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Evidence-Informed Guidelines for Pediatric Pandemic Planning and Response

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Evidence-Informed Guidelines for Pediatric
Pandemic Planning and Response

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Executive Summary

Overview

Pandemic events are unpredictable and inevitable. When they occur, the impact is both all-encompassing and asymmetrical; each pandemic targets specific, vulnerable populations, but ultimately impacts individuals, families and communities throughout the world. Regardless of origin or circumstances, the next pandemic will certainly count infants, children, and adolescents among its most vulnerable targets. As evidenced by the 2009 H1N1 influenza pandemic, children may be at higher risk than populations more typically seen as susceptible to pandemic illness (the elderly, those with weakened immune systems, etc.). Children also can function as disease vectors, spreading the virus through their ubiquitous presence in settings where they live, attend school, and play.

This document is the result of a two-year international, mixed-methods study of the physical, social, and mental health effects of pandemic on children and families – particularly the impact of quarantine and hospital isolation during these events. This project also examined the psychosocial effects of pandemic disaster on professionals who care for children before, during, and after pandemic. Based on the empirical findings of this study, researchers developed a set of evidence-informed, child-focused, best practice guidelines for use by stakeholders during future pandemics across a variety of relevant fields. In addition, data gathered and analyzed for the project have been used to create a set of Kentucky-specific recommendations that respond to the state's unique geographic and population needs.

Phases

This project was divided into two phases; the first phase consisted of a comprehensive literature review and content analysis with a focus on current knowledge relevant to the impact of disease containment strategies on the biopsychosocial responses of families and children.[1] Following the careful examination of literature from the areas of public health, social psychology, behavioral health, healthcare, and law, the research team then constructed and piloted a "toolkit," which included a range of surveys, interviews, and focus group schedules targeted for key respondents who were determined to have significant

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[1] Sprang, G., Clark, J., LaJoie, A.S., Leigh, P., Mohipp, C., Silman, M. & Smith, J. (2009). *Best Practices Guidelines for Pandemic Disaster Response: A Social Behavioral Evaluation. A Comprehensive Analysis of Pandemic and Quarantine Responses for Families and Children.* Lexington, KY: Center for the Study of Violence Against Children.

knowledge of pandemic.[2] Coincidentally, the 2009 H1N1 pandemic was occurring as field work was being planned and initiated, which allowed investigators to use the event as a "natural experiment" to learn how authorities in the United States (U.S.), Canada, and Mexico worked when faced with a true pandemic.

Individuals recruited to participate in the first phase of the project consisted of stakeholders and other professionals involved in pandemic planning and response: behavioral health professionals, healthcare workers, law and ethics experts, and public health officials. Recruitment was conducted through the use of multiple marketing and recruitment techniques (e.g., newspaper advertisements, flyers, snowball sampling). Data collection efforts also captured the experiences of children, youth and parents. Data was collected using a "follow the virus" sampling strategy, which focused efforts in the areas most impacted by pandemics in Mexico, Canada and the U.S. The information gathered was used to construct an expert database that included the experiences, knowledge, and description of data collected from a diverse set of 2,608 experts.[3]

Following the development and publication of a report on the evidence gathered during the data collection phase[4], phase one culminated with a preliminary draft of evidence-based recommendations to address identified deficits in child-focused pandemic planning and response.[5] These recommendations were then subjected to national and international field-testing to determine the utility and validity of the guidelines. The feedback phase consisted of three components: expert critiques of the overall findings and recommendations; responses from Kentucky stakeholders on the utility and relevance of the recommendations for state-level implementation; and comments from representatives of national professional organizations not previously queried.[6 & 7] Special focus was placed

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[2] Sprang, G., Clark, J., Jackson, C., LaJoie, A.S., Leigh, P., Mohipp, C., & Silman, M. (2009). *University of Kentucky Behavioral Health Research Toolkit: An Analysis of the Child and Family Experience.* Lexington, KY: Center for the Study of Violence Against Children.

[3] Sprang, G., Clark, J., Jackson, C., LaJoie, A.S., Leigh, P., Mohipp, C., & Silman, M. (2010). *University of Kentucky Best Practice Guidelines for Pandemic Disaster Response Expert Database.* Lexington, KY: Center for the Study of Violence Against Children.

[4] Sprang, G., Clark, J., Jackson, C., LaJoie, A.S., Leigh, P., Mohipp, C., Otis, M., & Silman, M. (2010). *A Comprehensive Analysis of Pandemic and Quarantine Responses for Families and Children: Integrative Report of New Evidence (Preliminary Findings).* Lexington, KY: Center for the Study of Violence Against Children.

[5] Sprang, G., Clark, J., Jackson, C., LaJoie, A.S., Leigh, P., Mohipp, C., & Silman, M. (2010). *New Directions in Pandemic Response: A Roadmap to Resilience.* Lexington, KY: Center for the Study of Violence Against Children.

[6] Sprang, G., Clark, J., Jackson, C., LaJoie, A.S., Leigh, P., & Silman, M. (2010). *Best Practice Guidelines for Pandemic Disaster Response: Response from the Field (Part 1).* Lexington, KY: Center for the Study of Violence Against Children.

on the translational utility of the recommendations, so that they would be practical in the "real world."

Evidence-Informed Guidelines

The guidelines are the result of the research team's data collection and analysis. It is the goal of this project to provide pandemic response stakeholders with specific, multi-disciplinary recommendations that are family- and child-focused, and evidence-informed. The related Public Health Preparedness Guidelines (2011)[8] are noted for each guideline as appropriate. The following evidence-informed guidelines also include links to relevant manuscripts, organizations, and resources that may be used to strengthen child-focused pandemic planning and response.

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[7] Sprang, G., Clark, J., Jackson, C., LaJoie, A.S., Leigh, P., & Silman, M. (2011). *Best Practice Guidelines for Pandemic Disaster Response: Response from the Field (Part 2).* Lexington, KY: Center for the Study of Violence Against Children.
[8] Centers for Disease Control and Prevention (March, 2011). *Public Health Preparedness Capabilities: National Standards for State and Local Planning.* Available at: www.cdc.gov/phpr/capabilities.

**Evidence-Informed Guidelines for Child-Focused
Pandemic Planning and Response**

Pandemic Infrastructure Development Strategies

1. The National Commission on Children and Disasters (NCCD) has issued a report calling for the development of a National Disaster Recovery Framework (NDRF) to specifically emphasize the short and long-term behavioral health and human recovery needs of children. The results of this study support this recommendation and suggest replication at the state and local levels. An additional proviso is that pandemic-specific planning and response strategies be included, as pandemics have unique features and impacts on children that require discrete but integrated efforts. **Pandemic preparedness and response for children and their families should be an integral part of an all-hazards approach to disaster response and included in the NDRF.** *(PHP Capability 1: Community Preparedness)*

2. **To facilitate cross-fertilization across disciplines and among behavioral health-specific professional organizations, a national meeting convened by the NCCD, or another national level group interested in children and pandemic preparedness, is advisable.** This meeting will increase the possibility that innovations, knowledge-advancements, and progress made by one organization will be shared and applied by other groups, thereby standardizing pediatric behavioral health practice guidelines and core competencies for providers responsible for the behavioral health response to pandemics. *(PHP Capability 6: Information Sharing; PHP Capability 1: Community Preparedness)*

3. The **creation of a Pediatric Pandemic Clearinghouse** would allow national planners and responders access to a database of relevant knowledge. This clearinghouse could function as an adjunct to or as part of the pediatric disaster clearinghouse recommended by the NCCD. *(PHP Capability 6: Information Sharing; PHP Capability 1: Community Preparedness)*

4. **To promote an effective focus on children during disaster planning and response, the behavioral health response should be organized using a child-focused boundary spanner/boundary spanning team.** The boundary spanner/boundary spanning team will take an all-hazards approach to disaster response while being specifically focused on the needs of children and their families. Although the boundary spanner can effectively operate from either Public Health or the Office of Emergency

Management, a crucial strategy is to connect these two divisions at the federal, state, and local levels to avoid duplication of effort and to promote the most effective child-focused planning to build resilient communities and systems. *(PHP Capability 1: Community Preparedness; PHP Capability 2: Community Recovery; PHP Capability 6: Information Sharing)*

5. Public health officials should **include the perspectives of heretofore excluded groups in pandemic planning and response efforts, such as parents, children, and vulnerable populations.** Such populations may include ethnic, cultural, and religious minorities. Representatives of these groups can be included in the development of risk messaging, and in the selection of behavioral health screening tools, and response frameworks. Proactive inclusion will increase the likelihood that the needs of these populations are attended to with developmentally and culturally appropriate services, messages or tools. Inclusion will also enhance cooperation with crucial public health approaches, and contribute to the well-being of children and families. *(PHP Capability 1: Community Preparedness; PHP Capability 6: Information Sharing; PHP Capability 2: Community Recovery)*

