

Elements and stages of development in continuity of care

Key structural and functional elements	Non-linear stages of development
<ul style="list-style-type: none"> • Clear criteria for identification of the target population for care • A central coordinating entity, available 24/7, that works directly with families and is acknowledged by other providers as being “in charge” of coordinating care and services • A network of hospital and non-hospital based providers who have explicit working relationships and defined communication mechanisms • A team-based care planning process, that includes family input, to develop and update a care plan built around the unique situation of each child and family • Care delivery based on the shared care plan • Simple and explicit lines of communication for the family to the entity “in charge” of care • Mechanisms to track families cared for, services provided to each family, and outcomes of care • A business plan outlining sources of funding for all services • A community outreach/information campaign • Mechanisms to increase the knowledge and skills of clinicians and other care providers 	<ul style="list-style-type: none"> • A committed group of individuals (who may represent one or more institutions) define the mission and goals of a coordinated program of services; • This group builds professional relationships among individual and institutional providers, developing a network/coalition of organizations and individuals who serve children with life-threatening conditions and their families. • The network/coalition, with input from families, begins to craft a model for delivering coordinated care, including the key structural and functional elements. • The network/coalition starts serving children and families, refining the care model through experience. • The network seeks to expand access to the program, conducting outreach to raise awareness and identify additional patients. • The network attempts to build competence and capacity. • The network/coalition addresses issues of longer-term sustainability (e.g., financial resources and leadership succession)

The **key structural and functional elements** are based on characteristics of successful care systems.

The **stages of development** are a composite of stages described by successful care systems. Note that they are not meant to describe a linear process.

Working with these two lists, we have identified six tracks along which most care systems will develop. An evolving care system may be at different stages in each track at the same time. The goal is to move to a more advanced stage on each track over time. These tracks, and the progression along each one, form the basis of the assessment of progress. The continuity assessment tool is available to emerging groups to measure their progress over time.

Six tracks for care system development:

1. Networking and collaboration	Potential partners serve children in the community but are not coordinated	➔	Full complement of participating partners
2. Critical elements of a continuity system	A few elements are planned and/or implemented	➔	All elements fully implemented
3. Funding	A few services are funded or have a plan for funding	➔	Services fully funded via sustainable sources
4. Access	Few patients getting coordinated care	➔	All targeted patients getting coordinated care
5. Clinical capacity building	A few education/ mentoring activities exist or are being planned	➔	Multiple opportunities for education and support
6. Outreach	Few outreach activities	➔	Multiple outreach activities