



nh cycc

Council for youths with chronic conditions

ANNUAL REPORT



2022

Dear Families and Friends of CYCC,

Reflecting on the year of 2022, we began with a commitment to continue our previous efforts, increase our understanding of the needs of those caring for children with chronic conditions and provide more opportunities to represent and assist those families.

This year our increase in collaboration with other agencies, organizations, stakeholders and other community groups offered us many new opportunities to engage with and represent the children and families we represent. Events such as the Gubernatorial Candidates Town Hall on Disability and Chronic Conditions, representation in the Title V stakeholder meetings, presentation to the NH Leadership Series and our Annual Celebration event to name a few.

Our annual Celebration event was held in person this year at the McAuliffe-Shepherd Discovery Center in Concord. Five amazing youth were spotlighted for their outstanding accomplishments through leadership and initiating community changes. Our photovoice gallery exhibit was a powerful representation of the joys and struggles of some of the over 64,000 children living with a chronic condition in NH. Many CYCC families, friends and members of other agencies and organizations attended and experienced this exhibition. This was only a small part of the Statewide Needs Assessment completed with JSI Research and Training Institute. The results of this assessment have provided recommendations for greater outreach for our council.

The insights gained from our work this past year will strengthen the CYCC's representation of our youth with chronic health conditions and their families in 2023.

*Sincerely,
Karen Livernois
Chair 2022*

Council Members

Name	Position	City
Karen Livernois	Chair/ Parent Appointed by Governor	Londonderry
Deodonne Bhattarai	Vice Chair	Concord
Tim Guidish	Treasurer	Merrimack
Kristin Bonny	Secretary	Barrington
Regan Lamphier	Parent	Nashua
Karin Mortimer	Parent	Merrimack
Nicole Parker	Parent	Tamworth
Leah Stagnone	Youth	Litchfield



NH State Advisors/Representatives/Appointed positions

DHHS: Deirdre Dunn
Community Based Agency Director: TBD
Education Department: TBD
Insurance Department: Josh Hilliard
NH House Representative: Representative Betty Gay
NH Senate: Senator Becky Whitley

Council Administrator: Audrey Gerkin

Professional/Community Organizations

Laurie Fleming: NH School Nurse Association
Sylvia Pelletier: NH Family Voices
Dr. Harohalli Shashidhar: Eliot Hospital Pediatric
GI Specialist
Kate Bailey: Epilepsy Foundation New England's
AmeriCorps Program



Who We Are:

The Council for Youths with Chronic Conditions (CYCC) is a parent-focused State council committed to being a voice for families of children with chronic health conditions. We educate and inform policymakers and stakeholders of the unique challenges and opportunities to expand access to affordable, quality health care, supportive work environments, and community-based services and to celebrate 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.

Definition of chronic health condition:

The Council for Youths with Chronic Conditions defines a chronic condition by four contributing factors:

- lasting for an extended period of time
- bringing about significant change in the life of the child
- biologically-based; and
- requiring more than usual medical care.

Mission:

The Council for Youths with Chronic Conditions is established to advocate 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.

- Promote the organized assessment of the needs of children and adolescents with chronic conditions and their families.
- Serve in an advisory capacity to the Department of Health and Human Services, Department of Education, and Insurance Department for Policy and Program Development.
- Collaborate with the Department of Health and Human Services, the Department of Education and their public and other public and private organizations statewide to enhance community-based family supports that meet the unique needs of children and adolescents with chronic health conditions and their families.
- Increase awareness in the public and private sector of the medical, social and educational issues that impact youth/children with chronic health conditions and their families.
- Provide consultation and testimony to the legislature on related issues.
- The Council shall report annually on or before December 1 to the Governor and the General Court regarding the progress being made to provide services and support to youth with chronic conditions and their families in regular educational and medical environments allowing them to remain in or near their own homes and communities.



History

The Council for Youth with Chronic Conditions dates back to 1993, when it was known as the Council for Children and Adolescents with Chronic Health Conditions (CCACHC). Then, Governor Stephen Merrill established this advisory Council by Executive Order to focus on issues that impact the lives of chronically ill children and their families. The signing of HB472 by Governor Jeanne Shaheen in July 1997, established officially the Council within the state statutes. Today, there are 15,000 youth in New Hampshire that are affected by chronic health conditions, that the council keeps in mind while educating and informing the public of their needs.