6. Due to differences in mission and focus between behavioral health organizations and public health entities, behavioral health services will not be effectively and fully integrated into the pandemic response unless prescribed, protocol-driven and collaboratively developed. This is best achieved through promoting the efforts of the child-focused boundary spanner, **the development of a behavioral health module in every state pandemic preparedness and response plan**, and the active involvement of behavioral heath professionals in the process. *(PHP Capability 1: Community Preparedness; PHP Capability 2: Community Recovery)*

   Essential Elements of the Behavioral Health Module:

   i. A clearly defined organizational structure for pediatric pandemic planning and response. The mental health response will best be organized by using the child-focused pandemic boundary spanner/boundary spanning team. Some state plans addressed mental health planning and response by delegating such issues to separate departments, or they included action items regarding the development of tools and protocols to address mental health needs. While these were steps in the right direction, follow-up and maintenance of action items also need to occur to ensure mental health services will be readily available for pandemic response in the short and long term. State plans should address the coordination of mental health providers with emergency

preparedness officials to deliver services. When these arrangements are secured, specific attention should be paid to the reporting structure, the training and qualification requirements of providers, communication pathways to ensure the efficient flow of information, and strategies for alternative service delivery. *(PHP Capability 1: Community Preparedness; PHP Capability 3: Emergency Operations Coordination; PHP Capability 2: Community Recovery)*

ii. Sample messages aimed at decreasing stigma, increasing compliance and promoting individual and community resiliency. *See the Risk Communication section of this document for detailed recommendations. (PHP Capability 4: Emergency Public Information and Warning; PHP Capability 6: Information Sharing; PHP Capability 1: Community Preparedness)*

iii. Psychoeducational materials that explicate normal versus abnormal responses of children and parents to pandemics. (For example, fact sheets about psychosocial and developmental responses with specific attention to vulnerable populations during disasters.) Information should be made available to parents via mental health hotlines (211 lines were used with success in many communities), and disseminated via websites, e-mail, schools, doctors' offices, community centers and other child-focused sites. Examples of useful materials that are available in the public domain follow. *(PHP Capability 4: Emergency Public Information and Warning; PHP Capability 6: Information Sharing; PHP Capability 7: Mass Care; PHP Capability 1: Community Preparedness)*

iv. Plans should specify that assessment and treatment services for children and adults be evidence-informed and protocol driven, thus allowing local experts to tailor intervention strategies to the needs of the community while ensuring consistent, quality service delivery. (*PHP Capability 7: Mass Care; PHP Capability 1: Community Preparedness*)

Pandemic Flu and Pediatric Traumatic Stress Fact Sheets

Pandemic Flu Fact Sheet: A Parents' Guide to Helping Families Cope with a Pandemic Flu
http://www.nctsn.org/sites/default/files/assets/pdfs/Pandemic_Flu_Factsheet.pdf

Influenza Pandémica: Guía de los padres' para ayudar a las familias a enfrentar la Influenza pandémica
http://www.nctsn.org/sites/default/files/assets/pdfs/Influenza_pandemica_Final_Spanish_Version0.pdf

Understanding Child Traumatic Stress
http://www.nctsn.org/sites/default/files/assets/pdfs/Understanding_Child_Traumatic_Stress_Brochure_9-29-05.pdf

Developmental Differences in Pediatric Traumatic Stress
http://www.healthcaretoolbox.org/pdf/Developmental_Differences.pdf

After the Trauma: Helping My Child Cope
http://www.healthcaretoolbox.org/pdf/After_the_trauma_child.pdf

At the Hospital: Helping my Child Cope With Illness
http://www.healthcaretoolbox.org/pdf/Hospital_Illness_Child.pdf

At the Hospital: Helping My Teen Cope With Illness
http://www.healthcaretoolbox.org/pdf/Hospital_Illness_Teen.pdf

After the Hospital: Helping My Child Cope
http://www.healthcaretoolbox.org/pdf/After_the_hospital_child.pdf

v. State and/or local pandemic response plans should provide specific criteria for when first responders or other emergency management personnel should make a behavioral health referral for assessment or treatment. These criteria should be created in conjunction with the identified behavioral health organization responsible for receiving the referrals to ensure compatibility between the established criteria and the admission and acceptance policies of the behavioral health agency. (*PHP Capability 1: Community Preparedness)*

vi. A continuum of evidence-informed, child-focused interventions ranging from stress prevention and support efforts to long-term

trauma-focused psychotherapeutic services should be available in each community. The importance of relationship-based interventions for young children exposed to pandemic conditions should inform all therapeutic services and be included in the continuum of available interventions. (*PHP Capability 7: Mass Care; PHP Capability 1: Community Preparedness*)

vii. A list of formal and informal community-based resources that can address the psychosocial needs of children and families affected by the pandemic should be included and regularly updated. (*PHP Capability 7: Mass Care; PHP Capability 1: Community Preparedness*)

viii. Alternative service delivery options (telemedicine delivery mechanisms, online support groups, etc.) for behavioral health services in times of quarantine or isolation should be developed and required. Specific advice to practitioners regarding financing and privacy implications of these substitute methods should also be included in the state pandemic plan. (*PHP Capability 7: Mass Care; PHP Capability 1: Community Preparedness; PHP Capability 2: Community Recovery*)

ix. Strategies for "just in time" training of behavioral health, public health and healthcare workers should be outlined to address staff turnover, procedural drift, recertification and the incorporation of new innovations. *(PHP Capability 2: Community Recovery; PHP Capability 7: Mass Care)*

x. Plans should include pandemic-specific ethical and legal guidance for behavioral health professionals working with children and families. The following resource may be useful in providing ethical and legal guidance to professionals. (See *Appendix I* for additional ethical and legal resources.)

> **Planning and Responding to Pandemic Influenza:**
> **Ethical Considerations Checklist**
> http://www.cdc.gov/od/science/integrity/phethics/
> Pan_Flu_Ethics_Checklist.3-15-07.final.doc

1. There are naturally occurring congregate sites (NOCS) in communities that are currently used as the default location for the public to obtain resources (housing, food, financial aid). These **NOCS should be**

identified and used to assist communities with resource distribution, risk communication and behavioral health screening of children and families in a pandemic situation. Examples of NOCS include libraries, community centers, schools, and centers of worship. Use of these sites may reduce stigma associated with accessing pandemic-related medical or behavioral healthcare, because they possess high familiarity, high accessibility, and provide a range of services for the local population. Some proposed criteria for the selection of a congregate site include: 1) it should be accessible on foot or by public transit; 2) the site should be welcoming to a wide range of people, including those from elusive/vulnerable communities; 3) the site should be conducive to conducting health and behavioral health interventions with children (e.g., can meet safety, privacy, and space needs); 4) it should be a child-friendly space; and 5) the site should be socially sanctioned by community as a place to gather, interact, communicate, and receive goods and services.

2. Faith-based organizations and houses of worship are often important components in the critical infrastructure responsible for supporting the social fabric of the community. Their experience in dealing with death and dying makes these organizations a natural resource for families in potentially lethal disasters. **Faith-based organizations and houses of worship should be included as collaborators in the development of pandemic preparedness plans, and they need adequate support and training in the peri- and post-pandemic environment**.

3. **Existing, informal therapeutic relationships (church, school, etc.) may be the most realistic avenue for providing support for most children, and should be identified and included in resource lists.** In addition to regular attendees, even marginally involved members and uninvolved persons will appear at houses of worship during crises, creating a naturally occurring congregate site. The Centers for Disease Control and Prevention (CDC) has produced a document, "H1N1 Flu: A Guide to Community and Faith Based Organizations," in recognition of the important role that faith-based or other community organizations may play during pandemic disaster. This document may be useful to pandemic planning and response officials. *(PHP Capability 2: Community Recovery; PHP Capability 6: Information Sharing; PHP Capability 4: Emergency Public Information and Warning).*

H1N1 Flu: A Guide to Community and Faith Based Organizations

This guide may be accessed at:
http://www.pandemicflu.gov/professional/community/cfboguidance.html

