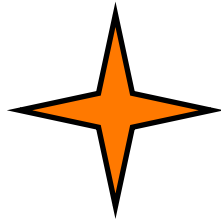




**Council for Youth
with Chronic
Conditions
Annual Report
2020**

Preface

This annual report is compiled in compliance with RSA 126-J:5. It contains general information pertaining to progress being made to reduce barriers in obtaining effective community and family-based services and support, and efforts on the part of the Council to educate and collaborate to improve the capacities of communities to respond to the needs of families with children and youth with chronic health conditions.



Submitted by:

Audrey Gerkin, Chair
Laurie Fleming, Secretary
Pamela Becker, Council Administrator

January, 2021

Dear Families and Friends of CYCC,

The year 2020 will long live in our memories as a year of sacrifice and hardship, but also of perseverance and strength. Shortly after a January 2020 Council retreat attended by many new council members, planning our new goals and our annual Children's Luncheon, we went into lockdown due to the historic COVID-19 Pandemic.

Unable to connect and communicate in person, we managed our way into the remote technology world. The families we represent hunkered down in their small family bubbles to stay safe from a potentially devastating virus that could cause even more health issues than they deal with already, and the risk of death loomed as a possibility. Children were sent home from attending school in person. Parents found themselves doing double duty of working as teacher assistants and school nurses, while juggling their full time jobs.

We joined together to find a new footing and the best way forward. The council joined a "Mask Up" initiative, partnering with a collaborative effort of many organizations in NH raising safety awareness around Personal Protective Equipment (PPE) and especially mask wearing to reduce the transmission of COVID-19. We worked with the Department of Health and Human Services (DHHS) to raise awareness around families struggling to receive proper in home medical supplies and PPE due to a shortage because supplies were being diverted to the care of COVID-19 patients. Our Annual Children's Luncheon was cancelled.

While cancelling this annual event was disappointing, the Council pivoted its focus to the formation of a Request for Proposal (RFP) grant, to assist a New Hampshire organization in supporting children with chronic health conditions, especially during this trying year. Building Community in NH was selected as the recipient of \$10,000. They are looking to assist the children of refugees and immigrants navigating the health care system. We were also able to supply Friends in Action with a grant of \$1600 to assist in creating virtual opportunities for young people with disabilities to meet and explore social and recreational opportunities.

Pam Becker, our Council Administrator, joined the Medical Care Advisory Committee (MCAC) meeting as a member, educating and informing the Committee about children struggling with the in-home nursing shortage. We closely monitored the rollout of the state's COVID-19 vaccine eligibility guidelines and communicated our concerns with the administration. The Council will continue working on these issues in the coming year.

Despite the unprecedented challenges, this year allowed us to learn more about one another's strengths and talents. We learned to work together as a group, respecting each other's opinions and ideas; pushing and communicating to find common ground to allow for the best support, advocacy, and public education for families and children who experience chronic health conditions.

We look forward to starting 2021 as a stronger, more cohesive Council, continuing to expand our relationships and partnerships with other New Hampshire organizations that are allied on the issues affecting the over 55,000 children with chronic health conditions.

Sincerely,
Audrey Gerkin
Chair 2020



Who are we?

The Council for Youth with Chronic Conditions is a parent-focused state council committed to being a voice for families of children with chronic health conditions. We educate and inform policy-makers and stakeholders about the unique challenges and opportunities to expand access to affordable, quality health care; foster supportive work environments; support community-based services, and celebrates the resiliency of children and their families.

Our guiding principles include ensuring that our children and youth with chronic conditions have affordable access to care, supportive home and community environments, and that our families have family-supportive work environments.

Who are the children and youths with chronic health conditions?

Children and youth with chronic health conditions include those with:

- Biologically based conditions
- Lasting an extended period (12 months or longer)
- Bringing about significant changes in the life of the child and family, and
- Requiring more than the usual amount of medical care from primary care and specialty providers that typically required by well child and acute illness visits that is not primarily defined as a mental illness or other emotional disability.

Mission

The Council for Youth with Chronic Conditions (CYCC) was established to educate and collaborate with state and local agencies to assess and improve the capacities of communities to effectively respond to needs of youth with chronic health conditions and to provide meaningful support to them and their families.

