



It takes a village...caring for the seriously ill child at home

Care across the continuum – an achievable goal



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A few foundational facts..

Pediatric palliative care (PPC) is for children who are not expected to reach adulthood.

Number of dying children is decreasing

Number of children with special health care needs increasing

Over 3 million could benefit from PPC

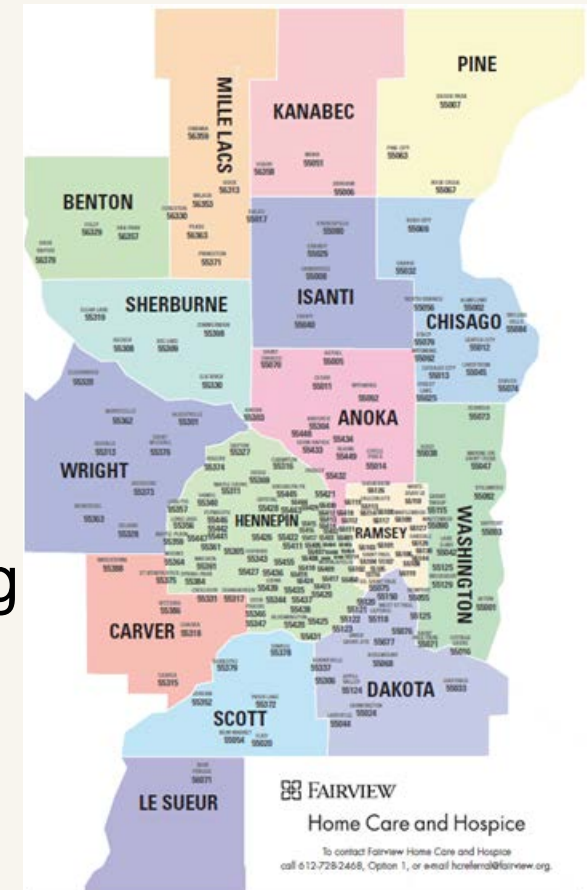
PPC home care showed 11% cost savings per month and 32% reductions in average number of hospital day

* Friebert ,Friebert, S. E., & Williams, C. (2015). NHPCO's facts and figures : Pediatric Palliative Care in America 2015 edition *National Hospice and Palliative Care Organization* (pp. 1-11). Alexandria, VA. https://www.nhpc.org/wp-content/uploads/2019/04/Pediatric_Facts-Figures-1.pdf



Fairview Health Services

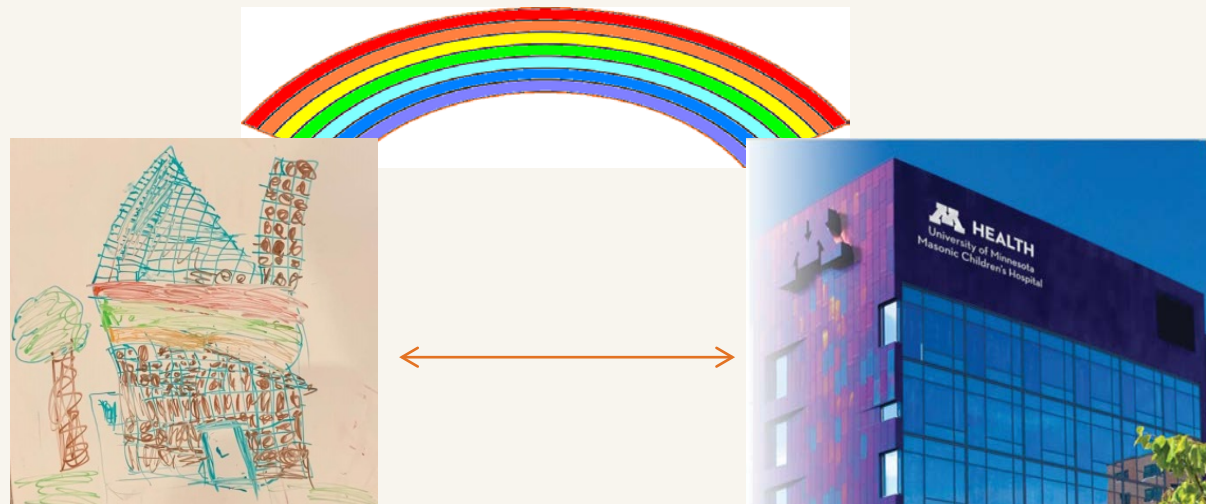
- Fairview Health Services - non profit, full spectrum, integrated health system in MN
- The Home Care and Hospice section serves 16 counties around the twin cities
- Urban and rural component
- 2013 Pediatric complex care, palliative care and hospice
- Growing to meet the need by cross training clinicians