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4. Disaster response, by its nature, is interdisciplinary. **Behavioral health professional organizations should collaborate and coordinate to develop professional standards of care for a pandemic response.** The following should be addressed when developing standards for behavioral health professionals responding to pandemic events:

    i. Identification and articulation of the unique roles and responsibilities of members in responding to a pandemic *(PHP Capability 1: Community Preparedness; PHP Capability 3; Emergency Operations Coordination; PHP Capability 6: Mass Care)*;

    ii. Guidelines for collaboration and coordination with other professions and emergency management personnel (*PHP Capability 6: Mass Care; PHP Capability 2: Community Recovery)*;

    iii. Specifications of the organizations' contractual agreements with the most appropriate disaster gatekeepers *(PHP Capability 3: Emergency Operations Coordination)*;

    iv. Recommendations regarding the standard of care for the assessment and treatment of children and adults who are suffering with behavioral health issues related to the pandemic. This may include the adoption of practice guidelines for a broad range of pandemic-related health and mental health conditions, including those developed by other organizations (*PHP Capability 6: Mass Care; PHP Capability 1: Community Preparedness);*

    v. Identification of educational, training and practice competencies that should be used by universities, professional schools, and training programs to develop pre-graduate curriculum and post-graduate continuing education (*PHP Capability 6: Mass Care; PHP Capability 1: Community Preparedness; PHP Capability 15: Volunteer Management);*

    vi. Provision of ethical and legal guidance for members on issues related to service provision during and after the pandemic crisis situation (*PHP Capability 3: Emergency Operations Coordination)*

    vii. Presentation of practical advice in the form of fact sheets or checklists for the public that is consistent across professions. (*PHP Capability 1: Community Preparedness; PHP Capability 4: Emergency Public Information and Warning)*

Risk Communication

5. As part of the planning process, **culturally-appropriate risk communication should be developed that incorporates input from**

diverse constituencies and includes *(PHP Capability 6: Information Sharing)*:

i. Age-appropriate messaging (both in content and method of delivery) that accounts for developmental differences in need and influence during different phases of childhood and adolescence *(PHP Capability 4: Emergency Public Information and Warning)*;

ii. Information regarding a child's normal and abnormal responses to a pandemic disaster and available resources from whom parents and guardians can seek mental health assistance *(PHP Capability 4: Emergency Public Information and Warning; PHP Capability 7: Mass Care)*;

iii. Psychoeducational programs targeted at decreasing uncertainty and anxiety, as well as increasing self-efficacy in children and their family caregivers *(PHP Capability 7: Mass Care)*;

iv. Information about strategies to reduce mental health stress during isolation and quarantine *(PHP Capability 11: Non-Pharmaceutical Interventions)*;

v. Counter-messaging to dispel myths and misconceptions that lead to stigmatizing behavior *(PHP Capability 4: Emergency Public Information and Warning)*; and

vi. Information on how to balance work-family responsibilities (e.g., legal options, questions to ask employers, community resources to provide financial or child care assistance) *(PHP Capability 14: Responder Safety and Health).*

6. The inherent tension between physicians' focus on individual patient care and public health's attention to promoting population health can create inconsistent messaging to families and the community. Such inconsistency can unintentionally generate confusion and mistrust. Public health officials should strive to close the gap between the medical community and government agencies regarding important issues related to pandemic planning and response (i.e., vaccine safety and distribution). **Pediatric and family medicine healthcare professionals should be involved in crafting and disseminating pandemic messaging (along with public health)** to increase the credibility of the message and the consistency of information *(PHP Capability 1: Community Preparedness; PHP Capability 4: Emergency Public Information and Warning).*

7. It is notable that **messages are more likely to be accepted, compliance increased, and stigma reduced when trusted community members (including *promotoras y promotores de salud*) are involved in the dissemination of information, and when risk communication is**

broadcast in the individual's first language. The utilization of culturally specific, age-appropriate, family-accessed communication channels is the best way to achieve this goal. Kentucky has developed the Kentucky Outreach and Information Network (KOIN) as a way of tapping into established, "trusted messengers" of information in disasters. The purpose of the KOIN is to ensure that communication channels are in place so that the state's most vulnerable and hard-to-reach populations receive critical health information from people they already know and trust. This network coordinates messaging with the Kentucky Department of Public Health and disseminates consistent information to vulnerable populations *(PHP Capability 4: Emergency Public Information and Warning)*

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> **Information about the KOIN** is available at:
> http://healthalerts.ky.gov/koin/Pages/default.aspx

Strategies for Behavioral Health Screening, Assessment and Intervention

8. The rates of Post-Traumatic Stress Disorder (PTSD) symptoms in parents and children indicate that the experience of disease containment created a stressful condition that was experienced as traumatic by some study respondents. Individual parents and children who experience quarantine or isolation appear to require behavioral health and other support services to prevent or mitigate the traumatic effects of such experiences. **Routine peri- and post-pandemic behavioral health assessment that includes trauma screening is indicated for parents and youth who experience isolation or quarantine** *(PHP Capability 7: Mass Care)*.

9. **Positive identification of PTSD in individuals indicates the need for an automatic assessment for the presence of behavioral health disorders in those individuals' family members**. Data from this study found that concurrent elevations in behavioral health stress symptoms in children and parents in the same family were not unusual *(PHP Capability 7: Mass Care)*.

10. **Children and families experiencing isolation and quarantine should be screened for anxiety-related symptoms as part of routine healthcare services** *(PHP Capability 11: Non-Pharmaceutical Interventions)*. Characteristics of integrated health/behavioral healthcare include:

   i. Use of pediatric healthcare providers to conduct behavioral health screenings during pandemic-related medical visits. Because mass congregate sites are unusual in pandemic events, screening should

occur during pandemic-related medical diagnosis, vaccination, quarantine and isolation. Screenings may need to be conducted again at follow-up contact, particularly after quarantine or isolation *(PHP Capability 11: Mass Care; PHP Capability 4: Emergency Public Information and Warning)*.

ii. Brief, empirically informed, behavioral health screening as part of the routine assessment of pandemic symptoms. Self-report tools may be most efficient and should focus on anxiety. Examples of brief, standardized instruments with good psychometric properties are included as *Appendix H*. *(PHP Capability 7: Mass Care)*

iii. Consideration of issues of culture, development, language and literacy to ensure screening tools have maximum utility and validity. *(PHP Capability 1: Community Preparedness; PHP Capability 7: Mass Care)*.

11. **Behavioral health interventions can and should be delivered effectively using alternative delivery media such as telemedicine and online support groups** to facilitate connections among patients, families and friends who are isolated. During the Severe Acute Respiratory Syndrome (SARS) pandemic, an online support group based in Canada proved to be a supportive and educational intervention for quarantined and isolated individuals *(PHP Capability 2: Community recovery; PHP Capability 7: Mass Care)*.

SARS Support Centre

The SARS online support group used in Canada is a good model of how to provide ongoing support for those experiencing stress due to a pandemic in a non-stigmatizing and disease-conscious manner.
http://www.sarssupportcentre.net/

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12. **Screening and assessment results should be linked to ongoing, integrated service provision** by behavioral health professionals trained in evidence-based protocols. Five essential elements of immediate and mid-term intervention that are supported by empirical evidence include the following activities *(PHP Capability 7: Mass Care)*:

i. ***Promote a sense of safety and well-being***. In pandemic situations, this requires adequate and timely medical intervention, protection from exposure, contagion and secondary loss, and disease containment *(PHP Capability 4: Emergency Public Information and Warning; PHP Capability 6: Information Sharing)*;.

ii. ***Promote calming***. Messaging should avoid unnecessary catastrophic language, opportunities for action and self-care should be clearly articulated, and strategies to promote family togetherness and resiliency should be implemented to capitalize on existing adaptive skills *(PHP Capability 4: Emergency Public Information and Sharing)*.

iii. ***Promote a sense of self and collective efficacy.*** Effective decision-making and resiliency in pandemic conditions requires the acquisition of accurate and appropriate information, opportunities for self-directed action, choice, and good communication with public health officials, healthcare providers and behavioral health professionals *(PHP Capability 7: Mass Care)*.

iv. ***Promote connectedness***. Family-centered care that maintains the protective qualities of the parent-child relationship in quarantine or isolation situations is preferable. The use of social media and telecommunication strategies should be implemented to promote social connectedness in times of isolation, shelter-in-place or quarantine *(PHP Capability 11: Non-Pharmaceutical Interventions)*.

v. ***Promote hope.*** Projected fatality rates and proposed risk profiles should be tempered and accompanied by concrete health and mental health promotion strategies and activities to prevent panic and despair. Existing individual and community strengths and resiliency should be identified and highlighted in media coverage of the pandemic event *(PHP Capability 4: Emergency Public Information and Warning; PHP Capability 6: Information Sharing)*.

