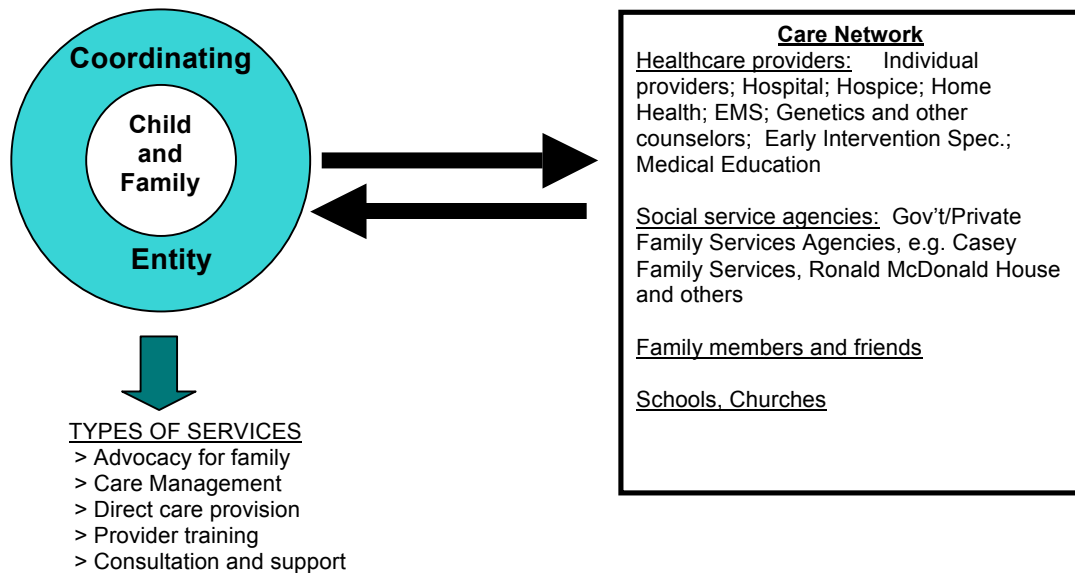


Components of comprehensive, coordinated pediatric palliative care



This diagram is based on interviews with key informants who have developed successful programs or systems for delivering palliative care that is coordinated across settings and time. Like snowflakes, no two programs were alike, but they comprised similar components.

They all featured a **coordinating entity** that transcended any one provider or agency and provided continuity across time and location. This coordinating entity might be an individual (plus back-up) or a team, and could be hospital-, home health-, hospice-based or independent of an institution. The coordinating entities had **relationships (some more formal than others) with other hospital and non-hospital-based healthcare providers**, social service agencies, and other organizations serving children and families dealing with life-threatening conditions in the community. Some programs were more focused on inpatient care and some were more focused on home-based care. The **services provided** by each program were different but fell into the categories listed in the diagram above.

All informants indicated that care coordination required significant time and resources, much more than direct patient care, and that the **key element was designation of a specific person or two (at the most) to be “in charge”** of care management for each child and family and identification of one or two contact persons available to the family 24 hours a day.