

## May 18th Community Advisory Council Summary

By Grace Martin, Founder of Lexington Writing Firm



On June 1, Minnesota Alliance for Patient Safety (MAPS) hosted a statewide forum for patient/resident and family advisors serving in health systems. Believing that patient, resident, and family input is critical to safety during the COVID-19 pandemic, MAPS launched this innovative Council for virtually sharing concerns, perspectives, and insights.

Catherine Hinz (Executive Director), Lisa Juliar (Engagement Specialist/Patient Partner), and Megan Daman (Project Manager) led the meeting, which focused on discussing visitor restrictions during COVID-19. MAPS thanks all patients, residents, family members, and healthcare leaders who took time to participate so soon after the murder of George Floyd in Minneapolis. We grieve beside you.

**Amy's story:** Amy is a vibrant 50-year-old woman living with cerebral palsy and other health conditions who communicates with sounds and facial expressions. Amy lives in a group home and receives support from her parents and two sisters—Mara and Erin—all of whom are her legal guardians. On May 7, Amy's caregivers called her family believing that she aspirated vomit and recommended that she receive care at an emergency department. Wanting to prevent Amy's parents from being exposed to COVID-19, Mara accompanied Amy.

When Amy was admitted to the hospital, the staff made an exception in their visitor policy to allow Mara to stay with her throughout care. Mara stayed in the hospital for 16 straight days advocating for her sister. During this time, Mara pointed out Amy's weight loss, increasing abdominal pain, and need for wound care, as well as helped with communication. "I was her voice," asserted Mara. The hospital's care team decided to allow other visitors, one at a time. Amy's parents, niece, and sister Erin have been helping at different times. The family decided to place a GI tube to help Amy live more comfortably. "The hospital team has appreciated us being there," explained Erin, "We hope that she will come home very soon."

**Discussion of care person:** The Council discussed the important role of a "care partner" or "patient partner" across all care settings. This role is more extensive than that of a visitor, because this individual:

- Advocates for the patient over the course of care and recovery (if acute care was needed)
- Provides an extra set of eyes and ears throughout care and stressful, complex conversations
- Helps remember and manage critical information about care
- Provides emotional support, which can help speed recovery and improve outcomes

During next week's discussion, the Council hopes to further define the role, using our wealth of experience and knowledge as patients, residents, and family members. This role will be explored first from the perspective of improving patient safety.

**Key takeaways for health systems:** Our advisors recommend that health leaders discuss the importance of a designated "care partner" or "patient partner" who is allowed to stay with certain hospitalized patients during COVID-19 and consider expanding this practice after the pandemic. Additionally, discuss the importance for this role beyond hospitalizations in other settings of care. Clear, public guidelines about "care partner" policies will help keep patients safe and feel more at ease.

For more information about the MAPS Community Advisory Council weekly conversations, email [info@mnpatientsafety.org](mailto:info@mnpatientsafety.org).