2022 Council Activities

- **2022 and ongoing:** Representation in Title V redesign stakeholder meetings
- **January 2022:** Dr. Jan McGonagle presented to CYCC on New Hampshire's Complex Care Network. This Network is supported under NH DHHS's Family Centered Services to support families caring for children with special health care needs. Dr. McGonagle included updates on COVID-19 pandemic and its effects on children.
- **March 2022:** CYCC Members Karen Livernois and Leah Stagnone presented to the NH Leadership Series about our council and chronic health conditions.
- **April 2022:** Attended Haven's Kids Are Our Business Breakfast.
- **May 2022:** Stephanie Locke, Emergency Preparedness Chief and Iain Watt, Deputy Director for NH's Public Health Department presented on the Bureau of Emergency Preparedness for Response and Recovery, Child Care Emergency Plan, and the Crisis Standards of Care Plan. CYCC was invited to participate in future community engagement forums on the Crisis Standards of Care Plan and to support future community partner emergency preparedness initiatives.
- **June 2022:** CYCC Celebration Event was held at the Christa McAuliffe Discovery Center in Concord. We celebrated the launching of our new website, new logo, new Google workspace platform, the completion of the Coming into Focus: PhotoVoice portion of the Needs Assessment, and the five 2022 CYCC Champion Award Winners.
- **September 2022:** CYCC hosted along with other NH state disability organizations, the Gubernatorial Candidates Town Hall on Disability and Chronic Conditions.
- **August 2022:** Selected as Seacoast Human Resource Association's Community Partner from March - May 2023, which includes funds awarded to our council.
- **October 2022:** Completion of the Needs Assessment in collaboration with Community Health Institute/JSI Research & Training Institute (JSI). The report was shared with many NH stakeholders and leaders working for the health systems of supports and services.
- **November 2022:** The JSI team who worked on the Needs Assessment returned to our council meeting for a presentation on the results. The presentation was recorded and will be shared along with future Coming Into Focus: PhotoVoice Gallery Exhibitions. Council Administrator, Audrey Gerkin, participated in a grant awarded emergency preparedness exercise alongside FEMA and NH Public Health, in regards to pediatric health needs.

2022 Meeting Schedule for the Council for Youths with Chronic Conditions

January 19 - 5:30pm
*Annual Meeting
Virtual, Zoom*

March 16 - 5:30pm
*Regular Meeting
Virtual, Zoom*

May 18 - 5:30pm
*Regular Meeting
Virtual, Zoom*

August 17 - 5:30pm
*Regular Meeting
Virtual, Zoom*

November 16 - 5:30pm
*Regular Meeting
Virtual, Zoom*

CYCC Celebration Event



Christa McAuliffe Discovery Center in Concord, NH



On the evening of June 23rd, over 100 attendees celebrated CYCC families and the council's work over the last couple of years at the McAuliffe-Shepard Discovery Center in Concord, NH. The highlights entailed; a PhotoVoice Gallery project that is apart of the the council's year long Needs Assessment in collaboration with JSI/Community Health Institute, and five CYCC Champion Award winners. We also celebrated launching our new logo and website.

The Coming Into Focus: 2022 PhotoVoice Project Gallery!

Eight families used photography to capture the joy and challenges of living with a chronic health condition. Although each families' experiences were unique, the images showed common threads that connect them to each other and to the larger disability community. The information gathered through the Photo Voice project and the broader Needs Assessment will be used by the Council and other stakeholders to better understand the unmet needs of families across the state and help inform future policy and advocacy efforts.

The year long in-depth Needs Assessment, completed in collaboration with JSI/Community Health Institute, dives into NH families caring for youths under the age of 21 with a chronic physical health condition. The assessment was completed this fall and presented to our council in November. The final report includes data and information gathered from a survey, listening forums, and individual and group interviews. The PhotoVoice Project is the visual representation portion of the assessment.



2022 PhotoVoice Project Gallery displayed at the Discovery Center with onlookers, Emma Parcels and mom.



PhotoVoice composition by Lily.

