Strategic Plan 2017-2020

Cedarcrest Center *for* Children with Disabilities
91 Maple Avenue
Keene, New Hampshire, 03431

Approved and adopted by the Cedarcrest Center Board of Trustees on July 11, 2016

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INTRODUCTION

In 2016, "strategic planning" is part of the vocabulary of virtually every non-profit trustee and management staff member – though there is rarely a uniform understanding of what it is, why it is important, or how it should be integrated into the work of a non-profit organization.

Although Cedarcrest's core mission has remained steadfast throughout its 69-year history – to provide residential care for children with medical and developmental needs – the world in which the Center operates has changed dramatically, and so have the ways in which the Center understands its role and responsibilities. Managing the changing expectations of state officials, funders, the disabilities community in general, and providers and families specifically, is possible only with a strong strategic planning process.

Cedarcrest Center understands itself as mission-driven rather than primarily market-driven. The principal question for the Center is always, "How does Cedarcrest (and can the Center realistically) respond to this or that emerging need?" Responding to needs – especially when there is sometimes no immediately apparent funding source – requires a different approach to planning.

In 2008, and again in 2012 and 2016, Cedarcrest Center applied a model for strategic planning known as "Strategic Positioning," based on the 2006 work of Thomas McLaughlin. Strategic planning is often carried out as brainstorming of ideas about what an organization wants to be in three, five or seven years. The deliverable is often a series of task lists and timelines, a compilation of activities the "planners" believe will lead to their goal. McLaughlin's approach focuses instead on strategy – planners decide **where to be** as an organization (i.e., how to position the organization) to meet the emerging needs of the population it serves and, only then, plan **what to do** operationally to achieve those positions. The deliverable in this approach is a set of strategic positions and broad operational initiatives. In the coming months, management and staff will undertake the development of work plans that chart the path necessary to reach or maintain identified strategic positions and implement each operational initiative.

What follows is a synthesis of work conducted in the spring of 2016 as part of Cedarcrest Center's periodic needs assessment and strategic positioning processes. More than 110 families and providers anonymously completed a comprehensive written survey about 'service trends and needs, and more than 80 individuals (listed in the acknowledgements) participated in one of six listening sessions held around the state to provide information, insight, and a range of perspectives as to the social, educational, economic, and medical issues impacting services for children with complex medical and developmental needs and their families.

This document summarizes that feedback in five key sections:

- Demand for Services
- Geography
- Collaborations
- Labor Force
- Sustainability

Statements of strategic position in each area follow. Each section concludes with a set of planning initiatives distilled from work completed by Cedarcrest Center trustees and management staff during a day-long retreat. The document concludes with a reiteration of the operational initiatives that will frame our work for the next several years.

MISSION, VISION and VALUES

Our Mission *(What is our purpose?)*
Cedarcrest Center enriches the lives of children with complex medical and developmental needs, supports their families, and collaborates with other community providers to build a continuum of care.

Our Vision *(What do we aspire to be?)*
Cedarcrest Center will be the model for best practices in the care and education of children with complex medical and developmental needs.

Our Values

(What qualities exemplify what we value in how staff members work as individuals?)

Integrity	We recognize the awesome responsibility we have in serving children and families. We pledge ourselves to serving them with integrity, embracing families as active partners in their children's care, fostering trust among families, providers, and members of the community through our commitment to continuous quality improvement and ethical behavior.
Compassion	We treat each child and family with compassion and we are passionate about ensuring each child the highest possible quality of life.
Accountability	We are accountable to our families, providers and service partners, employees, and donors for effective and transparent stewardship of the resources entrusted to us. Most of all, we are accountable to the children we care for, ensuring that their health, welfare and best interests guide every decision we make and action we take.
Responsibility	We embrace our responsibility to be a voice for families and their children with disabilities both at Cedarcrest Center and in the community. We accept it as our fiscal responsibility to assure the financial resources necessary to provide optimal care to children with complex needs and to invest in staff, programs, and facilities in order to meet emerging and future needs.
Enrichment	We believe that every child in our care has the right and deserves the opportunity to grow and learn to his or her maximum potential, and to live a life of the highest quality possible. Our focus is on enriching each child's life through the finest possible special education and therapy services, and to enable each child to enjoy the same cultural and recreational that children in the wider community enjoy.

(What characteristics reflect what we value in how staff members work together?)

Welcoming	We provide a warm, nurturing environment for children with complex needs. The tender-loving care that is our hallmark creates a welcoming place for their families and for their friends in the community.
Encouraging	We encourage families as they identify, choose, and sustain the best care option for their child at any given time. We encourage employee growth by providing scholarship support, tuition assistance, and opportunities for staff development.
Accepting	We accept each child, family member, and staff member for who they are. We believe that our capacity to work as a team and to respond effectively to the needs of children in our care is strengthened by our acceptance of differences in our backgrounds, abilities, and opinions.
Respectful	We respect the privacy of each child and family we serve, and treat each child with dignity. In our work, we actively promote mutual consideration of others' views, opinions and ideas, listening both to hear and to understand.
Excellent	We strive for excellence in all aspects of our services, working to provide exceptional, high-tech medical care and to exceed expectations in the quality of our educational and therapeutic programming.

