Palliative Care and Quality of Life Advisory Council Meeting
October 21, 2016

Present: Kevin Lewis, Kandyce Powell, Jim VanKirk, Deb O'Neil, Greg Burns, Lauren Michalakes, Elizabeth Keene, Sandra, Roland Joy, Jason Whitney, Bruce Condit, Katherine Pelletreau , Liza Eager, Dennis Fitzgibbons, Robin Hirsh-Wright, Denise Needham, Hilary Schneider, Margaret Belanger

Topic	Discussion	Follow up
Compassion care program	Hand outs were distributed	
Community Health Options Benefit Plan related to Palliative Care Kevin Lewis April Seddon	Mission and vision were reviewed. Value based insurance design, ACO collaboration, behavioral health integration, chronic illness program, care management focus, extensive network were discussed as parts of the organization. Enrollment: majority of membership is on exchange, 63%, group is majority is off exchange, silver group plan is most popular due to reduced cost sharing due to plan design, average age of enrollment is 41.75, Cumberland and York county have a larger population with up to 4000 member in Aroostook County, Palliative Care-included diagnosis CPT codes 99497 and 99498, 142 members with average age of 56.3 are eligible for the benefit, inpatient episodes are the highest cost claims and 1/3 of costs are associated with cancer. The age of palliative care is 60-65 and cost is striking as well. <u>Population Health Team Approach:</u> **Care management:** The team is made up of dietician, social work, nurse and navigators. At age 50 is when they begin engaging members. The nurse care manager does reach out to the members over 50 years of age based off the claims data that have chronic illnesses(i.e.) cancers, chf, copd, diabetes, difficult to approach palliative care and advanced directives due to sensitivity of issue. The team will support the decision they arrive at. The interventions are all by telephone. There is not face to face encounter at this time. The care manager attempts to coordinate with primary physician. There is a hospice benefit available if required by the members. There is no limit when palliative care may be applied.	It was asked how the hospice benefit provided coverage. The information was not available at this time

	Access to care: The care managers are flagging the patients to provider. It is about 50/50 if the provider picks up the discussion and care around palliative care. There are some transportation issues to helping the member attend the provider appointment. The care manager does help to access resources through the area agencies on aging for lodging, fuel and transportation. Examining use of telehealth options going forward for rural areas and examining technology challenges. The awareness of palliative care needs to be increased with members despite the shift in the care manager approach.	Discussion was held around home care palliative care as patients want to age at home through the use of telemedicine and home based services. There is a lack of presence of home based palliative services. Resources around connectivity are a huge issue for the state and needs to be addressed state wide to assist palliative services at home. On October 25th, there is a broadband conference at Maple Hill farm if people would like to attend.
Pediatric Palliative Care Greg Burns Sandra Bacon Katie Addicott	A presentation was given about pediatric palliative care. The history of the evolution of pediatric palliative care was presented. The scope is not only on the child but for the family as units due to the parents are the care decision makers. Most of the children requiring palliative care suffer from neurological disorders or genetic conditions. Children with cancer usually undergo aggressive treatment. The Jason Program was presented. It ran from 1999-2008 which the funding ended in 2008. Currently in Maine 824 children qualify for Palliative care.	Recommendations for Pediatric Palliative Care: Telemedicine use Education for all providers/clinicians Field training Adequate resources in the home setting Statewide Pediatric Palliative Network Undergraduate education in curriculum Education of pediatric dosing for palliative