Achieve the mission by:

- Promote timely, individualized needs assessments of children and adolescents with chronic health conditions and their families in language easily translated into actions.
- Provide education and promote family involvement at all levels of health care planning, policy making, advisory, and monitoring capacities.
- Educate and collaborate with the New Hampshire Department of Health and Human Services, the New Hampshire Department of Education, and the New Hampshire Insurance Department, as well as other public and private agencies and organizations that serve children and adolescents, in enhancing community-based family supports that meet the unique needs of children and adolescents with chronic health conditions and their families.
- Increase awareness and visibility in the public and private sector of the medical, educational, social, psychological, and financial issues that impact children and adolescents with chronic health conditions and their families.
- Facilitate family/physician collaboration at all levels of support and service delivery systems.
- Empower families with children with chronic health conditions through educational opportunities and the dissemination of information that is understandable, accessible, complete, and presented in a manner that is compassionate and caring.



2020 Board of Directors

Audrey Gerkin (Chair-Parent)
 Ann Marie Vanderwater-(Asst. Chair-Parent)
 Laurie Fleming (Secretary-Parent)
 Tim Guidish-(Treasurer-Parent)
 Déedonné Bhattarai-Parent
 Destinee DiPrima-Parent
 Kristin Bonny-Parent
 Karen Livernois-Parent
 Regan Lamphier -Parent
 Deirdre Dunn Tierney (NH DHHS representative)
 Latha Mangipudi (NH House representative)
 Heidi Petzold (PIH-Community Based Agency representative)
 Sylvia Pelletier (NHFV- Community Based Agency representative)
 Dr. Harohalli Shashidhar -Community member
 NH Senate- vacant
 NH Department of Education - vacant
 NH Insurance Dept.-vacant

 Pamela Becker (Council Administrator)

In accordance with RSA 126-J:1, Council membership includes: (a) one Senator, (b) one Representative, (c) one representative from each of the following departments: Health and Human Services, Education, and Insurance, appointed by their Commissioners (d) one family member appointed by the Governor (e) one director of the agency charged by the Council providing services to children and family with chronic health conditions (f) six representatives of professional and community organizations representing a cross-section of disciplines and constituencies and (g) up to 13 parents or guardians of children with chronic health conditions. The Council is the only statewide organization that has a legislative mandate to focus on the issues affecting children and adolescents with chronic health conditions.

Guiding Principles:

Guiding Principle #1: Collaborate to Ensure Quality, Affordable Health Care

Since one-third of all children with special health care needs rely on Medicaid or the Children's Health Insurance Program (CHIP) for their health care needs, state policies that govern private and public insurance are vitally important to our youth with chronic conditions. The CYCC has long focused on providing insights and information about the benefits of expanding high quality, community-based health care as well as the state's Medicaid Expansion Program or the NH Health Care Protection Plan. We've convened meetings with partner advocates to listen and assist them. We've found that our voice is larger when we join together.

Guiding Principle #2: Foster Supportive Home and Community Environments

One of the goals of the council is to support and showcase local initiatives that provide unique services, programs, and activities to youths with chronic conditions and their families. In the past, we have spotlighted Camp Sno Mo and Zebra Crossings who both run summer camps that serve children with special health care needs. Each year, the council also tries to recognize a small, local non-profit that is making a difference in the lives of NH youth who live with chronic conditions. The Spirit Award's past recipients have included the NH Chapter that supports those with Prader-Willi Syndrome, and Childhood Cancer Lifeline. Each year, the council also conducts an educational tour that expands our network and knowledge about home and community-based services.

Guiding Principle #3: Foster Family Supportive Work Environments

Balancing work and family is often listed as the most pressing problem for parents of young children. If a child in the family experiences a chronic condition, it becomes exponentially more difficult and for many, nearly impossible. Even though benefits exist for in-home care and support, NH parents continue to find it extremely difficult to find consistent, reliable care due to tight workforce challenges and entry restriction for some professions. Add to that, the financial demands of working less or not at all, and these demands can create havoc in the home. The CYCC is dedicated to fostering family-supportive work environments. In the past, the CYCC has collaborated with several partners to advocate for legislation to create a Family and Medical Leave program in our state.

2020 Council Activities

As the Council began 2020 with new leadership and strong membership, they needed to restructure their approach as so many did when faced with the Pandemic. We were able to quickly prioritize the needs of the families we represent and assist them in making the best of the limited resources and information. We used our voice to raise theirs so public and government officials could hear their needs and concerns. We sincerely thank all of the people who supported us in doing our work.

Furthering the Council's outreach and education efforts has been an overall goal for 2020. Building up resources on our website and social media channels as well as doing in-person presentations have helped to increase overall awareness of the Council and its mission. For example, two Council members presented to the UNH IOD's Leadership class of 2019-2020. Council members introduced Leadership students to the state-wide systems that the Council works to impact as well as how students can get involved.