SECTION 1. DEMAND FOR SERVICES

Research data and anecdotal information to clarify the circumstances in which we are likely to operate in the next several years and to understand the nature of ongoing and emerging service needs

HOW THE ENVIRONMENT HAS CHANGED. In 2016, the key concerns of both families who use our services and providers who may refer children to us differ little from two decades ago when Cedarcrest completed its first strategic plan. Those key concerns include inadequate in-home nursing support, insufficient respite care options, and need for better care coordination. Still, it would be too easy to say that little has changed in twenty years.

Just as survival rates among children born with medical complexity have increased dramatically, so, too, have the challenges of meeting their healthcare needs. A growing shortage of nurses and other clinical staff nationally has reached a crisis point in many places, including New Hampshire – particularly in relation to pediatrics and complex care. Without adequate in-home nursing support many families find securing appropriate respite care all but impossible. Increased survival among children with medical complexity has meant increased life expectancies as well. As a consequence, post-21 transition presents a host of new challenges and stresses for families around healthcare access, community integration and housing, and all these challenges now exist in the context of Medicaid Managed Care.

WHAT WE KNOW (from research and survey data)

- Providers re-confirmed several trends (from 2009 and 2013 needs assessments) as still significant or *very* significant for families of children with complex needs for whom they provide services:
  - Increased complexity of care needs (98% of respondents)
  - Increased need for medical knowledge (90% of respondents)
  - Decreased availability of respite options (88% of respondents)
  - Decreased availability of in-home nursing (85% of respondents)
  - Increased incidence of substance abuse (77% of respondents) [trend did not appear in 2009 or 2013]

  The last of these trends emerged as a new concern among providers from previous years. None of the other trends diminished in significance.

- Providers perceived the following as the greatest "unmet" needs among families of children with complex needs (in rank order):
  - In-home nursing support
  - Respite care
  - Behavioral health support
  - Vent support services

  In the Center's 2012 needs assessment survey, many families and some educators reported behavioral health support (mostly related to children on the autism spectrum) as an unmet need; the 2016 survey is the first in which providers across the board ranked behavioral health support as among families' most significant unmet needs.

- Families identified the following as their greatest "unmet" needs:
  - In-home nursing support
  - Respite care
  - Transition options for older adolescents

Families are totally consumed by issues related to "providing care." Their needs assessment survey responses about their most significant "unmet" needs largely parallel those identified by providers.

- Of families who had access to in-home nursing (funded hours),
  - 78% had staffing for less than half of allocated hours
  - 56% had staff for less than one quarter of allocated hours

  Providers perceived in-home nursing support as the most significant unmet need for families. Families, in both needs assessment surveys and in public "listening sessions," indicated that securing in-home nursing care – even when funding has been allocated – was nearly impossible. They voiced concerns that agency nurses often lacked pediatric experience or knowledge of or experience with complex care needs (trach care, high-tech equipment, and medications). Most reported that turnover was high, and that when an assigned nurse was "out," there was no back-up available.

- Families indicated that their greatest respite service needs were:
  - In-home nursing support
  - After school care
  - Overnight care

  Because of their children's round-the-clock care needs, families note that lack of respite care limits sleep for parents and opportunity to carry out many basic activities of daily living (grocery shopping, banking), participation in school and family activities with siblings, and even employment opportunities for the parent who acts as primary caregiver.

- Providers ranked residential services according to how "critical" they believed the need for them:
  - Respite care
  - Alternative to home / other clinical placement
  - Vent Support or IV therapy
  - Extended care for children born to addicted parents
  - NICU-to-home transition
  - Post-operative care

  When survey responses of healthcare providers were considered separately from educators and social and human services providers, the ranking was somewhat different: vent support was ranked highest, significantly ahead of other services; alternative placement was second, with respite care third, and NICU-to-home transition fourth.

- Both families and providers independently identified the same three transition (post-21) concerns:
  - Funding
  - Residential options
  - Medical care (access to a continuum of services)

  With the ever-increasing life expectancies of many children with complex needs, transition to adult services at age 21 is increasingly frequent and is becoming the focus of transition planning for many families. Because adult services are not generally available as entitlement programs, how such services can be funded is of major concern to parents and providers. Too few community-based or medically-based residential options and access to appropriate medical care under Medicaid Managed Care are also major concerns.

- Less than 20% of healthcare providers (fewer than 1 in 5) report any expertise in pediatric behavioral health issues; more than 70% of parents/caregivers report that their child's primary care physician is their principal resource for assistance with such issues.

- Only 50% of early intervention programs for children with or at risk of developmental delays (Early Supports and Services) have any mental health expertise embedded in their programs.
- One in five New Hampshire children under age five is at risk of developmental delay or behavior management issues.
- New Hampshire has only one child psychiatrist for every 10,000 children; there are none practicing in Carroll or Coos counties.

