

Creating a Managed Care Framework for Mental Health in Rare Diseases Using AI, Literature, and Expert Review:

Findings from AMCP Market Insights Expert Interviews

Noreen Matthews, BSN, MBA[#]; Terry Richardson, PharmD, BCACP^{*}; Michelle Rice[^]; Maureen Ellen Lyon, PhD, ABPP⁺; Michael Kobernick, MD, MS-HSA, MS-PoPH-FAAFP[†]; Lesa Brackbill, MA[°]

BACKGROUND

The Orphan Drug Act identifies a rare disease as any condition affecting fewer than 200,000 people in the United States. While treatments for rare diseases can offer significant health improvements over those for more common ailments, over 90% of rare diseases have no FDA-approved treatments, leading to a substantial unmet need. This includes prolonged diagnostic processes, scarce treatment options, and considerable psychosocial stress due to the absence of coordinated, comprehensive care. Using artificial intelligence (AI) can significantly enhance the efficiency of developing solutions and resources for health care professionals. AI can analyze vast amounts of data rapidly and identify patterns that might not be immediately obvious to humans.

OBJECTIVE

To develop a framework focused on the mental health of individuals with rare diseases, using a mix of traditional and AI methods, that supports the AMCP Market Insights panel discussion and assists managed care professionals in their efforts to support patients.

METHODS

In the fall of 2023, AMCP Market Insights undertook a targeted literature review to identify key areas where managed care professionals can impact the mental health of persons living with rare diseases. AI prompts in chat.gpt4 were then used to identify supporting actions for each area of focus from the literature review and were synthesized into a conceptual framework. During a panel discussion in 2023, AMCP Market Insights expert panelists reviewed and further refined the framework's components.