> For children needing therapeutic services for trauma-related disorders, trauma-informed, evidence-based protocols are needed. For a complete listing of best practices for the treatment of traumatic stress, see
> http://www.nctsn.org

13. **Behavioral health organizations should have in place clearly outlined and pre-determined behavioral health strategies and methods to screen persons who have been exposed to pandemic** and who may be in need of mental health services. (*See Appendix H, Recommendations for Brief Screening Tools.) (PHP Capability Community Preparedness; PHP Capability 7: Mass Care).*

14. **Behavioral health organizations should provide training for their employees who may be potential pandemic responders.** This training should be tested and updated regularly to keep pace with innovations in the field, and should promote the following:

i. Understanding and implementation of strategies to prevent adverse mental health responses to pandemic *(PHP Capability 1: Community Preparedness; PHP Capability 7: Mass Care)*;

ii. Competency in the use of evidence-informed, child- and pandemic-focused screening and intervention tools, with attention to the phase of the pandemic *(PHP Capability 7: Mass Care)*;

iii. Understanding of risk and protective factors for children and caretakers during pandemic disaster *(PHP Capability 1: Community Preparedness)*;

iv. Use of trauma framework for understanding a child's and parent's response to disease containment, and appropriate interventions that can be used to address trauma-related conditions *(PHP Capability 1: Community Preparedness)*;

v. Guidance on ethical decision-making in times of disasters *(PHP Capability 1: Community Preparedness; PHP Capability 7: Mass Care)*;

vi. Strategies for self-care *(PHP Capability 14: responder Safety and Well-Being)*;

vii. Opportunities and methods for collaborating effectively with public health, and strategies for utilizing and financing alternative service delivery options. Telemedicine or videoconferencing services that include interactive features between clients and providers are most likely to be fundable therapeutic encounters.

Strategies for Building Resilience in Youth, Families and Communities

21. Results of this study indicate little awareness on the part of education or public health officials of government food subsidies available to districts that experience school closures of five days or more due to pandemic crisis. To prevent a disruption of food supply to children who qualify for free or reduced school meals, **further training and education on the benefits available through the Pandemic Supplemental Nutrition Assistance Program (P-SNAP) is indicated** *(PHP Capability 1: Community Preparedness; PHP Capability 2: Community recovery; PHP Capability 6: Information Sharing)*.

22. In the event the P-SNAP program is utilized, issues of getting the food supply to children who are dependent upon the free or reduced school lunch program have not been addressed in most districts. **A food distribution plan should be developed that provides for three-deep workforce coverage in the event of school closures that exceed five days.** This plan should be able to accommodate worker illness or unavailability, and to ensure that children can access the food supply subsidized by the P-SNAP benefit *(PHP Capability 1: Community Preparedness)*.

Masters of Disaster

The American Red Cross' "Masters of Disaster" curriculum was frequently mentioned as an important school-based program that prepared children to deal with disasters. However, it is not pandemic focused.

Information about Masters of Disaster may be found at:
http://www.redcross.org/disaster/masters/

**Tips for Talking to Children After a Disaster:
A Guide for Parents and Teachers**

SAMHSA offers a fact sheet for parents and teachers with guidance on helping children after traumatic events.

This material may be accessed at:
http://www.samhsa.gov/MentalHealth/Tips_Talking_to_Children_After_Disaster.pdf

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Strategies for Healthcare Organizations

23. During a pandemic crisis, there is potential for caregivers and children to be separated in the hospital environment, causing distress and increased potential for parental non-compliance with medical orders for isolation and segregation. **Pandemic care in hospital settings should maintain and support child-focused and family-centered care practices** throughout pandemic response (e.g., allowing parents to remain with children, considering family quarantine rather than individual isolation) *(PHP Capability 7: Mass Care)*.

24. The continuation of pediatric-specific and family-centered care requires training sufficient numbers of child-focused professionals and first

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responders to provide uninterrupted, pediatric-specific services during all phases of a pandemic. Certain pediatric service areas are highly specialized and have been demonstrated to be especially vulnerable to workforce loss during a pandemic (e.g., NICU/PICU). **Advanced cross-training and three-deep coverage needs to be in place to ensure continuity of pediatric care during pandemic conditions** *(PHP Capability 15: Volunteer Management; PHP Capability 1: Community Preparedness).*

25. The current library of pandemic simulation exercises and drills focus on general healthcare and public health responses to widespread disease. **It is recommended that drills to test pediatric disaster preparedness, workforce coverage plans, and behavioral health readiness in pandemic crisis be developed and updated and utilized annually** *(PHP Capability 1: Community Preparedness).*

Influenza Drill and Simulation Digital Resource

"The Influenza Training Digital Library was created in response to a need for a common repository of standardized material involving multiple and diverse international partners involved in the delivery of influenza and pandemic preparedness training. This library provides up-to-date, peer-reviewed and easy accessible influenza-related training material and technical background documents."

Additional information may be found at:
http://influenzatraining.org

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26. All healthcare professionals and related support personnel need timely, accurate, current, and authoritative information before, during, and after a pandemic. The child-focused boundary spanner could be particularly effective in disseminating this information to professionals. **A "push" mode of information dissemination to healthcare providers should be used to ensure maximum child-focused pandemic literacy** (i.e., information is received automatically via e-mail or phone alert, which does not require any personal initiative or action to retrieve it). *(PHP Capability 6: Information Sharing).*

27. Data gathered during this study revealed that during recent pandemics, inconsistent disease control strategies were communicated across different government agencies. For example, during the 2009 H1N1 pandemic, the U.S. Occupational Safety and Health Administration (OSHA) and the CDC differed in their recommendations regarding the

most appropriate personal protective equipment (PPE) to use for adults and children. This created confusion and mistrust among healthcare providers and the parents of infected children. Therefore, **organizations should be transparent about inconsistencies in healthcare practices and public health recommendations and provide a clear rationale for divergence from these guidelines** to maximize parental trust and cooperation *(PHP Capability 4: Emergency Public Information and Warning; PHP Capability 7: Mass Care)*.

28. Based on the findings of this study, professionals at particular risk for traumatic stress responses to pandemic include: a) those who themselves were infected or who had family members who were ill; b) those who experienced a high number of fatalities in their professional and/or personal spheres; c) those who do not normally work with infectious disease, isolation or life-threatening illness and during the pandemic response were shifted into that role; and d) behavioral health professionals who worked with persons affected by isolation and quarantine procedures. Therefore, healthcare workers with direct or indirect exposure to traumatic events should be screened for secondary traumatic stress as a routine part of an organization's pandemic response *(PHP Capability 14: Responder Safety and Health)*.

    A. Proposed characteristics of behavioral health screening and intervention of healthcare workers include:

        i. Behavioral health screening and intervention should be available in a confidential and supportive manner to minimize potential for stigmatization of professionals requiring or accessing such services *(PHP Capability 14: Responder Safety and Health)*.;

        ii. Behavioral health screening should include recurrent opportunities for self-screening, peer assessment and supervisory assessment *(PHP Capability 14: Responder Safety and Health)*.;

        iii. Behavioral health screening should be available during and after a pandemic; the post-pandemic period may be the most critical *(PHP Capability 14: Responder Safety and Health)*.;

        iv. Follow-up services should include both screening for persistent mental health distress in the areas of depression and anxiety, as well as compassion fatigue/secondary traumatic stress *(PHP Capability 14: Responder Safety and Health; PHP Capability 2: Community Recovery)*..

30. Organizations should provide access to a range of interventions to address the deleterious effects of secondary traumatic stress. The possibilities range from preventative, group approaches to individualized, psychotherapeutic services. Our field work revealed that informal, supportive, and spontaneous gatherings were utilized more frequently than mandatory, formal interventions in the immediate aftermath of a crisis event (e.g., death of a child) *(PHP Capability 14: Responder Safety and Health).*

<mark>Continuum of Interventions to Prevent and Address Secondary Traumatic Stress in Professionals</mark>

<mark>[INSERT TABLE HERE}</mark>

Legal and Ethical Considerations

31. If government restricts a citizen's liberty (via isolation or other disease containment measures), it must provide opportunities or resources to address the effects of that restriction. For example, if government creates criminal sanctions for violation of compulsory quarantine, then government must provide the resources for families and children to mitigate the effects of those restrictions (e.g., food, income replacement). Jurisdictions should review their public health policies and statutes to identify possible violations of due process that create unintended effects, such as criminalizing family survival behaviors (e.g., breaking isolation/quarantine to maintain employment), and resolve these conflicts. The CDC's Social Distancing Law Project may be an example of how this could occur; however, only limited information about this project is available in the public domain *(PHP Capability 1: Community Preparedness; PHP Capability 11: Non-Pharmaceutical Interventions).*

32. **Courts that serve families and children (e.g., Family Court, Dependency Court, Juvenile Court) should take independent actions to ensure that key personnel have contact information for all court involved personnel so that a coordinated and effective pandemic response can be executed.** Professional personnel include judges, state attorneys, guardians *ad litem*, and court-appointed advocates, while other essential persons include foster parents and social services workers. Such pandemic preparedness may require funding for training, education and practice exercises for judges, court administrators, and other court personnel. The child-focused boundary spanner could assist jurisdictions' efforts through developing collaborations with the National Council of Juvenile and Family Court Judges and other relevant organizations. *(PHP Capability 6: Information Sharing; PHP Capability 3: Emergency Operations Coordination; PHP Capability 2: Community Recovery).*