  Some families have identified behavioral health issues (of a child with complex medical and developmental needs) as a significant concern; it is unclear how such needs are best addressed and in what care settings.

WHAT WE HEARD (at listening sessions)

- Parents and family members expressed grave concern about nursing support: even when in-home nursing support was available, too many nurses lacked appropriate training and experience in pediatric complex care.
- New Hampshire has not increased rates for in-home (agency) nurses in about a decade; many nurses decline and, perhaps, cannot afford to accept those positions. Without round-the-clock care, many children with complex needs are repeatedly hospitalized and often a parent must stay home full time. The Health Commissioner's office pledged increases of 25% - 46% in pay rates for in-home nurses effective 4/1/2016, pending federal Medicaid approval. (Subsequently implemented.)
- Pediatric tertiary care providers identified medical profiles keeping children in acute care facilities unnecessarily:
  - Respiratory compromise (requiring ventilator support, oxygen support)
  - Feeders/Growers – preterm infants needing to gain weight (26 in Keene in past 2 years born at DHMC; 16 in Brattleboro)
  - GI admissions: gastroschisis (long post-op care), nutritional optimization
  - Traumatic brain injuries or other multiple injuries – occasionally – requires long rehab
  - IV therapy (antibiotics) and TPN (total parenteral nutrition)
  - Children with no discharge plan: family circumstances, no appropriate foster home
  - NAS (Neo-natal Abstinence Syndrome – child born addicted of addicted mother)

  While at-home care for children born with medical complexity is still the norm, medical providers have expressed concern that there are children who, although they no longer require the level of care provided in the NICU or PICU, cannot go home for a range of medical, social, economic or legal reasons. Absent some intermediate care option, continued hospitalization is the only viable medical alternative for some.
- Respite care – in-home and day programs – was also identified as a significant post-21 issue. Through childhood, parents think of school as one form of respite for family members. At age 21, school ends for young adults and adult day programs do not fill the void.
- The need for behavior management and behavioral health support for many children with complex needs was identified by families and providers as critical – a significant change from previous years; providers also cited behavior management issues as an impediment to discharging some children from acute care settings.

IMPLICATIONS

➢ For the Healthcare System

- The increased incidence of substance abuse in New Hampshire and elsewhere is having a profound impact on child health of newborns in particular. There is need for a wrap-around response involving medical, social service, and mental health organizations.
- Parent and provider concerns about children's mental health needs in the context of complex care did not emerge in any previous needs assessment data gathering or strategic planning process at Cedarcrest. There is need to define and describe the mental health needs of children with complex medical needs and developmental disabilities.
- The increasing complexity of care required for children born with medical complexity – largely as the result of advances in medical science – has exacerbated the shortage of in-home nursing support and of appropriate respite resources for many families.
- Families increasingly expect that their young adult children born with medical complexity will not always live at home. There is a need for a broader range of residential options and specialized community-based programs. As a growing number of children with medical complexity reach adulthood, the challenge will only increase; governmental agencies must collaborate with community organizations to focus on this issue.

➢ For Cedarcrest Center

- Cedarcrest Center, were it to extend transition care to infants and children with medical profiles not typical of its current residents, must also consider the extent to which social service or mental health support among families of those infants would be needed, and whether it can procure or commit the financial and professional resources necessary to help children get healthy enough to transition home.
- Addressing families' most significant unmet needs in a broad way requires a systemic approach; Cedarcrest should consider how it might address these needs by convening or advocating for collaborations among organizations, providers, and agencies to address the larger issues of nursing shortage, inadequate respite care, and post-21 transition options.
- Families' concerns about in-home nurses inadequately trained/prepared to provide pediatric complex care provides opportunity for Cedarcrest to collaborate with home health agencies and nursing programs to provide specialized training, coaching, preceptorships, consultation related to necessary skills and experiences.
- Growing regard for Cedarcrest as an expert in pediatric complex care in New Hampshire essentially identifies the Center as a *medical facility*. Achieving balance between that identity and the Center's history and continuing commitment to maintaining the warm, home-like setting that is its hallmark will be a challenge.
- Cedarcrest must consider what role it can/will play in smoothing the transition to adult services for young adults with medical complexity. Are there opportunities to collaborate to provide local residential or programmatic options? Should the Center more aggressively advocate or attempt to convene organizations that can contribute to addressing this issue? Locally? Statewide?
- Although Cedarcrest does develop behavior management plans for residents and students, the Center will need to consider to what extent, if any, children with significant mental health needs could be integrated into our resident population relative to issues of physical setting, staffing, training, and safety. Cedarcrest should consider what, if any, additional behavioral health expertise it needs to develop.

STATEMENTS OF STRATEGIC POSITION: Demand for Services

- Cedarcrest Center for Children with Disabilities will serve as both an extended and short-term residential care option for children with complex medical and developmental needs.