Ensuring Access to Personal Protective Equipment (PPE):

It came to the attention of the Council through several parents that there was a lack of PPE for families trying to do everyday care for their children in the current COVID-19 environment. Those who are doing this care did not have the gloves and other needed supplies. NH DHHS was asked to investigate this matter and letters were sent to the Durable Medical Equipment supply companies. After investigation, it was determined that there was enough PPE, but the distribution was not equitable. Families were asked to purchase PPE on their own and then submit the bill to the insurance companies for reimbursement. Families were frustrated with this state of affairs. There was a shortage of respiratory supplies and vent circuits which cannot be bought on the open market. By participating in the Governor's listening sessions, the council was able to speak up for families so they could get their needed supplies in an equitable manner.

Messaging to protect children with chronic conditions:

The council worked on developing messages to encourage people to wear masks to protect the more than 55,000 children in New Hampshire with chronic conditions. We thanked the state government and community leaders for advocating for the public to wear masks in their businesses through letters and social media.



Request for Proposals for Innovative Supports for Youth with Chronic Health Conditions Grant:

Children with disabilities, including those with chronic health conditions, have been disproportionately affected by COVID-19. The recent experiments with remote and hybrid learning have adversely affected these children in ways that are not felt by their peers. Therefore, the CYCC looked to fund innovative ways to address these issues in the hope that these negative effects are not long-term.

A grant of \$10,000 was allotted for the winning proposal. We are very happy to report that we received quality applicants and we will fund a project with the Building Community in NH organization based in Manchester. They provide vital supports to the immigrant communities. Building Community in NH will collaborate with Parent Information Center (PIC) and Disability Rights Center (DRC-NH) to complete this project. In addition to this project the Council will fund a smaller project with the Friends in Action group that will fund virtual opportunities for children to attend “field trips” intended to entertain and educate.



In-Home Nursing Shortage:

The Council led by its Chair Audrey Gerkin has worked on initiatives with NH DHHS to help families who have not had nursing services, especially over night, to come up with solutions to this problem. There are three temporary solutions that have been considered including (1) direct parent payments, (2) an In Home Nursing Based (IHNB) waiver to hire someone to help do the work, and (3) nurses hired directly by the families and working directly with the pediatrician. The nurse would receive the whole Medicaid reimbursement rate instead of an agency getting a portion of the money. There is also a document being worked on with some Massachusetts families that will help create federal nursing goals. This is a priority of the Council and this will be one of its priorities throughout the coming year.

As of the printing of this document, the first option has been put into place for parents who are receiving less than 50% of their approved nursing hours. These parents will be paid for 50% of those hours at a rate of \$15.00 per hour. This is a very small step toward the nursing coverage these families need to care for their seriously ill children.



Children's Champions- Due to the COVID-19 Pandemic the Council had to cancel the luncheon celebrating children. The Council hopes to recognize the amazing work that the teachers and school nurses are doing to support the children in their care. Whether the children are able to attend school in person or virtually many of the teachers, paraprofessionals, nurses, and specialists have gone above and beyond to ensure that children with chronic conditions have continued to receive quality instruction and supports.

Work with NH DHHS:

The Council has strengthened their relationship with the NH Department of Health and Human Services by working on several projects including access to PPE, understanding the population and burden of care for those parents who have youth with chronic conditions, and asking for an FAQ specific to youth with chronic conditions as it relates to COVID-19. The Council is thankful for this partnership and the resources that NH DHHS has been able to provide.

Current needs and recommendations:

We are currently working with other organizations to bring in new parent council members. The Department of Insurance and the Department of Education has not sent a representative to attend council meetings despite the RSA requirements. As we grow we are committed to increasing the diversity of our Council as New Hampshire grows more diverse.

Recommendations

The 2021 Council for Children with Chronic Conditions recommends the following:

1. Department of Education- Fund the School Nurse Consultant position and appoint a member of the Council as per regulations
2. The Insurance Department appoints a member to the Council as per regulations.
3. Department of Health and Human Services.
 - Collect ACES data
 - Expand the home visit program
 - Invest in family resource centers
 - Recommend using the school immunization report to collect information about the number of children with chronic conditions in New Hampshire.
4. Promote the organized assessment of the need of youth with chronic conditions and their families.
5. Serve in an advisory capacity to DHHS, Dept. of Education, and Insurance

Department for policy & program development.

6. Collaborate with DHHS, Dept. of Education, and other public & private organizations statewide to enhance community-based family supports that meet the unique needs of youth with chronic conditions and their families.
7. Increase awareness in the public and private sector of the medical, social, and educational issues which impact youth with chronic conditions and their families.

Thank you for supporting the important
work of the NH Council for Youth with
Chronic Conditions.

We look forward to another year of speaking for
the families and youth of New Hampshire.

Council for Youths with Chronic Conditions

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