National Council of Juvenile and Family Court Judges
http://www.ncjfcj.org/

Emergency Preparedness in Dependency Courts: Ten Questions That Courts Serving Abused and Neglected Children Must Address
http://www.icmeducation.org/katrina/chapter2.html

**Guidelines for Pandemic Emergency Preparedness Planning:
A Road Map for Courts**
http://www2a.cdc.gov/phlp/docs/Judiciary%20-%20BJA%20Road%20Map%20for%20Courts.pdf

33. **Key decision makers, such as state, city and public health officials, should have training in ethical decision-making to assist children and families in crisis as a dimension of pandemic preparedness.** Public health and/or national security funding should be dedicated to developing this skill set in officials and employees in systematic ways. The CDC's "Ethical Considerations Checklist" provides one viable starting point for exploration and discussion. (See *Appendix I* for additional ethical and legal resources.) *(PHP Capability 7: Mass Care; PHP Capability 1: Community Preparedness).*

34. Behavioral health professionals may be called upon or feel morally compelled to provide professional services across state lines, including states where they do not hold a license. Some jurisdictions have passed legislation waiving such licensure and liability claims as a way to incentivize behavioral professionals' participation in disaster response, especially in areas that suffer from shortages of these professionals. **State governments should consider implementing "Good Samaritan" measures in their jurisdictions to provide maximum flexibility to behavioral health professionals who want to assist children and families in pandemic situations.** *(PHP Capability 15: Volunteer Management; PHP Capability 6: Information Sharing; PHP Capability 3: Emergency Operations Coordination; PHP Capability 2: Community Recovery)*

35. During H1N1, healthcare labor organizations filed lawsuits to contest employer-mandated vaccination policies. During SARS, workplace mandates penalized infected and ill employees who were unable to return to work in a timely manner. **To limit workplace conflicts that compromise care for children and families, a pandemic-related federal agency should convene a meeting to expand local solution options from dichotomous, adversarial positions to a broad menu of pragmatic approaches.** The CDC or National Academies might be the appropriate group to convene this meeting. *(PHP Capability 6: Information Sharing; PHP Capability 3: Emergency Operations Coordination; PHP Capability 2: Community Recovery)*

Considerations for Pandemic Planning in Kentucky

30. Primary care providers deliver pediatric healthcare in many rural communities across the nation. However, there is a shortage of primary care providers in some areas of Kentucky, and some families get primary healthcare from emergency departments. **Behavioral health screening protocols will need to be disseminated to these healthcare delivery settings, and they should be treated as *defacto* pediatric primary care sites** *(PHP Capability 7: Mass Care; PHP Capability 1: Community Preparedness)*.

37. In many Kentucky communities, internet services are either unavailable or unreliable. **Phone trees were identified as a viable mode of communication in crisis situations and may be a preferred method for pandemic risk communication message delivery to families and children living in rural areas**. Organizations like the Kentucky Outreach and Information Network (KOIN) are recommended because they identify methods of risk communication for vulnerable populations that are specific to their unique needs *(PHP Capability 4: Emergency Public Information and Warning; PHP Capability 6: Information Sharing)*.

38. **Synchronous service delivery via telemedicine services is a reimbursable alternative in pandemic situations in Kentucky by all private insurers and should be utilized during periods of pandemic and social distancing to ensure continuity of behavioral healthcare**. The Kentucky Department of Insurance policy language is quite broad and states "a health benefit plan shall not exclude a service from coverage solely because the service is provided through telehealth and not provided through a face to face consultation if the consultation is provided through the telehealth network established under KRS 194A.125" (KRS 304.17A-138, p. 1). This legislation mandates that behavioral health telemedicine encounters be reimbursable by Kentucky's private, third-party providers, and allows that services can be delivered by a larger pool of qualified behavioral health professionals than what is provided in the Medicaid regulation. These approved providers include: psychologists, psychological associates, licensed clinical social workers, psychiatric nurse practitioners, marriage and family therapists, and psychiatrists. All of these provisions are based on the following definition of telehealth services "use of interactive audio, video, or other electronic media to deliver healthcare" (KRS 45A. 605, p.29). This means that store and forward technologies or audio-only applications (i.e., phone counseling) are disallowed as reimbursable encounters and would not be viable alternative service delivery methods. *(PHP Capability 4: Emergency Public Information and Warning; PHP Capability 6: Information Sharing)*.

39. In Kentucky, current Medicaid regulations list behavioral health evaluation and consultation services delivered via telemedicine as a covered expense if provided by a physician, nurse practitioner, physician's assistant or community mental health center (required provider credentials not specified; 907 KAR 3:170). Furthermore, the majority of behavioral health services delivered at community mental health centers are NOT provided by medical personnel. For this benefit to be adequately realized, delineation of the required credentials of providers in community-based centers should be developed. Since the majority of behavioral health services are provided by non-physicians, this stipulation will limit the use of other professionals in a pandemic unless an emergency regulation was

executed to amend this order. The regulation states "for a member under the age of 21 years…individual psychotherapy CPT codes 90804 through 90809 may be billed as a telehealth service if provided by a psychiatrist" (907 KAR 3:170, p. 2). The reality in Kentucky and most states is that psychiatrists focus primarily on psychopharmacology and the majority of behavioral health services are delivered by other disciplines. **A policy that qualifies an expanded list of providers (disciplines other than psychiatry) for reimbursable service delivery in times of pandemic crisis should be developed so that needed behavioral health services can be delivered to low-income children and families in a manner consistent with private health insurance procedures in Kentucky** *(PHP Capability 2: Community Recovery; PHP Capability 7: Mass Care; Capability 1: Community Preparedness).*

40. **In Kentucky, school-based Family Resource and Youth Service Centers (FRYSCs) provide psychosocial and material assistance to at-risk families. FRYSCs may be important partners in pandemic planning and response in Kentucky, but are currently underutilized in these efforts.** According to the results of this field work, it appears that they are underutilized in disaster plans, but are eager to partner with others to address the needs of their constituencies. In other parts of the country the FRYSC model may not exist, but there are other entities that can be utilized in a similar manner *PHP Capability 6: Information Sharing; PHP Capability 4: Emergency Public Information and Sharing).*

41. Kentucky borders seven other states; this creates inter-jurisdictional issues regarding coordination in border regions and for populations that move back and forth across state borders. These seven states differ culturally from one another and from Kentucky, making coordination difficult. Kentucky responses should consider the impact of these states on the planning and response of bordering Kentucky counties. These types of interjurisdictional differences are evident between other state and at national borders. **Interjurisdictional differences require coordination with adjacent state and national pandemic planning authorities on issues related to school closure procedures, vaccine distribution approaches, designation of vulnerable populations, consistency of risk communication, social distancing measures, professional licensure and credentialing, and insurance reimbursement policies regarding alternative service delivery** *(PHP Capability 3: emergency Operations Coordination; PHP Capability 4: Emergency Public Information and Warning; PHP Capability 15: Volunteer Management; PHP Capability 1: Community Preparedness) .*

42. The Kentucky Chamber of Commerce has been active in H1N1 planning and response, and has participated in other health activities sponsored by the Kentucky Department of Public Health. Long-term anticipation of a

pandemic is quite difficult for business leaders who have immediate and short-term planning considerations as priorities. Bringing businesses on board for pandemic planning will require very clear and persuasive planning materials, including specific economic models that convince business leaders to see the importance of participating in pandemic planning and response. **Incentivizing businesses to create family-friendly pandemic preparedness planning might include strategies such as federal or state tax credits, assistance with federal or state employment law compliance, or special recognition for proactive contributions to pandemic response.** The following are examples of successful strategies utilized around the country that could be replicated *PHP Capability 2: Community Recovery; PHP Capability 1: Community Preparedness)*

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Business Pandemic Influenza Planning Checklist
To assist businesses in pandemic planning with an emphasis on protecting employees' health and safety, as well as limiting the negative impact to the economy and society, the Department of Health and Human Services (HHS) and the CDC have developed a checklist. It identifies important, specific activities large businesses can do to prepare.
http://www.flu.gov/professional/business/businesschecklist.html

Business Not As Usual: Preparing for a Pandemic Flu
Public Health – Seattle and King County (Washington) have downloadable resources to facilitate business and government preparedness. Topics include:
- Business Pandemic Influenza Planning Checklist
- Continuity of government issues that should be addressed by local agencies
- "It's Not Flu As Usual" Brochure
- Guidance on Preparing Workplaces for an Influenza Pandemic
- Preventing the Spread of Influenza
- Guidance for employers on returning to work after influenza illness
http://www.kingcounty.gov/healthservices/health/preparedness/pandemicflu/video.aspx