- Cedarcrest Center will serve children from infancy through age 21. Necessitated by increasing survival rates among infants and the growing medical complexity of children being referred to the Center by providers, the Center will:
  - serve children with a broad range of complex needs, including high-tech medical needs and medical profiles that may differ from current ones.
  - provide intermediate step-down care in hospital-to-home transitions for children for whom extended hospitalization may be the only other viable care option.
  - support increasing numbers of requests for respite care and short-term stays.
  - meet the educational needs of nursing professionals, educators, and caregivers who will require ever more sophisticated training in light of the growing complexity of children we serve.

- Cedarcrest Center will collaborate with other providers and community organizations and agencies to ensure a continuum of care for children and young adults with complex medical and developmental needs by:
  - ensuring training resources and support for families and in-home caregivers.
  - providing educational and therapy outreach and outpatient services.
  - initiating efforts in conjunction with other collaborators and partners to address a range of post-21 service needs.

PLANNING INITIATIVES: Demand for Services

- Expand range of and scope of marketing to providers and families

- Extend scope of services to include children with medical profiles not typical of current Cedarcrest Center residents

- Implement/maximize use of technology to improve care coordination and communication among children's providers

- Extend/Expand respite services

- Initiate efforts in conjunction with other community agencies and providers to address a range of post-21 transition needs (continuum of medical services)

- Collaborate with community providers and agencies to strengthen support for families in the Monadnock region caring for children with complex needs at home (e.g., parent training, resource library, integrated daycare)

SECTION II: GEOGRAPHY

Research data and anecdotal information describing the effects of geographic factors on access to services for children with medical complexity and on the ability of providers to meet emerging needs of that population

HOW THE ENVIRONMENT HAS CHANGED. A significant change in the past decade was the opening of New Hampshire's Children's Hospital at Elliot Medical Center in Manchester, NH (subsequently re-branded as Elliot Medical Center Pediatrics). Because of under-utilization, Elliot Medical Center Pediatrics closed its Pediatric Intensive Care Unit in April 2016, leaving only the Children's Hospital (CHaD) at Dartmouth-Hitchcock Medical Center with such a unit. Elliot continues to operate a Neo-natal Intensive Care Unit (NICU), but is in conversation with Dartmouth-Hitchcock re: an affiliation agreement of some sort (May 2016).

The rise in homelessness and the epidemic of opioid abuse in the past few years has reduced the resources of many New Hampshire and Vermont families, including for transportation. Neither state has any significant statewide public transportation.

WHAT WE KNOW (from research and data gathering)

- Families continue to find travel to Cedarcrest Center a challenge
  - Long distances from a home community continue to be an impediment to admission
  - Long distances from a home community render respite stay at Cedarcrest unviable.
- The geographic distribution of children served at Cedarcrest (excluding outpatients) based on home community tends to track according to the distribution of the population generally.
  - Neither historically nor currently has the Center served significant numbers of residents from Strafford County.
  - Cedarcrest has not had occasion to serve children from Carroll County (earliest data is from 1991).

NH Counties	% historically of CC residents, short-stays, and day students	% current CC residents, short stays, and day students	# of NH's ten largest towns (population centers) in the county
Belmont	3%	11%	0
Carroll	0%	0%	0
Cheshire	21%	14%	1 Keene
Coos	3%	0%	0
Grafton	9%	11%	0
Hillsborough	27%	21%	3 Manchester, Merrimack, Nashua
Merrimack	18%	21%	2 Concord, East Concord
Rockingham	6%	7%	2 Derry, Salem
Strafford	1%	0%	2 Dover, Rochester
Sullivan	6%	7%	0
Out of State	9%	6%	-

- In rural areas, geography and transportation significantly limit access to primary health care, and even more to specialty medical care related to chronic health conditions.
- East-west travel in New Hampshire continues to be challenging (travel time is out of proportion to actual distance).
- Medical trips for specialty physician visits (Lebanon and Boston) have a significant impact on nursing schedules and effective resource use (215 trips in 2014-2015).
- In the period 2013-2016, a significant majority of Cedarcrest's constituents, donors, and charitable dollars came from the Monadnock region.

Region	% Constituents	% Donors	% Dollars	% Participation*
Capital	2.5	3.0	11.0	14.0
Lakes	1.6	< 1.0	<1.0	4.9
Manchester Area	3.7	4.0	1.9	12.6
Monadnock	61.0	62.0	56.0	12.0
Nashua Area	1.7	1.0	<1.0	5.7
North Country	1.1	2.0	<1.0	20.5
Seacoast/Piscataqua	2.0	2.5	1.0	14.9
Upper Valley	3.2	2.7	2.1	10.3
New England (not NH)	13.8	13.8	10.9	11.8
US (not New England)	8.8	8.0	17.0	10.9
**participation reflects % of constituents in region who made a contribution*				

WHAT WE HEARD (at listening sessions)

- Cedarcrest Center's location (in the southwestern NH) is an impediment for many families:
  - Extended care – many families in urban areas (Manchester and Nashua) do not have transportation, so it is difficult to visit and participate in their child's care; for families on the Seacoast or in the North Country, a visit to their child is not a "day" trip, and can be expensive; some need accommodations overnight.
  - Respite care – travel distances to Keene from many locations in the state make "weekend" or other short stays impractical.
  - Outpatient services and Day Education options work only for families in the fairly immediate region around Cedarcrest.
- Many families of children with complex needs on the Seacoast and in southeastern NH are oriented toward Boston when seeking specialty medical care (travel time, actual distance, employment, etc.)
  - Managed care companies sometimes refer NH children to Boston-based facilities.
  - Marketing to key Boston medical facilities re: Cedarcrest capability/capacity is important.
  - More communication to families and providers in Seacoast and southeastern NH regarding Cedarcrest resources is warranted.

