEPS FOR ChiPACC:

• *Ongoing* Technical Assistance
• Evaluation
• Quality Assurance
• Research
• Legislation
PROGRESS to date includes:

- CMS expanded policy for ChiPACC
- ChiPACC Bill introduced
- Concurrent Care Health Reform Provision
- ChiPACC Bill (revised) re-introduced
I SUPPORT
The Mattie & Melinda Bill. Chi PACC Act
ChiPACC Bill

Children’s Program of All-inclusive Coordinated Care

“Mattie & Melinda Bill”

Reintroduced January 27, 2009, U.S. Congress
Congressmen Jim Moran (D VA) & Bill Young (R FL)

-One sentence included in 2010 Healthcare Reform Bill-
Provision for concurrent care

Revised Bill re-introduced 2014
ChiPACC “Mattie & Melinda” Bill

*Ultimately serving 1.2 million children and families in U.S.A. (many more worldwide)*

- **The ChiPACC Bill:** Based on the collaborative model of care developed by CHI, the Children's Program of All-inclusive, Coordinated Care (ChiPACC) which provides each enrolled child an *individualized* treatment plan that includes and manages services from providers across the health care spectrum.

- **ChiPACC:** Services will improve upon the often inconsistent care that is currently available to seriously ill children under Medicaid, doing so at a savings to taxpayers.

- **ChiPACC:** Goes *beyond* hospice and palliative care – while incorporating these critical components

- **ChiPACC:** Exceeds IOM 2002 Report recommendations for children’s palliative care

- **ChiPACC:** Cost effective!
ChiPACC benefits everyone!

In addition to saving taxpayers money, ChiPACC benefits:

- **Child & Family:** Increased quality of care
- **Healthcare Providers:** Reimbursed for ChiPACC services
- **Healthcare Programs & Institutions:** Reimbursed for ChiPACC services
- **Society:** ChiPACC is preventive medicine, decreasing dysfunction within the family and society, and allowing families to continue productive lives in their communities
On Being a Champion

A champion is a winner,
A hero…
Someone who never gives up
Even when the going gets rough,
A Champion is a member of
A winning team…
Someone who overcomes challenges
Even when it requires creative solutions.
A champion is an optimist,
A hopeful spirit…
Someone who plays the game,
Even when the game is called life…
Especially when the game is called life.
There can be a champion in each of us,
If we live as a winner,
If we live as a member of the team,
If we live with a hopeful spirit,
For life.

Mattie J.T. Stepanek, September 1999
I’ll miss you guys!
Children’s Hospice International

For information:

Web:  www.CHIanline.org
Email:  Info@CHIanline.org
Legislative Update

Children’s Program of All-Inclusive Coordinated Care Act (ChiPACC) of 2018

Sara Linder, Roxana Boyd, Taylor Cazeault, Arnold & Porter
David Pore, Hance Scarborough, LLP

September 14, 2018
Introductions

David Pore
Hance
Scarborough

Sara Linder
Arnold &
Porter

Roxana
Boyd
Arnold &
Porter

Taylor
Cazeault
Arnold &
Porter
Legislative Overview

Legislative History

- ChiPACC legislation previously introduced in the 110th, 111th, 112th, and 113th Congress
- Congress appropriated funds in the early 2000s for state demonstration projects
- Five states (FL, CO, CA, NY, ND) pursued Medicaid waivers to operate ChiPACC programs

ChiPACC Act of 2018

- Amends Title XIX of the Social Security Act by adding a new section 1947, Children’s Program of All-Inclusive Coordinated Care
- Allows a state the option to submit a State plan amendment under their Medicaid program to provide medical assistance to ChiPACC eligible individuals
- Applicable to CHIP
H.R. 6560 - The Children’s Program of All-Inclusive Coordinated Care (ChiPACC) Act of 2018

- Introduced on July 26, 2018
- Led by Reps. Diana DeGette (D-CO) and Michael McCaul (R-TX)
- Referred to the House Energy and Commerce Committee
Original Sponsors of H.R. 6560

