**NYC PEDIATRIC DISASTER COALITION**

New York City

Pediatric Disaster

Coalition



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**Deliverable 8.2 Develop mental health and communications guidance for caregivers/family members of pediatric patients receiving critical care during large-scale infectious disease outbreaks**

As part of Deliverable 8 the New York City Pediatric Disaster Coalition has been tasked with developing drafted and finalized mental health and communications guidance for caregivers/family members of pediatric patients receiving critical care during large-scale infectious disease outbreaks. PDC began this project with the recruitment of experts in Pediatric Mental Health, Pediatric Intensive Care, Child Life, Social Work and Pediatric Emergency and Disaster Medicine. Ten members were selected to make up the working group including three representing the PDC and a total of seven external members from three different organizations. A listing of the names and affiliations of the committee members can be found below.

*Committee members:*

* Michael Frogel (Co-Principal Investigator, NYC Pediatric Disaster Coalition)
* Merritt Schreiber (Professor of Clinical Pediatrics, Department of Pediatrics, Lundquist Institute, Harbor-UCLA Medical Center, David Geffen School of Medicine at UCLA)
* Tona McGuire (Co-Lead, Behavioral Health Strike Team - WA State, Dept of Health)
* Bruce Greenwald (Chief, Division of Pediatric Critical Care Medicine - NYP/Weill Cornell)
* Rebecca Jacobowtiz (Pediatric Critical Care Fellow - NYP/Weill Cornell)
* Brian Jonat (Pediatric Critical Care Attending - NYP/Morgan Stanley Children's Hospital)
* Madison Elkow (Pediatric Critical Care Child Life Specialist - NYP/Weill Cornell)
* Drisdy Kee (Senior Social Worker, PICU - NYP/Weill Cornell)
* John Jermyn (Project Director, NYC Pediatric Disaster Coalition)
* Sofia Rivera-Perez (Project Coordinator, NYC Pediatric Disaster Coalition)

After establishing the working group, the next step included conducting a literature search. PDC coordinated with ASPR/TRACIE to conduct a comprehensive search on topics related to mental health and pediatric intensive care patients, their families/support system, and PICU providers. The search revealed a total of 19 sources related to relevant studies and webpages. In addition, direct sources were provided by committee member Merritt Schreiber, which included eight scholarly articles. All of the results were shared with the committee members for review, Follow up discussions took place on select information with intended use for this project.

The next phase of the project was to bring the working group together for participation in a total of three webinars over the course of two months. The purpose of the webinars was to introduce the project; discuss the project’s overview, timeline and goals; considerations for the content of the guidelines; the most effective method to develop these resources; assignment of individual roles and responsibly; and sharing of the project model and its progress.

Background:

Children are the most prevalent vulnerable population in US society and have unique needs during the response to and recovery from public health emergencies. The physiological, behavioral, developmental, social, and mental health differences of children require specific attention in preparedness efforts.  Behavioral differences in children based on their stages of development, such as more hand-to-mouth contact, underdeveloped sense of self-preservation, more time spent outdoors and, on the ground, and difficulty communicating symptoms, can make them more likely to be exposed to a hazard or less able to protect themselves from its effects. Beyond this, children have substantially more daily person-to-person social contact than adults, making them especially vulnerable to contagious threats. Children in disasters may develop mental health problems, including acute stress disorders, posttraumatic stress disorder, and depression amongst others.

Children’s vulnerability can vary according to individual factors as well; some children live with disabilities or are dependent on medical technology, and more than 30% of all US children live below poverty levels.

Additionally, mental health considerations for children in disasters require more attention and better understanding. Although children can be incredibly resilient, unattended mental health problems can be quite damaging and cause avoidable long-term disability. Children may have great difficulty coping with traumatic events, as was apparent in the aftermath of the September 11th terrorist attacks and Hurricane Katrina. These events showed that in such situations, children can be expected to reflect their caregivers’ mental health problems and that they are highly susceptible to media influence.Six months after the September 11 event, 29% of schoolchildren in New York City in grades 4 through 12 had at least one anxiety or depressive disorder, and 15% of the children from families in Hurricane Katrina’s path were found to have a “serious emotional disturbance,” compared with 4% to 7% in communities nationally. By integrating children’s mental health needs into planning and response efforts, national planners, hospitals, outpatient departments, community-based health care providers, schools, and childcare centers can improve pediatric and family outcomes during and after disasters. A resource needs assessment of available mental health provider assets is essential to defining the parameters of an appropriate response and then developing an operations plan to be adopted and implemented.