IMPLICATIONS

For the Healthcare System

- Although high-tech medical support is technically available to families statewide, residential care services (particularly respite care) are not uniformly accessible or practical for families.

- Dartmouth-Hitchcock (CHaD) now has the only pediatric intensive care unit in the state; families caring for children with medical complexity in many seacoast and southeastern communities often go to Boston (referred by MCOs) for emergency or high-tech care.
- CHaD's location in the Upper Valley presents issues of access to specialty physicians and emergency medical care for many families of children who are born with medical complexity.

➢ **For Cedarcrest Center**

- Cedarcrest should explore "better" overnight arrangements for residents' families living at some distance from the Center as a means to support families' engagement in their children's care.
- Cedarcrest should explore feasibility of various respite options with medical/nursing support in other locations around the state.
- Explore ways to reduce number of medical trips without compromising continuity and quality of specialty medical care.
- Explore feasilbility and strategy for expanding constituents and donors in key regions around the state, particularly Manchester, Nashua, Capital, and Upper Valley regions to parallel areas of heaviest service utilization.

STATEMENTS OF STRATEGIC POSITION: Geography

➢ Cedarcrest Center will focus on providing inpatient services to families and children from New Hampshire, extending services to children in other states as appropriate.

➢ Cedarcrest Center will support families whose home community is at a significant distance from the Center to minimize impediments to their full participation as a partner in their child's care planning and to increase access to Cedarcrest's ancillary services for families caring for their children at home (respite care, day education services).

➢ Cedarcrest Center will be the provider of choice in serving children with complex medical and developmental needs; medical professionals and human services professionals throughout the state and in the greater Boston area will recognize the Center's unique role and capabilities.

PLANNING INITIATIVES: Geography

[These initiatives are incorporated in other sections of this document as noted.]

- **[Continuum of Care]** Expand range and scope of marketing to providers and families
- **[Continuum of Care]** Extend/Expand respite services
- **[Collaborations]** Initiate partnerships to assess and plan for respite and other services for children with complex needs in New Hampshire at locations other than Cedarcrest/Keene
- **[Collaborations]** Convene advocates, influencers, and providers to assess and respond to service needs of young adults with complex needs as they transition (post-21) to adult services (residential options, community integration)

SECTION III: COLLABORATIONS

Research data and anecdotal information highlighting concerns about care coordination and opportunities for collaborative relationships among providers and agencies for more effective service delivery

How the environment has changed.

Driven in part by a need to contain costs, to meet federal and state mandates to reduce re-hospitalizations, and to ensure better patient outcomes, affiliation agreements, mergers and other alignments have become the norm among healthcare providers. Similarly, as the "medical home" model evolves, many primary care physicians now practice within clinics owned by hospital systems rather than as independent practitioners. Within these clinics, care coordinators are increasingly important partners for Cedarcrest Center in the referral and admission process.

In the arena of pediatric complex care, the sense that the current healthcare system is not working adequately to meet the needs of children born with medical complexity is fostering conversations about additional collaborations among providers. As part of Medicaid Managed Care, Managed Care Organizations are new to the table in the past two years; collaboration with MCOs is essential to ensure clarity regarding many unique aspects of the prior approval and reimbursement processes in long-term pediatric complex care. Also, as a post-acute care facility, Cedarcrest has been involved in conversations with physicians at tertiary care facilities about meeting children's needs more effectively and ensuring coordination of care for them across a range of care settings.

WHAT WE KNOW (from research and data gathering)

- Cedarcrest remains unique in its licensure and service profile in NH
- Cedarcrest has a rich history of collaboration in building a continuum of care for children with complex needs, and is linked with more than 75 agencies and organizations related to medical services, special education, rehabilitation services, family resources and supports, and administrative, legal and regulatory requirements at local, state and national levels. Cedarcrest is also an active participant in more than a dozen professional and provider networks.
- Because Cedarcrest provides comprehensive care, the Center is uniquely positioned to convene others serving the same special population to explore issues related to service needs and care coordination.

WHAT WE HEARD (at listening sessions)

- Cedarcrest, because it serves children from infants to age 21, is in a unique position to collaborate with other organizations around transitional care:
  - with tertiary care hospitals re: step-down care for hospital-to-home.
  - with area agencies, Special Medical Services, schools, and others regarding: post-21 options for young adults with medical complexity.
- Cedarcrest, because it provides residential services to children across the state, is positioned to explore extension of respite and other services in additional locations around the state.