Pediatric Advanced Complex Care Team (PACCT)

- Intra-disciplinary team- professionals and family
- Extended team- school, county and others
- Across the trajectory





What does this look like in real life?

- https://urldefense.proofpoint.com/v2/url?u=https-3A_youtu.be_oFufDtS5a-2DU&d=DwlCAg&c=e0qWO0MXWFiQgGWE0UmXdQ&r=3BNcDI8H3NAK97eakl9rjK6XV1KuX7yZSGmTHL_u580&m=INFDGSYi-rYFNh7qUon2fqGgwNzf-tCe-OZEa_ewmXs&s=ZXt1H0KFJhMML-SSWc5Ubx--pFvZ_SbpLhWwoe39cUE&e=

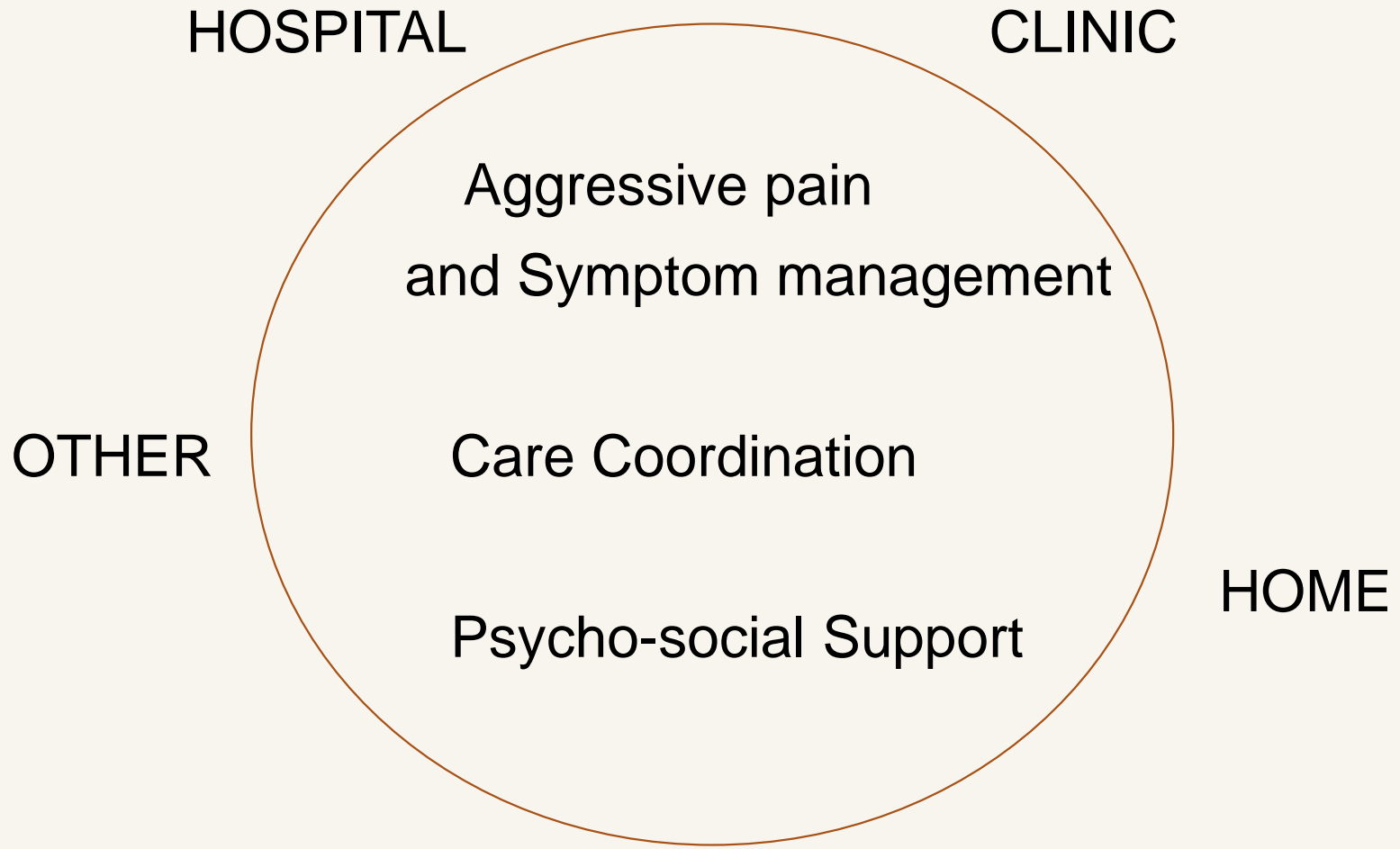


How do we do this?

- Develop collaborative relationships across silos- private duty agencies, multiple providers and health care institutions.
- With parents permission - collaborate with community:
 - *school or day care
 - *county waivers and programs
 - *extended family
 - *others