2022 Champion

Since 2008, CYCC has chosen people that exemplify the definition of being leaders in their community, while at the same time educating the public on chronic health conditions. Currently, the Champion award is given to youth with chronic conditions who have shown extraordinary leadership in and/or commitment to their school and community. This year we chose five tremendous youth leaders who all live up to the definition of Champion Award winners.

Champion Sadie McCallum



*2022 CYCC Champion Winner Sadie McCallum
with her parents and Wonder Woman*

Sadie McCallum is a Sophomore in High School from Weare, NH. She was nominated by Kelly Cleveland, PTA.

Sadie uses her lived experience with Cerebral Palsy to invent equipment to facilitate a walker going up over a curb. She is a recognized inventor and has been featured on television programs showcasing young inventors. She participated in an internship where she advised engineers on medical and mobility equipment. Her goal is to become a software engineer for biomedical equipment.

Sadie influenced changes to her school campus for safe universal access and participates in forums to educate others about her

diagnosis and its challenges. She also runs audio-visual equipment for drama productions at her school for fun and recently initiated a pen-pal relationship with a disability rights activist highlighted in Netflix's Crip Camp documentary.

Champion Emma Parcels



*2022 CYCC Champion Award Winner Emma
Parcells and her mom*

Emma Parcels, a student at Concord High School, was nominated by Elizabeth Young. Emma is opening up access to other students in her community since she herself experienced discrimination.

This led Emma to advocate for automatic doors near the school's main office. She worked hard with the high school's staff and compliance officer for a comprehensive wheelchair checklist. The checklist includes showing students in wheelchairs around the building, knowing the location of all the ramps, first floor lockers, wheelchair map of the building, access to lab tables and any accommodations within classrooms, accessible lunch lines and seating.

She is currently advocating for inclusive adaptive sports and participates with the Yeah Council, a youth driven council. On the side, she volunteers for Make a Wish and recently spoke to 400 people about the impact of her wish and what she is up to today.

Awards

Champion Liberty Frink



2022 Champion Award winner Liberty Frink surrounded by her family

Liberty Frink is a 15 year old student from Lancaster, NH. She attends the White Mountain Regional High School. Joyce Bernier from FCS/PIH recognized her leadership talents and sent in her nomination.

She is an outstanding student that cares for the needs and concerns of her community. She volunteers at the local food pantry, mobile pantries, Partners in Health and the local church. At school she participates in the robotics program and is currently helping to resource the school's greenhouse with an automated system to work during the off seasons for teachers and staff.

Champion Bayleigh Clock



Megan Truesdale, Michele Clock, Bayleigh Clock (Champion Award Winner) and Mikey Kessler

Bayleigh from Exeter, NH attends Exeter High School as a Senior. Her mom Michele Theresa Clock nominated her.

Bayleigh learned to be a strong self advocate and independent learner, going from a low academic track to demanding she have access to college prep course and was inducted into the national honors society this past year. After advocating for inclusiveness at school, administrators and teachers consult with Bayleigh for school wide events. Bayleigh assisted in making the Winter Carnival inclusive for all students with disabilities. For Prom, a sensory friendly area to take a break from the excitement was made due to her suggestions. She is a leader for others deserving of an equitable inclusive educational experience.

Champion Lillian Brady



2022 CYCC Champion Award Winner Lillian Brady with Wonder Woman and her family.

Lillian (Lily) Brady from Hollis, NH was nominated by her mom, Amy Brady for our 2022 CYCC Champion Awards. Lily also participated in our PhotoVoice Project. This goes to show how Lily gives it her all in everything she does.

Lily organizes food and donation drives for the Nashua Shelter and food kitchen. She educates her peers and the student population on Type 1 diabetes. She reads to her other classmates with special needs and translated a presentation once to Portuguese for a new classmate. Lily advocates for herself and others especially regarding equity, disability awareness and justice, which includes writing to her state, and federal lawmakers, including the President

of the United States, of her concerns and recommendations. She is also an accomplished red belt in Karate and makes cookies for her teachers.



Council for Youths with Chronic Conditions

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Report prepared by Audrey Gerkin, Council Administrator