IMPLICATIONS

➢ For the Healthcare System

- The current system of care is failing to meet the needs of some children with complex needs – especially in the eastern portion of the state. A full continuum of care options for parents is, if technically existent, not practically available for many families.

➢ For Cedarcrest Center

- Cedarcrest, is uniquely positioned to increase focus on and response to hospital-to-home transitional care for children born extremely premature.
- Cedarcrest should be proactive as a convener/initiator of "work groups" focused on improving care coordination and on more effectively meeting existing and emerging needs of children born with medical complexity.

STATEMENTS OF STRATEGIC POSITION: Collaborations

- ➢ Cedarcrest Center is a model for best practices in the care and education of children with complex medical and developmental needs.
- ➢ Cedarcrest Center embraces a continuum of whatever care options are in the best interests of children and their families, fostering collaborative relationships for service delivery across the state.

PLANNING INITIATIVES: Collaborations

- Initiate partnerships to assess and plan for respite and other services for children with complex needs in New Hampshire at locations other than Cedarcrest/Keene
- Collaborate with home health agencies and nursing groups for training, services, consultation and technical assistance to ensure experience with and development of key skills in pediatric complex care for home-care nurses, school nurses and others
- Convene advocates, influencers, and providers to assess and respond to service needs of young adults with complex needs as they transition (post-21) to adult services (residential options, community integration)

SECTION IV: LABOR FORCE

Research data and anecdotal information documenting the impact of a changing work force on the healthcare industry in general and providers of services to children born with medical complexity in particular

How the environment has changed.

The most significant labor change in the past decade is the proverbial "graying" of the work force. The impact of that change is particularly critical among nurses. An enormous number of nurses –mostly Baby Boomers – will presumably retire over the next 20 years. Historically nursing was one of two professions most women felt open to them – the other being teaching. In the past half-century, as women have moved into virtually every career option open to men, the demand for nurses is outpacing the supply.

Nursing educators, who must have doctoral degrees for BSN programs or master's degrees for LPN programs, as well as advanced credentials, are retiring at similar rates; meeting the demand for nurses requires both sufficient numbers of students pursuing nursing credentials and nursing educators to train them. In recent years, the number of LPN programs in New Hampshire has declined to two.

Beginning in 2016 and running through 2020, New Hampshire will have access to $150 million in Medicaid funds through a special waiver program in order to create seven or more Integrated Delivery Networks (consortia of providers and other service agencies) around the state. Although designed to address the state's mental health and substance abuse crises by fostering integration of physical and mental health care, two elements of the waiver program may hold significance for Cedarcrest Center, namely, the requirement that each IDN implement a health information technology project and a healthcare work force capcity-building project. It is unclear what direct impact IDNs will have on Cedarcrest Center as a provider.

WHAT WE KNOW (from research and data gathering)

- There is an LNA shortage.
  - By 2020 the direct care workforce (LNAs, home health aides, allied health occupations) will be the largest occupational group in the nation (more than 5,000,000), ahead of retail, teachers, public safety, fast food and RNs.
  - Direct care staff account for 30% of the healthcare workforce.
  - Demand for LNAs is expected to increase 20% by 2020, to fill as many as 300,000 new jobs. (Cedarcrest Center has recently reinstituted hosting of LNA training programs in partnership with LNA Health Careers, LLC).
  - In the decade from 2003-2012 real wages (inflation adjusted hourly wages) declined for all direct care workers; the median wage for nursing assistants was $11.74/hour,
  - 47% of all direct care jobs are less than full-time, yielding median annual earnings of $17,000 ($20,000 for LNAs).
  - About half of direct care workers live in households earning less than 200% of the federal poverty level income, making them eligible for most federal and state assistance programs
- There is a nursing shortage.
  - The shortage is nationwide, even global. The U.S. vacancy rate in RN positions exceeds 8%.
  - 78 million Baby Boomers will be eligible for Medicare over the next 20 years.
  - Nursing positions nationally are expected to increase by 574,000 jobs (some estimates are as high as 712,000) by 2022 which, with retirements and attrition, will require 1.13 million new nurses.
  - Hospital job growth for nurses is about 15%; growth in community settings, including skilled nursing facilities, is expected to exceed 40%.

- New England faces a significant challenge due to a significantly older nursing population; the single largest age cohort among nurses includes those born between 1951 and 1959. The impact of Baby Boomer retirements will be a significant knowledge/experience drain.
- In 2015 the median salary for an RN (nationwide) was $67,490 ($32.45/hour). In some settings, a new nurse after 1-2 years of pediatric experience could command a salary of $68,000 or more (above the median for all nurses).
- Only 5.8% of practicing RNs are in home health care. Average annual salary for a home health RN was about $65,000; the median, however, was only about $56,800.
- By 2025, one million nurses will have left the field (30% of all new RNs change jobs or leave the field within the first 3 years of clinical practice).
- Increasing levels of student debt resulting from clinical education are deterring individuals from entering the field or driving them to higher paying positions.
- 20% of nurses in New Hampshire eventually go to Massachusetts for work at higher wages.

