

# SHAPING THE FUTURE OF SERIOUS ILLNESS CARE: A CONVENING TO DEFINE CONCURRENT CARE

## EXECUTIVE SUMMARY

On Tuesday, **February 6, 2024**, leaders from across the country gathered for *Shaping the Future of Serious Illness Care: A Convening to Define Concurrent Care*.

This one-day working session was held from 9 a.m. to 4 p.m. at the Hilton Baltimore BWI Airport in Linthicum, MD.



The Convening was made possible thanks to support from the **National Hospice and Palliative Care Organization, National Coalition for Hospice & Palliative Care, and National Association for Home Care and Hospice**. Driven by a shared intent of unifying the knowledge and goals of concurrent care, a **cohort of 45** clinicians, patient advocates, and leaders from across the serious illness care sector started a process of discovery, by exploring areas of consensus on the fundamental elements of concurrent care. These conversations set the stage for the shared visioning, strategy planning, and statutory, regulatory, and policy efforts needed to advance concurrent care.

### GOALS

- *Gather serious illness care providers, academicians, and other thought leaders for a one-day working session to unify knowledge and pursue a common understanding of concurrent care.*
- *Provide a forum for open discussion and sharing of ideas to advance improved benefits and access for all people with serious illness care.*
- *Produce a report summarizing discussions throughout the day, including areas of consensus, additional areas to be researched, and options for continued efforts to move forward serious illness care in the United States.*

## RESEARCH AND DISCOVERY

Attendees received an advance packet of materials, including current **descriptions**, past **models**, and timely **studies**.



**DEFINITIONS**



**MODELS**



**RESEARCH**

## EMERGING FACTORS ON THE HORIZON

Attendees were asked to explore what emerging factors they see in the next 5-15 years that will impact the language around concurrent care and should be considered. Outlined below are several topics that will be important in navigating concurrent care in the years ahead:

- **Advancing Health Equity** - including calls for increased cultural competency and advocating for access for all.
- **Demographic Shifts** - driving greater demand and possible access issues, due to the confluence of a population that grows older and more diverse at the same time as we see a decline in the available workforce.
- **Flexibility** - from moves towards individualized care delivery that embraces caregivers, to the integration of new technologies, such as telehealth and artificial intelligence.
- **Partnerships** - both formal and informal, across the care continuum and in advocacy campaigns.
- **Increased Caregiver Burdens** - requiring the service of caregivers alongside patients, increasing use of home and community-based services, and shifting responsibilities to families in benefit design.
- **Public Perceptions and Understanding** - challenges will grow at the crossroad of complex care delivery and payment systems, with potential for erosion of public trust in healthcare institutions, and a growing focus on fraud and abuse.
- **Payment Reform** - shifts towards the commercialization of healthcare, value-based models and expanded access, such as Early Pediatric Screening Diagnostic and Treatment (EPSDT) services.

## CORE PRINCIPLES

Attendees were asked what they see as the core principles, ideas, and goals of concurrent care. **The most resonant point was that concurrent care is not just about medical treatment; it's about fostering meaningful, empowering conversations throughout the healthcare journey, leaving people in control of their own care.** Common language used throughout the day, which offers the initial seeds of draft principles:

- **Person-Centered and Goal-Directed** - active engagement of all stakeholders helps to ensure that the voices and choices of all people being served (patients/caregivers) are driving the decisions and setting unique goals and values.
- **Holistic “Vibe”** - care that is comprehensive, culturally humble, compassionate, and operating largely in the background, with intentional and personalized messaging.
- **Intentionality of Equity** - prioritizing equitable access and delivery across age and geography, with a thoughtful approach from community-based caregivers trained to be aware of implicit bias.
- **High Quality and Flexible Delivery** - providing high-quality interdisciplinary services known for standardized access, flexible delivery, and needs-based customization.
- **Asset Mindset** - advancing feasible and realistic solutions, acknowledging financial realities and avoiding a race to the bottom by titrating resources to meet needs.



## PAIN POINTS

In one of the most powerful conversations, attendees were asked what they saw as the main sources of confusion. Feedback centered on how concurrent care aims to provide holistic, compassionate, and responsive care, yet it grapples with a series of challenges spanning high-level **strategic concepts** as well as **operational considerations**. These include a complexity of communication issues, a resource scarcity mindset, a lack of coordination among providers and payers, bureaucratic barriers, a focus on ROI-driven models, a general lack of clarity on shared vision, differences in the sense of urgency, and a delicate tension in the need for standardization amidst calls for operational flexibility.

## STRATEGY CHALLENGES

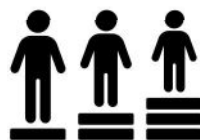
- **The Inertia Challenge** - questions arise on the urgency and timing of needed changes, the players needed for large-scale success, and the risks of losing essential components of care. This leads to tensions in balancing a need for rapid change with concerns of risk by others related to unintended consequences and having sufficient buy-in.
- **Systemic Barriers** - political polarization, issue complexity, benefit vs. gatekeeper dynamics, and entrenched interests in maintaining the status quo are hindering collaborative care delivery and innovation.
- **Resource Scarcity Mindset** - concerns focused on funding and payment, potential for fraud and profiteering, and the lack of critical access to care for patients. In addition to bureaucratic barriers, a focus on return on investment (ROI) seems to drive most thinking, policy, and marketplace decisions.