Commonwealth of Virginia Emergency Operations Plan
Pandemic Influenza Plan Annex Volume VI (2009)
The Virginia Emergency Operations Pandemic Influenza Plan (Volume VI) states that the Virginia Employment Commission will "assist private-sector workers who may lose jobs or be unable to work" because they are ill or a family member is ill and they need to stay home to care for them. Families who experience pandemic-related financial instability may access emergency unemployment benefits, receive information on employment services, crisis counseling or referral, and resource brokering.
http://www.vaemergency.com/sites/default/files/COVEOPVolumeVIPanFluPlanSeptember2007Version91609.pdf

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43. Kentucky is unique in sustainability and duration of public health leadership. The Commissioner of Public Health has been in his job for many years, as have many other top agency leaders. This is unique nationally, and this stability provides for the continuity of processes and follow-through on innovations. Public health leaders also happen to be pediatricians, and this provides for more sensitivity toward children. Based on the high rates of turnover in public health leadership in the U.S., **it is especially important to ensure child-specific knowledge and practices are institutionalized for pandemic and disaster response planning in the event of public health leadership changes** *(PHP Capability 6: Information Sharing)..*

44. Kentucky Educational Television (KET) provides a statewide footprint for risk communication messaging and pandemic response directions. This statewide media coverage allows for greater ease in disseminating consistent messages. Similarly, there are only two major newspapers that cover most of the state, so print messaging can be consistent. **KET, the *Lexington Herald-Leader* and the *Louisville Courier-Journal* should be utilized fully in all pandemic communications, and representatives from these organizations should be included in planning and response efforts.** This would ensure that they are fully briefed in current pandemic strategies at all times *(PHP Capability 4: Emergency Public Information and Warning; HP Capability 6: Information Sharing).*

45. **Kentucky has developed a bench book for judges, "Public Health Law Judicial Reference Guide for Kentucky Courts," that addresses public health law during a disaster or pandemic that should be integrated into judicial education programs** *(PHP Capability 3: Emergency Operations Coordination).*

**Public Health Law Judicial Reference Guide
For Kentucky Courts**
http://www2a.cdc.gov/phlp/docs/KY%20Benchbook-Final.pdf

Project Background and Methods

Summary of Project Activities

Evidence-Informed Guidelines for Child-Focused Pandemic Planning and Response is the result of an extensive and systematic investigation into the impact of pandemic events, particularly disease containment strategies, with regard to children and their families. This exploration examined the psychosocial effects of pandemic events on children, families and the professionals who care for them before, during and after these events. These evidence-informed guidelines include data from the extant literature, experiences and observations of professionals, parents, and youth, and a review of relevant documents.

The significance of this work has become clear in the aftermath of the recent H1N1 pandemic. Although the overall effects of this outbreak were limited, it provides a cautionary lesson, as noted by World Health Organization (WHO) Director-General Dr. Margaret Chan (2010):

> This pandemic has turned out to be much more
> fortunate than what we feared a little over a year ago.
> This time around, we have been aided by pure good
> luck….Had things gone wrong in any of these areas,
> we would be in a very different situation today.

Worldwide, the WHO estimates that 18,449 people died from laboratory confirmed pandemic H1N1 infections, but the true death toll is thought to be much higher because most victims were probably never officially tested. Further, the Writing Committee of the WHO Consultation on Clinical Aspects of Pandemic (H1N1) 2009 Influenza concluded their summary of "lessons learned" with humility equal to the Director-General's:

> A large amount of information about the natural history
> and clinical management of 2009 H1N1 virus infection
> has been obtained in a remarkably short period of time,
> *but considerable gaps remain*. The uncertain evolution of
> this virus among humans and potentially other species
> highlights the need for continued virologic surveillance…
> [P]*ublic health efforts to reduce risk factors and to identify
> at-risk populations for the purpose of providing
> immunizations and early care, including the use of
> antiviral drugs, should focus on social as well as clinical
> factors* (emphasis added). (WHO Writing Committee,
> 2010, p. 1708).

Although pandemic is not new to the U.S. or other populations, each pandemic presents novel characteristics that require immediate but flexible public health

responses. The CDC has developed one model of the next avian influenza outbreak, estimating 89,000-207,000 American fatalities and 47 million additional illnesses with direct (illness- related) costs of $71-$416 billion. The nature of the virus will determine the most vulnerable population groups, but infants, children, and adolescents are likely to be among the most affected. These child victims may also prove to be powerful disease vectors, spreading the virus through their ubiquitous presence in daycares, schools, hospitals, and in other settings where they live, attend school, and play. Efforts to contain the spread of future pandemics are likely to include confinement techniques, including patient isolation and quarantine. Although the terms "quarantine" and "patient isolation" are used interchangeably in much of the literature, they actually represent distinct concepts, and in application, may prompt differential emotional responses in those affected.   Patient isolation – the separation of individuals who are known to have a specific disease – is a less drastic alternative to quarantine, which refers to isolating and restricting the movement of people who are not yet ill, but have been exposed or are at risk of exposure to an infectious agent. Exploration and understanding of the biopsychosocial effects of quarantine and patient isolation in the context of pandemic disease confinement is important for understanding the types of supportive interventions that may be necessary to prevent and address the negative responses to forced confinement or isolation.

The renowned twentieth-century sociologist Robert K. Merton (1936) anticipated the manifest and latent challenges that modernity, urbanization, and exploding technological advances would present to policy makers and social planners, especially those operating in democratic nations. According to Merton, the explicit and rational are only part of a more complex context generated by social problems under consideration, for a whole host of unpleasant reasons. He warns those planning to tackle immense public problems that well-intended policies and plans inevitably generate unintended consequences because: (1) leaders are under great pressure to act decisively and swiftly with limited understanding of the problems to which they are responding, including limited knowledge of the nature and extent of resources at hand; (2) error is an unavoidable component of all social action and errors specific to rational planning are often discoverable only after plans are implemented; and (3) planners' rational strategies are more likely to address the desired, proximate outcomes of their actions — the usual definition and structure of a plan — and this focus will usually exclude significant attention to the desirable or undesirable remote outcomes that cascade from those actions and proximate outcomes.

When we consider pandemic preparedness planning, it is not difficult to gauge the relevance of Merton's analysis. The failure to rigorously anticipate and address probable or foreseeable outcomes of pandemic response plans may significantly undermine the overall implementation and effectiveness of any containment strategy. Social distancing strategies and mandated confinements such as isolation and quarantine, which are designed to contain disease transmission, might instead create unanticipated and additional problems for the

persons who are confined, their families, and the public. Canada's experience with SARS pandemic is instructive regarding the unanticipated consequences for policies and practices for families and children. The WHO's emphasis on the powerful, but only partially understood, set of social factors that shape the effectiveness of pandemic response as well as the dire predictions of future potential influenza pandemics by the CDC provide a powerful argument for the serious consideration of Merton's cautionary approach. This project has explored the obvious and nuanced, anticipated and unanticipated, expected and capricious responses of children and families to pandemic to develop these Evidence-Informed Guidelines to assist planners in preparing for and responding to future pandemics.

Project Assumptions and Principles

Evidence-informed guidelines for child-focused pandemic planning and response must be deemed beneficial to both professionals and the constituents they will impact. Evidence-informed guidelines must have translational utility in the "real world" (e.g., be practical and realistic for implementation). Thus, **translational utility is paramount.**

Coincidentally, the 2009-2010 H1N1 pandemic was occurring as field work was being planned and initiated. The pandemic served as a "natural experiment," in that it allowed the investigators to discover how preparedness and planning approaches developed in the U.S., Canada and Mexico actually worked when faced with a true pandemic.

Both the exploratory nature of the research and the development of the H1N1 pandemic required that all aspects of the project be necessarily flexible and iterative to maximize ecological validity and translational utility. The project was also necessarily democratic and inclusive: all members of the research team were expected and encouraged to contribute ideas and feedback to the group.

To ensure the project achieved translational utility and maximized ecological validity, the following assumptions guided all aspects of the research and analysis:

1. Activities were designed and tools developed, enhanced and/or discarded according to: (a) **their relevance to the goals of the grant**; (b) their **focus on children and families**; (c) implications for the **behavioral health dimensions** of quarantine and isolation; and (d) **feasibility**, including state of the science, project team capacities, and perceived availability of sample.