WHAT WE HEARD (at listening sessions)

- Availability of in-home nursing support continues to decline as a result of the nursing shortage
  - Families report high turnover, even when nurses are available
  - Families report lack of clinical experience in trach care, ostomy care, and medication management related to children with high-tech needs
  - Families report lack of pediatric experience in general
- Families and agency staff suggest that "nursing shortage" is only part of the issue
  - In-home nursing is "not respected" in the profession.
  - Some nurses are terrified of complex care, being "on their own" with no back-up. There is fear of making a "bad call."
  - Beyond lack of training or experience with high-tech medical care, many agency nurses have no experience caring for non-verbal children or those with significant cognitive delays

IMPLICATIONS

For the Healthcare System

- While concern about an impending shortage of nurses is more than a decade old, and certainly extends beyond New Hampshire, the crisis that shortage has caused in in-home pediatric complex care will require government officials, managed care organizations and key providers to collaborate to find ways to increase respectability of at-home nursing care, ensure coordinated and systematic training and education opportunities in pediatric complex care, and provide wages/reimbursement rates competitive with other nursing specialties.

For Cedarcrest Center

- As families, school districts, and human service agencies look to Cedarcrest Center as the "expert" in pediatric complex care in this state, Cedarcrest should explore ways it can support the training and experience needs of school nurses, agency nurses, and nursing students in building confidence and critical skills in caring for children with high-tech needs.
- Cedarcrest Center should maintain a working environment, wage/benefits structure, and professional development program that enable the Center to attract and retain the very best clinical staff.

STATEMENTS OF STRATEGIC POSITION: Labor Force

- Cedarcrest Center invests in its staff (through wages, benefits, staff development, and position flexibility) in order to
  - maintain its history of low turnover and high job satisfaction.
  - enable the Center to attract and retain nursing and therapy professionals in the midst of a general shortage of such professionals.
  - ensure continuity of leadership and management strength at all levels of the organization.

PLANNING INITIATIVES: Labor Force

- Implement changes to wage/benefit design to incentivize employee loyalty (minimize turnover) and to support the creation of career ladders
- Assess and implement changes to the current organizational structure to support expanded leadership development
- Implement formalized succession planning at multiple levels
- Identify and implement policies to support Cedarcrest Center as an even more family-friendly employer and workplace
- Identify and assess Cedarcrest Center's current and future workforce needs

SECTION V: SUSTAINABILITY

Research data and anecdotal information identifying factors that, in the long-term, either facilitate or impede access to necessary services by families of children with medical complexity and the ability of providers to build and maintain a continuity of care

How the environment has changed.

The outlook for charitable giving is positive, but not without uncertainties. The outlook for Medicaid and school funding, while not in peril, brings uncertainties as well.

The Affordable Care Act has significantly impacted healthcare business models. The Centers for Medicare and Medicaid are encouraging that physicians, primarily those who serve Medicare patients at this point, align themselves with an Accountable Care Organization. Consolidation and other forms of institutional alignment offer financial and operational strength for many healthcare institutions' core missions. What remains unclear is whether consolidation will change public perception of institutional identity and whether those perceptions will have significant impact on fundraising from individuals, which most often has its impetus in appealing to "grateful" patients.

Cedarcrest stands apart from most healthcare provider institutions in that regard. Unlike hospitals the Center's charitable support depends almost entirely on attracting the generosity of those who have no need of our services. More than 75% of our donor base either lives in the Monadnock region of New Hampshire or includes former residents of the area or their family members now living out-of-state. Only some 15% of donors are New Hampshire residents beyond Cedarcrest's immediate geographic community.

Although in the past 40 years, charitable giving in the healthcare sector has increased by 761%, that increase is only 79% in inflation-adjusted dollars.

Implementation of Medicaid Managed Care is underway, but not without some challenges. The working relationships with managed care organizations have largely been a positive force relative to care coordination, but, in the context of extended residential pediatric complex care, the implementation challenges around medications, high-tech support, and payment for services will be ongoing for some time.

As a consequence of the Center's expanded services for children with high-tech medical needs in recent years, the higher acuity needs of children in Cedarcrest School have necessitated increased nursing support during the school day; the increased costs of providing special education with high-tech nursing support have been exceeding the virtually insignificant rate increases authorized by the NH Department of Education in recent years (0.72% for the 2016-2017 school year).

WHAT WE KNOW (from research and data gathering)

- After a period of substantial decline in charitable contributions following the 2008 financial collapse, charitable contributions nationwide have slowly begun to grow again in the past three years, but not at equal rates for all non-profit sectors.
  - Charitable giving for healthcare is growing again, but its rate of recovery has been slower than other sectors.
  - In 2012 the rate of growth was negative (-3.4%); in 2015, the growth rate for the sector went positive (1.9%).
- Individuals remain the single largest source of charitable support: 72% of charitable dollars in 2014, while foundations were at 15% and corporations 5%. At Cedarcrest, those percentages were 62%, 12% and 26% respectively.