	Current issues: There is a lack of training and trained staff in the pediatric palliative specialty. Funding for pediatric programs is not as much of a priority as other programs are at this time. Barbara Bush Children's Hospital has agreed to support a 0.8 FTE for pediatric palliative care that will support inpatient and outpatient needs. There is cost savings for the program by decreasing hospitalizations and ED visits and increasing family satisfaction, quality outcomes and confidence in caring for ill children. Two very touching case studies were presented that demonstrated the need for availability for pediatric services for the entire care team including nurses and physicians. Access pediatric palliative care is extremely limited in a large part of the state. Most pediatric end of life care occurs in hospital setting. Traumatic situations may be avoided with proper resources and education for these children and their families.	medications. Case Managers for pediatric palliative cases Expand Maine Care Services – concurrent care for children Nursing shortage impacts access – trouble staffing block time hours to allow children to stay at home; no nursing homes for kids, lack of respite for parents
SAGE Maine Doug Kimmel	Sage was founded in New York City and in now in 30 States. Maine established its chapters in 2013 as a non profit. There are drop-in centers in Bangor and Damiscotta, Presque Isle and attempting to establish in Farmington. They have a telephone drop in center state wide for support as well. They had a dinner in Portland last evening. Board is state wide and meets virtually. They have interest with LGBT population. They have acquired an office are in Portland. A video called GEN SILENT was shared with special interest towards Palliative Care. There were 2 cases one focusing on palliative care and one for hospice. Sage does offer training programs for staff that can be done around the state 2- 4 hour sessions. It can be customized for your organization. The video is available in multiple settings. Maine does provide the Human Right Protection in any facility. The legalization of marriage has helped move things alone. Jim shared an experience at his facility that the partner of a patient was discarded and the provider went to other family members for decision making.	Discussion was held if we are doing better in providing care better to LGBTQ community. Mr. Kimmel stated that it is better especially in the VA system. Medicare will pay for transgender surgery if medically necessary. Tremendous progress is being made but in the general practice it has work to be done. Kandyce recommended reading "Knowing Nicole" to help with a better understanding. The family depicted is in Maine

Alpha One Dennis Fitzgibbons	Dennis began speaking about suicide prevention and presented a TED talk by Stella Young on disabilities: "I'm Not Your Inspiration". Most disabled individuals live in poverty throughout the nation. The focus on how to make the most of life with your current state. Healthcare costs are high in this population. **Other areas of discussion**: independent living paradigm versus model of self held, encouraging aspirations, education, and employment. Unemployment is doubled in the disabled population, housing environment, health care relationships, and patient engagement, ACA changing increasing accessibility, transportation, and quality of life. **Barriers** for this population to access palliative care. Barriers identified were isolation, lack of transportation, fear, lack of trust, not being taken seriously, lack of education of what the services provide. It is important that the person are taken seriously and respected in their decisions including children. Important to leave all bias at the door. Need to investigate what the reality is for the person in all aspects. Fostering communication is vital. The question was asked if people with disabilities are over or under treated. The consensus was both. An example of standard of care was presented of weighing patients who are disabled in physician offices. A healthcare system did make changes after it was brought to their attention.	
Consumers Affordable Care Act Emily Bosteck	Emily began by referencing the adjacent article. The United States spends more money on health care than any other country. 50% of all expenditures are on end of life care or those who are seriously ill. A graph of how the US is providing inpatient palliative care was displayed. According to the graph, Maine is doing well. In reality, it displays hospitals that have greater than 50 beds which is a low number for our state leaving the numbers skewed. **Barriers to Palliative Care**: costs, underinsured, lack of insurance, decreased access to care, lack of communication and palliative care, and fragmented care Aetna did a concurrent case study offering palliative and hospice	Article referenced: http://www.content.healthaffairs.org/content/34/12/2192.full

	care simultaneously that demonstrated effective outcomes. CAHCE will assist people trying to obtain healthcare coverage. They will work with people around co-payments. They will assist consumers with communication with their insurance company to ensure proper care, facilitate cost conversations around insurance and co-payments and affordable treatment decisions, and coverage for alternative treatments.	
Meetings for the next year	Quarterly meeting: the fourth Friday of the first month of each quarter January 27, April 28, July 28 and October 27	The meetings will be full day meetings.
Informal steering committee of the group	Discussion was held if there needed to be a steering committee for agenda and planning purposes. These meetings can be open to the public if people want to attend.	The current members, who are communicating in this group, will continue. This process has been informal. If you want to be involved, please let Kandyce know.
Yearly report	Discussion was held as to when the report needs to be completed. It needs to be completed online. That is the only option. The report that was submitted by Kandyce last year. It needs to be completed by January 1.	The steering committee will complete first draft of this document for committee to review. Others are welcome to assist in the report if they desire to do so.
Community Comments	A thank you for serving on the council was given due to the work that is being done. The information presented today was a blessing and beneficial.	
Next meeting	January 27, 2017	
		Respectfully submitted: Alicia Mooney RN, MSN, CHPN