Rep. Diana DeGette (D-CO)

Rep. Michael McCaul (R-TX)

Rep. G.K. Butterfield (D-NC)

Rep. Jackie Speier (D-CA)

Rep. Mike Kelly (R-PA)
H.R. 6560: Summary

- **State Flexibility**
  - States can tailor program based on their needs
  - States may establish geographical and numerical limitations in program design and establish a process for determining criteria for individuals who may enroll in the program

- **Individuals enrolled under the program are provided with:**
  - Comprehensive, integrated palliative and curative services
  - Long-term care services and supports under State plan
  - Counseling services and expressive therapies
  - Respite care
  - Anticipatory bereavement services to immediate family members of ChiPACC individual
H.R. 6560 Summary

Eligibility

- **Determinations** – In order to determine an individual is ChiPACC eligible, the State administering agency must conduct an independent evaluation that includes:
  - Consultation with appropriate health professionals
  - Examine individual’s relevant history, medical records, care and support needs
  - Consultation with individual and their family or guardian

- **Participants** –
  - Individual is under the age of 21 at the time of enrollment
  - Eligible for medical assistance under State Plan
  - Suffers from serious illness or health condition where there is a reasonable likelihood their life will be threatened by such illness or condition
  - Health status is expected to decline due to the illness or condition before reaching the age of 21
H.R. 6560 Summary

- **ChiPACC Coordinator**
  - Supervises the coordination of comprehensive services to the ChiPACC eligible individual
  - Ensures health professionals are continually involved

- **Interdisciplinary Health Professional Team**
  - Physician
  - Registered Nurse
  - Social Worker
  - Case Manager

- **Payment to ChiPACC Coordinator and Interdisciplinary Health Professional Team**
  - Shall be paid on a capitated or fee-for-service basis
Next Steps

- Introduce a Senate-companion bill
- Educate members and build cosponsor support for H.R. 6560
- Outreach to stakeholders groups to garner endorsements
- Planning for 2019 Family Advocacy Day
Questions?
Contact Information

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CMS Participation
2018 CHI PACC
Technical Assistance Webinar

Melissa Harris, Senior Policy Advisor
Disabled and Elderly Health Programs Group
Medicaid Services

States must cover certain services under Medicaid, including:

- Inpatient and outpatient hospital services
- Laboratory and X-ray services
- Home health services
- Physicians services
- Nurse practitioner and nurse-midwife services
- Federally Qualified health clinic and Rural health clinic services
- Nursing facility services
States have the option to cover many other services:

- Dental services
- Physical and Occupational therapy
- Prescription drugs
- Personal care services
- Hospice care
- Private duty nursing
- Targeted case management
- Mental health and substance use disorder treatment
EPSDT Provisions

- Early and Periodic Screening, Diagnostic and Treatment
- Key component of Medicaid
- Requires the provision of services found in section 1905(a) of the Social Security Act to Medicaid beneficiaries under age 21
- Medical necessity criteria determines eligibility and utilization
- Some variation across states still exists
Medicaid State Plan

• Describes a state’s Medicaid program
• Each state has a unique State Plan
• Many components
  – Eligibility categories
  – Benefit descriptions and provider qualifications
  – Payment structures
• Amendments to the Plan must be approved by CMS
States have the flexibility to operate the following waivers:
• 1915 (c) home and community-based services waivers
• 1915 (b) managed care waivers
• 1115 demonstrations
HCBS Waivers

- Institutional level of care required
  - Nursing facility
  - Hospital
  - Intermediate care facility for individuals with intellectual disabilities

- Allows states to provide services not normally covered under the state plan, such as respite care.

- Allows states to not count parents’ or spouse’s income and resources.