- Health and healthcare receive a smaller portion of charitable dollars than other key non-profit sectors: religion (32%), education (15%), human services (12%), health care (8%), and arts/humanities/culture 6%).
- Medicaid remains the Center's primary funding source.
- There has been no Medicaid reimbursement rate increase since 2009, although there have been additional rates set for children on vents and those receiving "high-tech" care.
- Education reimbursement rates (set by the NH Department of Education) are lagging significantly behind the actual cost of providing school services.
- The long-term future of the federal "provider tax" is unclear.
- The transition to funding by MCOs in phase two of the implementation of Medicaid Managed Care will add challenges and additional demands on staff time.

WHAT WE HEARD (from providers, families and others)

- Medicaid Managed Care presented some reimbursement and billing challenges initially, and has presented some additional challenges to families relative to the prior approval process.
- Trends:
  - On-line giving has grown to 7-11% of charitable contributions (depending on sector) since 2012.
  - While much of the recent growth in charitable giving has been attributed to economic recovery, in the healthcare sector it has come in large part from planned gifts and bequests.

IMPLICATIONS

- **For the Healthcare System**
  - Lack of certainty around Medicaid Managed Care , especially the prior approval process and funding of long-term care, creates a threat to sustainability for providers of programs for individuals with medical complexity
- **For Cedarcrest Center**
  - Lack of real diversification in sustainable funding streams challenges the Center's capacity to plan long-term.
  - The challenge of diversifying funding, of securing Medicaid reimbursement rates commensurate with levels of high-tech care provided, and of educational rates set consistently below Cedarcrest's actual costs, suggest a need for a long-term strategy discussion around appropriate use of board-designated funds.
  - That recovery in healthcare fundraising stems largely from planned gifts and bequests suggests a greater focus of Cedarcrest's fundraising energies in that area.

STATEMENTS OF STRATEGIC POSITION: Sustainability

- Cedarcrest Center will ensure long-term sustainability by:
  - focusing on strategic expansion and use of board-designated funds
  - focusing on securing bequests and other planned gifts
  - aligning with key partners to develop fundable, collaborative service delivery models

PLANNING INITIATIVES: Sustainability

- Initiate ongoing conversations, negotiations, private and/or public meetings with managed care representatives, state agency staff, elected officials, parents and providers as appropriate re: Medicaid differential reimbursement rates, school tuition rates, etc.
- Develop and implement a policy/procedure re: expansion, role, and strategic use of the Center's board-designated investment funds
- Elevate bequest/planned giving efforts to be the principal focus of the Center's development program
- Establish a "task force" to assess the Center's long-term needs (capital, programmatic, personnel) with parallel projection of resources required (estimated amounts and likely sources)
- Align with other partners to build fundable programmatic or service collaborations

SUMMARY OF PLANNING INITIATIVES

As the outcome to a 6-month period of gathering, processing, and distilling an enormous amount of data and information, the Board of Trustees and management staff of Cedarcrest Center have determined to move forward between 2017 and 2020 with several initiatives. Those planning initiatives are extracted from the 2017-2020 Strategic Plan and listed below.

While they represent the culmination of the Center's quadrennial strategic positioning process, these initiatives also represent the starting point of the operational planning work that management and staff must undertake to translate them into the actions and activities that will ultimately address the current and emerging needs of children born with medical complexity across New Hampshire and beyond.

Continuum of Care

- Expand range of and scope of marketing to providers
- Extend scope of services to include children with medical profiles not typical of current Cedarcrest Center residents
- Implement/maximize use of technology to improve care coordination and communication among children's providers
- Extend/Expand respite services
- Initiate efforts in conjunction with other community agencies and providers to address a range of post-21 transition needs (continuum of medical services)
- Collaborate with community providers and agencies to strengthen support for families in the Monadnock region caring for children with complex needs at home (e.g., parent training, resource library, integrated daycare)

Collaborations

- Initiate partnerships to assess and plan for respite and other services for children with complex needs in New Hampshire at locations other than Cedarcrest
- Collaborate with home health agencies and nursing groups for training, services, consultation and technical assistance to ensure experience with and development of key skills in pediatric complex care for home-care nurses, school nurses and others
- Convene advocates, influencers, and providers to assess and respond to service needs of young adults with complex needs as they transition to adult services (residential options, community integration)

Labor Force

- Implement changes to wage/benefit design to incentivize employee loyalty (minimize turnover) and to support the creation of career ladders
- Assess and implement changes to the current organizational structure to support expanded leadership development
- Implement formalized succession planning at multiple levels
- Identify and implement policies to support Cedarcrest Center as an even more family-friendly employer and workplace
- Identify and assess Cedarcrest Center's current and future workforce needs

Sustainability

- Initiate ongoing conversations, negotiations, private and/or public meetings with managed care representatives, state agency staff, elected officials, parents and providers as appropriate re: Medicaid differential reimbursement rates, school tuition rates, etc.
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