2. **A "follow the virus" method was utilized.** The 2009-2010 H1N1 pandemic occurred just as the research team was planning and beginning the fieldwork for the project. This provided a unique opportunity to use it

as a naturally occurring experiment to study and understand pandemic planning and response. A "follow the virus" sampling strategy was developed to do so: the team used a map of the northern hemisphere to catalogue a wide range of pandemic events so that experience-close and experience-distant locations could be identified and selected. U.S. sites were included that had the highest rates of H1N1 confirmed cases pediatric deaths, and overall deaths attributable to influenza-like illness as of December 12, 2009. Additionally, Mexico was selected because this was the epicenter of the initial H1N1 outbreak, and Toronto, Canada was included as a study site due to the significant SARS outbreak experienced in that city in 2003.

3. **Efforts were made to maximize ecological validity.** No *a priori* assumptions were made about who would ultimately be in a sampling group. By using this sampling scheme, locations were selected based on the intensity of the pandemic experience. Due to the variations in each locale (based on culture, standards of practice, and symptom expression), samples were defined so as to maximize ecological validity. Therefore, local knowledge and practices took precedence over global definitions of population subgroups.

4. **Geographic distribution was desirable.** A concerted effort was made to recognize the distinguishing factors of a variety of environments to identify areas of convergence and divergence. The variety of geographic environments included rural, suburban and urban, different parts of the country, different parts of Kentucky, and a range of natural environments influencing culture (mountains, delta, farmlands, etc.).

5. **Cultural diversity was desirable.** To identify the essential core elements of evidence-informed guidelines, the common requirements of a range of populations need to be clearly understood. Key informants and experts who could elucidate specific needs of particular populations, as well as understand the shared requirements across populations, were targeted.

6. **Vulnerable populations must be broadly defined.** Vulnerable populations may include communities and populations who are disenfranchised by virtue of socioeconomics, ethnicity or race, religion, geography, age, or physical, cognitive or emotional disability. However, during pandemic events, other groups are also vulnerable, including persons with chronic medical illnesses, infants, children, adolescents, and pregnant women. In addition, children in out-of-home placement, state custody, or living in residential settings may lack caretakers who will protect and advocate for their needs with the same degree of fierce devotion as parents, leaving them exposed to ethical and legal inequities, in addition to the medical dangers posed by the pandemic.

7. **A range of expertise was desirable.** Pandemic disaster expertise is rare, and when it does exist is usually focused on disease process and containment and rarely on psychosocial effects of and responses to pandemic. Thus, experts from related domains (e.g., behavioral health, pediatric disaster, infectious disease, public health) were included. Expertise was recognized as potentially emerging from formal and informal paths of training and experience and the expert database included political appointees, new hires and lifelong civil servants, government and nongovernment employees, on-the-ground service providers, and citizens of all ages. Relevant experience was dictated by the indeterminate realities of pandemic disease and the probabilistic nature of planning and response. In this situation, experts may include many persons who are not formally or officially labeled as such, but persons who offer valuable information. Therefore, this project has defined expertise across the spectrum and includes persons in positions of ultimate authority, those responsible for the vanguard application of policies and protocols, and the recipients of these procedures and processes. Also included are persons who have analyzed pandemic from academic and scientific perspectives. Some of these experts hold simultaneous roles in diverse fields (e.g., a scientist who is also a public health official). Interview and focus group respondents were selected and assigned as key informants in a domain that best characterized their relevance to this study.

8. **A convergence approach was preferred.** The process of data collection and interpretation was enhanced by using a variety of methodological approaches and assessments of convergence and dissonance of themes strengthened by variation and triangulation of research methods (Kuper, Lingard & Levinson, 2008). The research process was guided by a need to verify emergent data by identifying areas of convergence across multiple study sites and methodologies. Quantitative and qualitative methods in the form of surveys, focus groups and interviews, were all utilized in both the initial data collection and feedback stages of the project. Examination of areas of convergence ensured that novel findings or phenomenon were thoroughly investigated. Data collection, feedback and interpretation were intentionally iterative: emerging information was shared at regular research team meetings for verification and further investigation; field notes were immediately posted on a secure server accessible only to study personnel for review to inform subsequent waves of data collection from key informants; and interpretation of findings was a collaborative and inclusive process involving all team members.

9. **Confirmability required a broad range of sources and methods.** The triangulation of methods approach was utilized to ensure that measurement bias was minimized and to enhance convergence of evidence across multiple methods and respondent groups. Data were

collected from a range of different respondents and key informants throughout the sample area, and feedback was solicited from key informants with a broad range of experience and expertise. This convergence of evidence across multiple methods and respondent groups enhanced the representativeness, reliability and validity, objectivity, potential replicability, and utility of the findings and evidence-informed guidelines.

10. **Research methods and tools were informed by the extant literature.** Although a comprehensive review of the literature was conducted as the first stage of the project, this research area is relatively new and the team found it necessary to develop its own tools and approaches. Wherever possible, standardized screens and instruments were included if they proved relevant and useful for the phenomena under investigation. The process of measurement development respected standard requirements for psychometric construction found in social science research. For example, survey development included attention to question ordering effects, item exclusivity, and clear and consistent use of key terms (Sudman & Bradburn, 1988). Focus group and interview questions were formatted according to recommended approaches, including the use of a semi-structured interview schedule (Ehrmann & Etter, 1997). The development of the *State Plan Review Template* and the *Professional Organization Standards Review* were guided by standard content analysis guidelines.

11. **Consistency across domains, methods and researchers was preferable.** Consistency in level of detail, content addressed, and presentation of information (language, terminology, matrices, etc.) was possible, while also enabling and supporting targeted approaches to different members of the sample. Experts and key informants were encouraged to review and provide feedback in their areas of knowledge and expertise first and foremost. Consistency in how each recommendation was presented, the manner in which feedback was recorded and documented, and the specific areas for rating the feedback was rigorously maintained.

12. **Confidentiality and anonymity were privileged as essential components of the data collection process.** Participants in this study were involved in the data collection process in a way that is protected by human subject protection regulations and standards. All protocols and procedures were reviewed and approved by the University of Kentucky's Institutional Review Board and all study personnel were required to obtain human subject protection training and certification. It is highly probable that these confidentiality and anonymity assurances enhanced the candor of the interviews and comments and the validity of the data collected. In accordance to the project's Institutional Review Board guidelines, the

names, employers (where applicable) and specific locations of respondents have been disguised or omitted and will not be tied to future findings.

13. **Conceptual rigor was fundamental.** The distinctive needs of specific populations, geographic regions and professional fields could not be comprehensively articulated in evidence-informed guidelines. Thus, a strong conceptual core that could be adapted as appropriate to the specific needs of individual populations, regions or professions was necessary to maintain and maximize translational utility.

Project Phase 1

Literature Review (Deliverable 5a: *Best Practices Guidelines for Pandemic Disaster Response: A Social Behavioral Evaluation*). A comprehensive literature review and content analysis of historical and contemporary empirical reports, accounts, policy studies, and research studies, analyzing extant knowledge relevant to the disease containment strategies including isolation and quarantine of children and families was conducted. (See *Appendix D* for additional information.) The review identified core concepts for pandemic preparedness and response, identification of relevant domains of inquiry, recognition of gaps in the literature, and identification of areas of related literature. This document examined work in the areas of public health, social psychology, behavioral health, healthcare, and law and ethics. Throughout the literature review phase, the research team met frequently to engage in discussion for the purpose of reductive processing to ensure the focus of the review and analysis remained on children and families experiencing disease containment strategies, to ensure that no area of significance was overlooked, and to inhibit any expansion of research domains beyond the bounds of feasibility and effectiveness.

Toolkit Development (Deliverable 5b: *University of Kentucky Behavioral Health Research Toolkit*). Drawing on the literature review, the research team conceptualized, constructed, and piloted a range of survey, focus group and interview schedules targeted for key respondents who were determined to have significant knowledge of pandemic experiences. Additionally, the team constructed content evaluation tools to assess existing preparedness plans in addressing the needs, particularly the behavioral health needs, of families and children. These instruments were developed following a rigorous process of analytic reduction of the findings from the extant literature to critical domains for empirical investigation within the scope of the project goals. The Research Toolkit was developed to: (1) identify and query officials who have important decision-making roles in implementation of disease containment strategies and have formal and informal evaluative knowledge about these events; (2) collect information from families and children who have personal experiences with pandemic response strategies and knowledge of the sequelae of those

experiences; (3) assess the perceived relevance of national and state level planning (as it relates to children and families); (4) extract data from existing documents to facilitate formal evaluation of the child-specific pandemic planning process across settings and sites; and (5) assess the function of systems of care, specific to children (e.g., schools, public child welfare, courts of justice) in quarantine or isolation situations.