The work of programs such as the National Child Traumatic Stress Network, established by Congress in 2000, can facilitate raising the standard of care while increasing access to pediatric mental health services.(The National Child Traumatic Stress Network. National Child Traumatic Stress Network empirically supported treatments and promising practices. Available at: <http://www.nctsn.org/resources/topics/treatments-that-work/promising-practices>. Accessed January 1, 2016. [Google Scholar](http://scholar.google.com/scholar?hl=en&q=The+National+Child+Traumatic+Stress+Network.+National+Child+Traumatic+Stress+Network+empirically+supported+treatments+and+promising+practices.+Available+at%3A+http%3A%2F%2Fwww.nctsn.org%2Fresources%2Ftopics%2Ftreatments-that-work%2Fpromising-practices.+Accessed+January+1%2C+2016.))

Children can be more severely affected in public health emergencies. New strains of influenza and other emerging infections (Zika) often disproportionately attack the young, who have no immunity to earlier circulating strains with similar antigenic properties. \*

\*\*Eric J. Dziuban, Georgina Peacock, and Michael Frogel, 2017:

[**A Child’s Health Is the Public’s Health: Progress and Gaps in Addressing Pediatric Needs in Public Health Emergencies**](https://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2017.303950)

American Journal of Public Health **107**, S134, S137, [**https://doi.org/10.2105/AJPH.2017.303950**](https://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2017.303950)

Introduction:

COVID-19 thus far has had the greatest impact on adults, however, some children are vulnerable to COVID-19 infections and subsequent Multi-system Inflammatory Syndrome in Children (MISC), while many suffer from secondary effects related to loss of time at school, psychosocial and family related issues.

Current or future new infectious outbreaks may show great variability in regard to the impact on children. Critically ill children requiring care in Pediatric Intensive Care Units (PICUs), regardless of etiology, are at high risk for deleterious behavioral and mental health outcomes. Caregivers, family members, as well as PICU providers are impacted in this highly stressful environment. Patients in PICUs have acute and chronic complex conditions that are often life threatening and require continuous medical, surgical, subspecialty, respiratory and nursing care. This often involves the use of specialized equipment and therapeutic interventions including e.g., ventilators, parenteral nutrition support, chest tubes, ECMO. During infectious disease outbreaks attention has to be given to strict infection control measures that can include isolation, PPE, quarantine and patient cohorting. Further-more lengths of stays are very variable ranging from hours to months. During surge events such as pandemics shortages of space staff and equipment may develop. Altered standards of care may become necessary. All of these measures can have serious mental health impacts that need to be addressed for both patients and their caregivers.

The project has been informed by a team of subject matter experts in Pediatric Intensive Care, Emergency and Disaster Medicine, Social Work, Child-Life and Pediatric Disaster related Behavioral and Mental Health. Special recognition to Drs Schreiber and McGuire, Nationally recognized experts in Pediatric Behavioral, Mental Health for their tireless efforts and contributions to the working group and their development of the attached document “The Disaster Mental Health Concept of Operations for the NYC Pediatric PICU Critical Care Workgroup”. The goal is to provide guidance for patients, caregivers/family members and PICU providers that addresses the special mental health needs of children requiring critical care as well as those caring for them. The different groups addressed above will benefit from a screening process, educational and training material, triage of patients at high risk and referral treatment strategies.

The background and introduction material as well as The Disaster Mental Health Concept of Operations for the NYC Pediatric PICU Critical Care Workgroup are designed to be utilized by the Pediatric Intensive care unit staff to provide PICU disaster mental health screening, referral, educational and training material and resources for patients and their caregivers as well as, PICU providers. Where possible it should be integrated in to existing PICU protocols and incorporated into operational plans for all patient encounters as part of the admission and ongoing care and follow-up activities.