Continuity



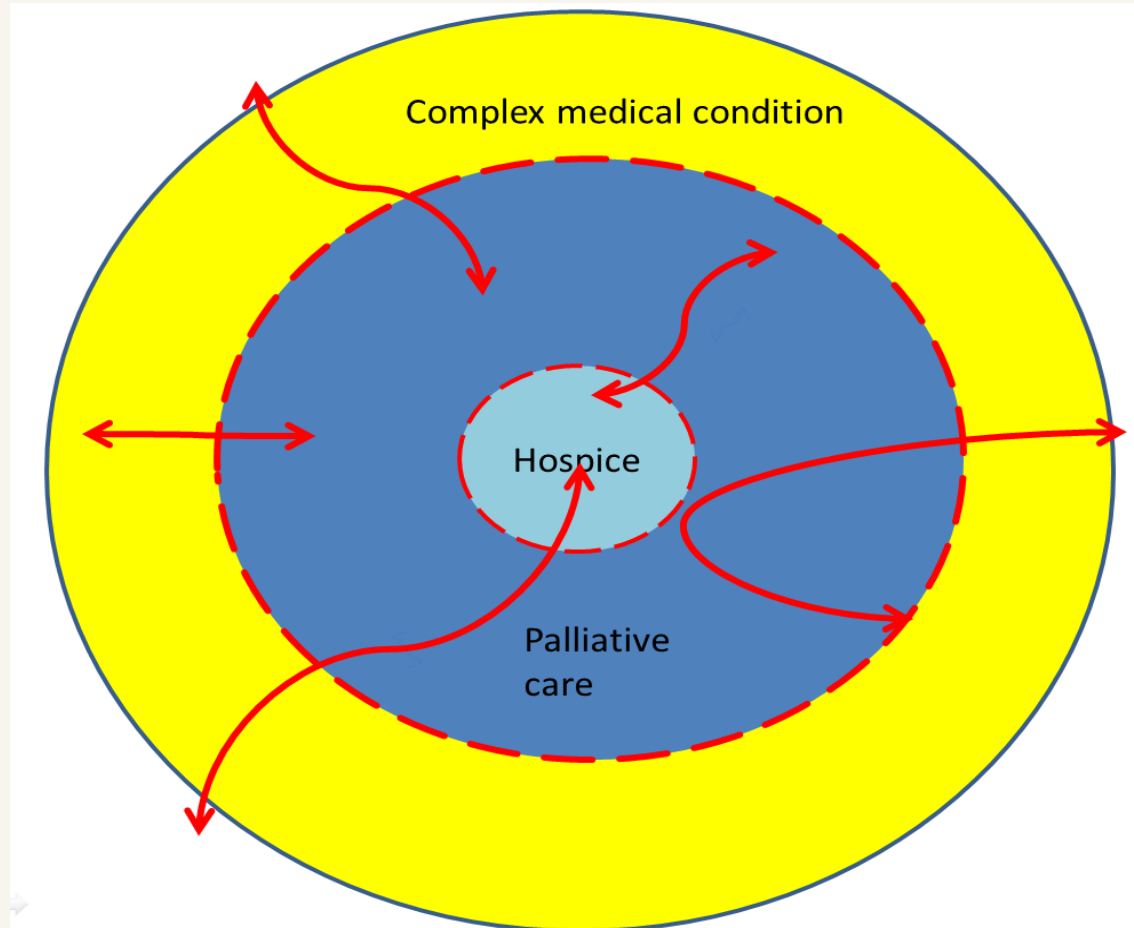


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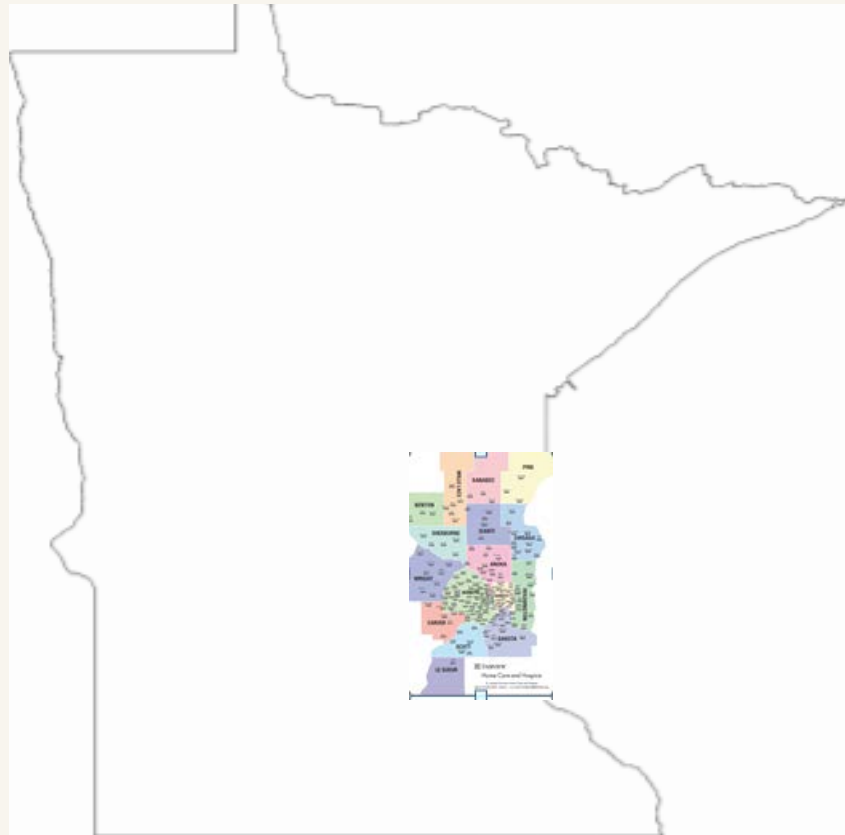


Need for Flexibility





Covering 13 counties but what about the rest??





Reaching out to rural MN

- In person visits not always workable
- Working with who is there- family, public health nurse, EMT
- Distance support telephone, email, video visits
- Strong collaboration with state association





But how do you do this work??

Finding and keeping staff

- Awareness of need
- Training and education
- Self care
- Leadership support
- Good team work



Teams.. They don't just happen..

If they don't have scars, they haven't worked on a team. Teams don't just happen. They slowly and painfully evolve. The process is never complete. The work involved is usually underestimated."

Balfour Mount, MD

It takes :

- Hard work
- Communication
- Conflict resolution
- Education
- Adequate funding



Funding Needs to be..

- Focused on provision of services at home
- Flexible and responsive to often rapid change in condition
- Financially feasible, at least break even!
- Accessible across boundaries and insurance companies



In summary..

Nevaeh

We need

- Palliative care education for clinicians
- Accessibility to services
- Appropriate funding
- Program flexibility
- Compassion above all

“A Nation's Greatness Is Measured By How It Treats Its Weakest Members” Mahatma Gandhi