## OPERATIONAL CHALLENGES

- **Messaging Complexity** - confusion arises due to the abundance of discipline-specific terminology, silos, and misperceptions about motives. Confusion also stems from technical language that doesn't resonate with various audiences, from patients to policymakers, causing reactions from fear to disengagement.
- **Pediatric and Adult Care** - specific challenges also include differences of note between pediatric and adult care and a general lack of shared definitions on "standard" terms.
- **Provider and Payer Pain Points** - providers grapple with eligibility criteria, assessing effectiveness, care coordination, and unclear care pathways while payers face uncertainty about inclusions, competition, and measuring quality and costs.
- **Standards and Operational Alignment** - while flexibility in care delivery and workforce is crucial, there is a desire for general standards and operational alignment to help accelerate discussions on the design of models for care delivery, how variances in care get reflected, prognostic uncertainty, and clarity on eligibility and payments.



**SECTOR  
COORDINATION**



**EQUITABLE  
ACCESS TO CARE**



**POLICY AND  
PAYMENT REFORM**

## LANGUAGE MATTERS

In an exploration of specific language that attendees felt was key to talking about concurrent care, they identified preferred **phrases, terms, or concepts by key audiences**. Below is a sample of the full profiles developed to ensure seamless access to concurrent care. Across all, there is a desire to create **universal, accessible language using layman’s terms**.

**RESPONSIVE + NEEDS-BASED  
EQUITY + ACCESS + ALIGNED  
PERSON-DIRECTED + HOPE  
FEASIBLE + RESPONSIBLE  
CULTURALLY HUMBLE  
REALISTIC + FLEXIBLE  
EVOLVING + CHOICE**

## PATIENTS + FAMILIES

Prioritize continuity of care, holistic approaches, choice and the *addition* of options.

## PAYERS

Highlight potential financial benefits, efficiency, high quality and patient outcomes.

## REGULATORY + POLICYMAKERS

Advocate for adaptability, flexibility, and feasibility to implement in models and policies.

## PROVIDERS + CLINICIANS

Stress maintaining relationships and continuing necessary treatments uninterrupted.

## LAWMAKERS

Utilize a mix of data and stories about continuity and person-centered approaches.



## PEDIATRIC CONCURRENT CARE

## EQUITY CASE STUDY

As an example of the need for nuance and flexibility in this work, one topic echoed throughout each conversation: *how differently care for children and their families was than for adults*. From the pioneering policy known as “Concurrent Care for Children” established in Section 2302 of the Affordable Care Act we’ve seen differences emerge in what can be prolonged dying processes, desired language/terms, or needed decision-making supports. What works for one population can be quite different than others.

## LEVERS OF CHANGE

As the Convening moved into a synthesis and sensemaking phase, attendees worked to identify a series of potential activities that could effectively drive change and proposed action steps that could be considered going forward.

**Organizing for Greater Impact** - remains a clear opportunity, as leaders explored the power and potential that comes by deepening relationships and infrastructure in shared work. More than a fancy way of saying we're working together - it would be a powerful, cross-sector collaborative approach to establish social change and advance a common agenda, such as co-creating a *Concurrent Care Strategic Plan* that lays out a multi-year, sector-wide vision, organizing strategies, outcomes, metrics and action steps to address priority pain points or co-creating an ongoing collaboration and communication structure.

One possible pathway forward is to consider a **Collective Impact Theory** framework, including development of a **common agenda, shared measurement, mutually reinforcing activities, continuous communication, and a "backbone" support team.**

**Co-Creating Shared Work Products** - garnered a high level of interest from those ready to design tangible solutions. This could range from creating a platform to share information and resources, to a cross-sector volunteer committee process that offers space, time, and rules of engagement for interested players to co-design, test, and advance materials. From jointly building a flexible care delivery model for adaption and replication or using a rubric that reviews payment models to help successfully scale a solution on the national stage, potential projects include: *A Landscape Assessment of Concurrent Care, Core Principles of Concurrent Care, Definitions Related to Concurrent Care, Core Components and Contextual Adaptations to Concurrent Care Models, Designing Our Future: A Review of Concurrent Care Payment Models, or Quality Standards of Concurrent Care*

**Advocating for Concurrent Care** - remains a galvanizing opportunity of high interest. Ways to showcase compelling stories, develop savvy policy, and package the data needed to move the hearts and minds of lawmakers require a deeper exploration of the language and strategies needed to engage the public in understanding concurrent care as well as create greater political will for change. Potential projects include a process to co-create shared public policy agenda(s), congressional issue briefs on need and financial implications, or a public messaging initiative that recruits and features stories of patients and families