As there is significant variation in PICU capabilities in general and especially related to social work, child life and behavioral mental health resources the guidance should be adapted to align resources to needs for best outcomes.

The following mental health resources and materials are for utilization by patients, parents, and caretakers in PICUs.

**Coping with Intensive Care (See attached PDF in deliverable email submission)**

Tips for coping with intensive care including: Responses to PICU and Support, Self-Care, and Communication

**Anticipate, Plan, Cope:** this fact sheet was designed to help families: anticipate stress factors and reactions in their child or teen, plan for potential impacts or challenges due to COVID-19, and cope helps parents build active coping tool kits. **(See attached PDF in deliverable email submission)**

**Anticipate, Plan, Cope (Frontline):** this fact sheet was designed to help PICU providers who are parents plan for and cope with the impacts of COVID-19. **(See attached PDF in deliverable email submission)**

**At the Hospital Helping My Child or Teen Cope:** The following fact sheets details potential things parents or caregivers can do while their child or teen is hospitalized. It explains what the child or parent might experience during this time and offers eight ways to help your child cope. **(See attached two PDFs (Child and Teen version) in deliverable email submission)**

*Resources for Children and Teens*

* Podcasts and stories to distract children or teens can be helpful during a stressful hospital stays
* Guided Breathing and Relaxation for Teens
	+ <https://kidshealth.org/ChildrensHospitalWisconsin/en/teens/relax-breathing.html>
* Guided Imagery for Children
	+ <https://www.choc.org/programs-services/integrative-health/guided-imagery/>
	+ <http://www.talesfromthelilypad.com/>

*Resources to Help Siblings of Patients in the Hospital and ICU*

* <https://icusteps.org/assets/files/activity-book/visitingICU.pdf>
* <https://www.chop.edu/health-resources/support-siblings-hospitalized-child>
* <https://www.seattlechildrens.org/globalassets/documents/for-patients-and-families/pfe/pe2434.pdf>

*Resources for Parents*

* Helping your child cope with pain
	+ <https://www.mottchildren.org/mott-patient-visitor-guide/coping-with-pain>
* Helping your child cope with hospitalization
	+ <https://m.ufhealth.org/child-life-program/tips-help-your-child-cope-hospitalization>
* Tips for preparing your child for the hospital
	+ <https://www.uclahealth.org/mattel/preparing-for-your-childs-hospital-stay>
* Tips for coping with intensive care including: Responses to PICU and Support, Self Care, and Communication

**At the Hospital Helping My Child or Teen Cope:** The following fact sheets details potential things parents or caregivers can do while their child or teen is hospitalized. It explains what the child or parent might experience during this time and offers 8 ways to help your child or teen cope. Available both in English and Spanish. **(See attached PDF in deliverable email submission)**

**NY Project Hope, Coping with COVID** was created to provide resources for New Yorkers including an Emotional Support Helpline. They have a section specific to children and family members that includes: recognizing and coping with stress for children and adolescents, talking with children and adolescents, and how parents can help.

* <https://nyprojecthope.org/recognizing-coping-with-stress-for-children-and-adolescents/>

**The National Child Traumatic Stress Network (NCSTN):** provides evidence informed intervention designs to put in place after a disaster, terror event, and other emergencies. The following is a tip sheet to help parents with infants and toddlers after a disaster.

* <https://www.nctsn.org/sites/default/files/resources/pfa_parent_tips_for_helping_infants_and_toddlers_after_disasters.pdf>

**The Behavioral Health Toolbox for Families:** is a comprehensive toolbox created by the Washington State DOH for families specific to the COVID-19 pandemic to help support children and teens during the pandemic. It includes: self-care recommendations, detailed coping strategies, recognizing behavioral changes, and additional resources.

* <https://www.doh.wa.gov/Portals/1/Documents/1600/coronavirus/BHG-COVID19-FamilyToolbox.pdf>

In addition please see the attached:

* The Disaster Mental Health Concept of Operations for the NYC Pediatric PICU Critical Care Workgroup
* Appendix A Literature Search

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