- Cost neutrality test – waiver costs must be no more than cost to serve waiver population in an institution
Managed Care Waivers

• Allows states to mandate populations into managed care
• Allows states to mandate the provision of additional services through managed care savings
• Has been used by at least one state to authorize services to children with life-threatening conditions
1115 Demonstrations

- Broadest authority for state innovations
- Authorizes Federal payment for additional services
- Waives provisions of the Social Security Act
- Budget neutrality requirement
- Could be used if states want flexibility beyond the parameters of state plan or waivers
Concurrent Care for Children Provision

- Children electing hospice care may continue to receive curative treatment services covered in the Medicaid State Plan.
- Many states amended their Plan to reference this requirement, but the provision applies to all states regardless.
1915(i) State Plan Authority

- Authorized in the 2005 Deficit Reduction Act
- Provides the same benefit package as available under 1915(c) waivers
- Does not require individuals to meet an institutional level of care
- States develop needs-based criteria to determine eligibility and utilization
Health Homes for Individuals with Chronic Conditions

- New state plan authority in the Affordable Care Act
- Provides enhanced Federal match (90%) for the first 8 quarters of program implementation
- Offers care coordination for individuals with chronic conditions (state flexibility in determining the targeting criteria)
- Could allow utilization of a broad range of pediatric specialties
CMS stands ready to work with states on state plan or waiver programs, which can be a critical tool in providing services – above hospice – that complete the CHI PACC model (i.e., respite and expressive therapies).

melissa.harris@cms.hhs.gov
What is the CMS Plan PIC:TFK Program?

Partner’s in Care: Together for Kids (PIC:TFK)

- Florida’s Program for All Inclusive Care for Children (PACC)
- A pediatric palliative care support service
- Available to children enrolled in CMS Managed Care Plan
- A collaboration of partnerships statewide
Florida PACC Model

State Level

- Department of Health
- Children’s Medical Services (CMS) Plan
- Agency for Healthcare Administration (AHCA)
- Florida Hospice and Palliative Care Association

Local Level

- Children’s Medical Services Area Office
- Hospice Provider
History

Development Phase 2000-2003
- Implementation Guidelines
- Billing codes
- Partnerships

Legislative Phase 2004-2005
- Title XXI State Plan Amendment
- 1915(b)(3) CHI PACC Waiver

Implementation Phase 2005-2007
- 7 Sites

Expansion Phase 2009-2014
- Transition to 1115 Waiver
- CMS became a statewide plan for Medicaid (MMA)
Current Status

Present

• 1115 MMA Waiver extended through June 30, 2022
• 10 providers covering 32 counties
• Pending expansion to an additional 15 counties
# Population Served

Children enrolled in the CMS Plan who have a life-threatening illness

<table>
<thead>
<tr>
<th>Number of Enrollments Annually</th>
<th></th>
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<tbody>
<tr>
<td>FY 2017-2018</td>
<td>530</td>
</tr>
<tr>
<td>FY 2016-2017</td>
<td>615</td>
</tr>
<tr>
<td>FY 2015-2016</td>
<td>717</td>
</tr>
<tr>
<td>FY 2014-2015</td>
<td>723</td>
</tr>
<tr>
<td>FY 2013-2014</td>
<td>770</td>
</tr>
</tbody>
</table>
Data FY 2017-2018

Total Clients receiving PIC:TFK services: 530

Total amount of claims paid: $322,603

Average cost per recipient: $609
CMS Registered Nurse Consultant
Cynthia L. Smith, RN, BSN
(850)245-4326
Cynthia.Smith@FLHealth.gov

Florida Hospices and Palliative Care (FHCPC) Executive Director
Paul Ledford,
(850) 878-2632 (office)
(850) 922-7907 (direct)
Paul@FloridaHospices.org
Colorado Medicaid Waiver for Pediatric Palliative and Hospice Care

Brian Greffe, MD
Candace Bailey

September 14, 2018
Our Mission

Improving health care access and outcomes for the people we serve while demonstrating sound stewardship of financial resources
The Butterfly Program along with Colorado Medicaid began working on a waiver in 2001 to provide pediatric palliative care services to Medicaid eligible patients from time of diagnosis.