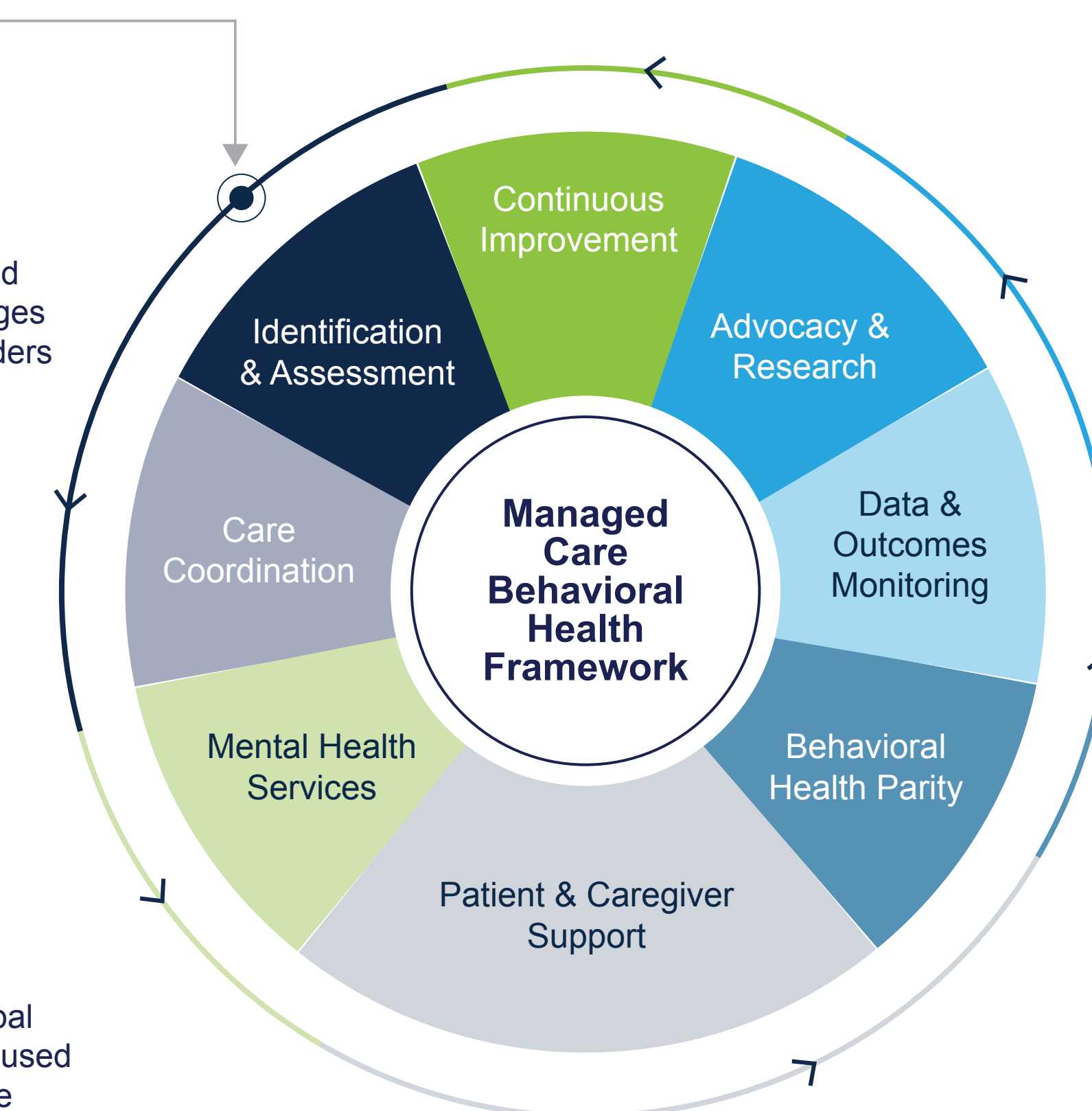
RESULTS

The literature review identified eight critical areas where managed care professionals can influence the mental health of those with rare diseases. These areas are Identification and Assessment, Care Coordination, Mental Health Services, Patient and Caregiver Support, Behavioral Health Parity, Data and Outcomes Monitoring, Advocacy and Research, and Continuous Improvement. AI added additional tactics for each area and organized it into a framework. A panel of experts reviewed and refined the framework for accuracy.

Sample of AI Prompts in ChatGPT-4

- How can managed care professionals support patients with rare diseases?
- What are the key behavioral health issues that need to be assessed in patients with rare diseases?
- What are the best practices for implementing routine mental health screening in patients with rare diseases?
- How can mental health care disparities be addressed for patients with rare diseases?
- What types of educational resources are needed to help patients and caregivers understand rare diseases and their behavioral health implications?
- What areas of research should be prioritized to improve mental health outcomes for patients with rare diseases?
- What policies are needed to support the mental health needs of patients with rare diseases?
- What quality metrics should be established to track the effectiveness of the managed care behavioral health framework?
- How can organizations ensure compliance with mental health parity laws when providing behavioral health services?
- What approaches can be used to ensure treatment plans align with patients' preferences and values?

Conceptual Managed Care Behavioral Health Framework



IDENTIFICATION & ASSESSMENT:

- **Patient Identification:** Identify patients with rare diseases within the managed care system
- **Risk Assessment:** Assess behavioral health issues, including depression, anxiety, and caregiver stress

CARE COORDINATION:

- **Specialized Care Teams:** Collaborate with specialized care teams that understand behavioral health challenges
- **Primary Care Integration:** Inform primary care providers about the patient's rare disease and its potential behavioral health impacts

MENTAL HEALTH SERVICES:

- **Access to Mental Health Specialists:** Experienced in treating patients with chronic and rare conditions
- **Routine Mental Health Screening:** To identify and address behavioral health issues early
- **Telehealth Services:** For patients who may not have access to in-person mental health services

PATIENT & CAREGIVER SUPPORT:

- **Respite Care Services:** To temporarily relieve and reduce caregivers' stress
- **Caregiver Education:** To help them cope with the emotional and practical challenges of caring for someone with a rare disease
- **Peer Support Specialists:** New CMS rule for "Principal Illness Navigation" services that apply to the services used to help people diagnosed with high-risk conditions, like cancer, get linked up to the right support and resources
- **Education & Resources:** Provide resources to help patients and caregivers understand the rare disease, its behavioral health implications, and coping strategies
- **Support Groups:** Connect patients and caregivers with support groups for emotional support

CONTINUOUS IMPROVEMENT

- **Feedback Loops:** From patients, caregivers, and health care providers to refine and improve the managed care framework
- **Adaptability:** To accommodate changes in rare disease treatment and behavioral health best practices

ADVOCACY & RESEARCH:

- **Research:** Advocate for increased research funding for rare diseases and innovative treatment options to improve outcomes and reduce mental health stressors
- **Policy:** Advocate for policies that support mental health needs of patients with rare diseases

DATA & OUTCOMES MONITORING:

- **Data Collection:** Analyze data on the mental health and overall health outcomes of patients with rare diseases to identify areas for improvement
- **Quality Metrics:** Establish metrics and benchmarks to track the effectiveness of the managed care behavioral health framework

BEHAVIORAL HEALTH PARITY:

- **Compliance:** Ensure the organization complies with mental health parity laws, treating behavioral health services on par with physical health services

PATIENT-CENTERED CARE:

- **Shared Decision-Making:** Ensure treatment plans align with patients' preferences and values
- **Individualized Care Plans:** Based on the patient's rare disease and behavioral health needs

Download  Listen 

CONCLUSIONS

The framework, designed to enhance mental health care for individuals with rare diseases, identifies key areas for managed care professional influence. The use of a targeted literature review and AI have streamlined the process of condensing extensive data into a framework for experts to review.