Based on Children’s Hospice International Program for All-Inclusive Care for Children and Their Families.

SB 04-206 was signed by Governor Owens in June 2004 authorizing Department of Health Care Policy and Financing (HCPF) to craft a waiver.


First 1915c Home and Community Based Waiver for pediatric palliative and end of life care in U.S.

California’s 1915c waiver approved 2009.
State Medicaid Waiver

• It was estimated 4000 Medicaid eligible children could benefit from waiver

• Introduction of pediatric palliative care earlier in the course of a life limiting illness estimated to save $20,000/child/year
  ➢ Decrease unnecessary ED visits and hospitalizations

• 200 slots available in current waiver
  ➢ Children with Life Limiting Illness (CLLI) Waiver has 169 individuals enrolled as of June 2018
1915c Home and Community Based Waiver

- Medicaid eligible children with a life limiting diagnosis

- Services available from the time of diagnosis of the illness
  - Child must be at risk of hospitalization
  - Curative therapies may continue

- Services include specialized nursing, counseling, spiritual support, respite, expressive therapies such as art and music therapy, anticipatory grief therapy
Current Waiver Services

• Expressive Therapy
  ➢ Art and Play Therapy
  ➢ Music Therapy

• Massage Therapy

• Palliative/Supportive Care
  ➢ Care Coordination
  ➢ Pain and Symptom Management

• Respite Care

• Therapeutic Services
  ➢ Bereavement Counseling
  ➢ Therapeutic Life Limiting Illness Support - Individual/Family/Group
Waiver Success

- HCPF projects the CLLI Waiver will save Medicaid $304,000 per member, per year for the year 2018
- No waitlist for enrollment onto the CLLI Waiver
- HCPF is adding more providers to ensure access to valuable services across the state
- CLLI Waiver will be up for renewal with CMS in 2020
Concurrent Care

• Provision of Affordable Care Act

• Allows for individuals 20 years and under who are on Medicaid and enrolled in hospice (prognosis of 6 months or less) to receive curative therapies

• Colorado Medicaid has amended State Plan to account for this change and also has amended the hospice rules
Web Resources

• CLLI Waiver website
  ➢ www.colorado.gov/hcpf/children-life-limiting-illness-waiver-clli

• Long-Term Services and Supports Programs website
  ➢ www.colorado.gov/hcpf/long-term-services-and-supports-programs
Questions or Concerns?
Contact Information

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Medical Director- HOPE Survivorship, Reach, and Butterfly Programs
Children’s Hospital Colorado
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Children’s Hospice International
Helpful Resources
www.chionline.org/helpful-resources/

- **Publications**

- **Videos**
  - CHI video, 2015
  - Fantasy Flight 2015 photos
  - Fantasy Flight 2015 A Magical Journey
  - Arch Children’s video 2015
  - The Purple Balloon— the perfect tool for opening discussions between adults & children

- **World Congress**
  - CHI’s World Congresses
  - Kirby’s Scholars

- **News and Events**
  - Kate Middleton speaks about hospice
  - Fantasy Flight
  - ChiPACC 2014 Webinar
  - CHI’s 13th Annual ChiPACC Technical Conference
  - CHI’s 25th Anniversary
  - Review the ChiPACC Bill (Mattie & Melinda Bill) – July 2018
  - Press Release: ChiPACC Bill (Mattie & Melinda Bill) re-introduced to Congress – July 2018

- **Families and Stories**
  - Invitation to Share and Contact/Submission Info
  - CHI’s Right of Publicity Release
  - Mattie and Jen’s Story
  - Timmy’s Story
  - Melinda’s Story
  - Kirby Hospice Journeys
  - Kirby and Tutu Scholars
Children’s Hospice
International
Helpful Resources
www.chionline.org/helpful-resources/

- Partnership with Penn State
- Student Health Policy Interns
- ChiPACC Implementation Manual “Refresh”
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