Expert Database (Deliverable 5c: *University of Kentucky Best Practices Guidelines for Pandemic Disaster Response Expert Database*). The Expert Database was the result of the first phase of field work and documents the methods used to collect data, the expertise represented in the database, and a summary and description of all data collected. This database includes the experiences, knowledge and recommendations of a diverse set of 2,608 experts who provided information on a broad range of critical problems and concerns relevant to the psychosocial responses of children and families to pandemic. This dataset represents the findings from surveys, interviews, and focus groups from five U.S. states identified through the "follow the virus" method, as well as Kentucky, and select cities in Mexico and Canada. In addition, the expert database includes several systematic content analyses of pertinent documents and records, including state pandemic plans and professional behavioral health organizations' pandemic or disaster response guidelines. (See *Appendices A and B* for description of expert database.)

Report of New Evidence (Deliverable 5d: *A Comprehensive Analysis of Pandemic and Quarantine Responses for Families and Children: Integrative Report of New Evidence, Preliminary Findings*). The fourth phase of the project continued the analysis of the Expert Database to more fully understand children's experiences of isolation or quarantine, the decision processes implemented by key persons associated with these disease containment measures, and lessons learned from the SARS epidemic of 2003 and the 2009 H1N1 pandemic outbreak. This report presents the results and analysis of the data collected on pandemic planning and response from professionals (public health officials, healthcare workers, behavioral health professionals, legal experts), consumer groups (families and children), and content analysis of the District of Columbia and all 50 U.S. state pandemic plans, the SARS Online Support Network, and a Professional Organizations Standards Review for six national behavioral health professional groups. This extensive data collection process resulted in an understanding of broad and critical problems and concerns across diverse respondents and yielded important information about the responses of children, families and professionals to their experiences of pandemic, isolation, or quarantine, but no attempts were made to identify or portray cause-and-effect relationships, or to generalize beyond the sample parameters.

Response from the Field on Findings and Recommendations (Deliverable 5e: *New Directions in Pandemic Response: A Roadmap to Resilience*). Based on findings from extensive fieldwork and data collection in the U.S., Mexico, and Canada, preliminary evidence-based recommendations were drafted to address the current deficits in child-focused pandemic planning and response and provide testable guidelines for successful quarantine and isolation that can be used to reduce the potential negative psychosocial effects of disease containment strategies on children and their families. These preliminary evidence-based recommendations were subjected to national and international pilot testing and expert review to determine the utility and viability of the guidelines. Results of the review are presented in Phase 2 (Deliverables 5g and 5h) of the project.

Project Phase 2

Development of Best Practice Guidelines (Deliverables 5g and 5h: *Best Practice Guidelines for Pandemic Disaster Response: Response from the Field, Part 1 and Part 2*). Feedback from experts and key informants on the findings and preliminary recommendations comprised this phase. The purpose of this "response from the field" stage of the project was to collect feedback from experts and key informants to confirm the understanding of the findings and interpretation of them into recommendations. The feedback response phase included three components: (1) feedback on the overall findings and recommendations from national and international level experts and stakeholders; (2) feedback from Kentucky stakeholders on the utility and relevance of the proposed findings and recommendations to identify the required adaptations and modifications for implementation at the state level; and (3) feedback from representatives of national professional organizations not previously queried. Emphasis was placed on understanding how general guidelines could be adapted for specific regions and Kentucky served in this project as the example of how this adaptation might be achieved. (See *Appendix G* for instrument template used for feedback response.)

Finalization of Best Practice Guidelines (Deliverable 5i: *Evidence – Informed Guidelines for Child-Focused Pandemic Planning and Response*). The final development of the Evidence-Informed Guidelines for Child-Focused Pandemic Planning and Response yielded the current document. This is the culmination of the initial data collection phase, analysis and interpretation of the data, and two rounds of field-testing of findings.

Methods

Multi-Modal and Mixed Methods Approach

This project has been characterized by the consistent utilization of multi-modal approaches to data collection and analysis in all phases of study. This mixed methods approach ensured opportunities to maximize ecological validity through inclusion of a range of sources of data, enhanced ability for convergence and confirmability of data across and among sources, and required a high degree of consistency across sources and respondents as well as among team members. The project was also characterized by an iterative and inclusive process that included review and input from all members of the team in every phase and at every step. Further, the project valued and seriously considered the multi-disciplinary perspectives offered by team members and respondents, and assumed that the exploratory nature of the study necessitated an evolving, responsive, flexible approach to the data and findings as they emerged.

The mixed methods approach utilized both quantitative and qualitative approaches to data collection and analysis through surveys, focus groups and interviews soliciting input in the form of ratings, multiple choice responses and open responses. For example, in developing the measurement instruments for the Toolkit, the project team developed at least two methods for data collection so that convergent validity might later be evaluated. This approach was also evident in the use of original and standardized measurement instruments. While new tools were developed as needed, whenever possible existing standardized measures were utilized if they proved the most relevant and useful for the phenomena under investigation. The mixed method approach utilizing survey, focus group and interview data was employed during all phases of field work, the initial data collection, and development of the Expert Database. It was evident and used across all types of respondents as well -- professionals in the fields of public health, healthcare, behavioral health and law and ethics, as well as youth and family consumers. The mixed methods approach was also reflected in the initial and ongoing reviews of the relevant literature: a range of disciplines (public health, medicine, behavioral health, social psychology, law and ethics, government policy, etc.); types of literature (empirical studies, pilot studies, exploratory investigations, first person accounts, theoretical propositions, editorials, cautionary recommendations and practical guidance); sources of literature and data (academic journals, popular media, professional organization publications, public health information, government policy, case law, hotline transcripts, etc.) and different pandemic and disaster scenarios (SARS, H1N1, Avian Flu, natural and man-made disasters, table-top exercises, etc.) were examined with equal interest.

Data analysis continued the mixed methods approach. Descriptive analysis of all the data was conducted at every phase of the study to understand the number, type, demographic characteristics (age, gender, race/ethnicity, socioeconomic

status, etc.), geographical and professional distribution and pandemic exposure and experience of the respondents, as well as the distribution and description of the data. As allowed, inferential statistical approaches were subsequently utilized. Qualitative data (e.g., field notes) were analyzed using standard categorization strategies. Documents and websites were analyzed using standard content analysis approaches. Data analysis generated findings that converged across multiple study sites and methodologies. Findings with high levels of convergence were considered more significant than those with low levels. Generally speaking, when analysis revealed only a single source, this data was not utilized to generate a finding.

The inclusion of the feedback response phase also incorporated a mixed methods approach. Reactions to the preliminary recommendations by experts and key informants served to strengthen representativeness, reactivity, reliability, potential replicability of the findings (Miles & Huberman, 1994), and bolstered validity, minimized bias, and enhanced the practical utility of the recommendations. The multi-modal process enabled the various elements of the recommendations as well as the various populations affected to be considered. Both quantitative and qualitative data were compared for convergence and dissonance. As with other stages of this project, the process continued to be iterative and inclusive, with all team members participating in all aspects of the work (planning, development of instruments, field work, documentation, data analysis and interpretation) and developing means for triangulating findings to facilitate critical review and confirmability (Farmer, Robinson, Elliott, & Eyles, 2006).

Standardization of Process and Content Components

Standardization across phases, team members, respondents and types of data was accomplished in several ways. Toolkit instruments followed a similar structure, moving through various domains, asking similar questions in the same domain, and providing opportunities for quantitative and qualitative responses. Semi-structured interview schedules were used to guide focus group and interview discussions to ensure that all respondents from all disciplines were queried across a number of domains. The domains determined to be most germane to the project goals following a reductive analysis of the extant literature included the following:

- Behavioral health screening, assessment and service provision;
- Psychosocial responses and experiences of children and parents to disease containment and pandemic;
- Psychosocial responses and experiences of healthcare professionals and behavioral health providers to disease containment and pandemic;
- Risk communication to children, families, professionals, and the community;

- Inter-disciplinary coordination and collaboration between public health, healthcare, behavioral health and emergency responders;
- Legal issues, especially potential conflicts between parental rights and public health laws, regulations, and orders;
- Ethical issues, with special attention to the planning for or achievement of just and fair outcomes in disease containment concerning families and children, especially those from vulnerable populations.

Templates for field notes ensured inclusion of and attention to the same process and content areas across domains, disciplines, respondents and types of data. These tools were utilized to review documents as well with the development of the *State Plan Review Template* and the *Professional Organization Standards Review*, to guarantee standardization of review across documents and reviewers. In addition, all documents were reviewed by at least two team members and in areas lacking agreement, re-review was conducted until consensus was achieved.

Standardization was also apparent in the approach to data collection during the initial and feedback phases. Surveys were available online through SurveyMonkey© in order to standardize collection formats, provide a user-friendly format, and provide consistent presentation of the queries to respondents. Paper surveys were a printed version of the online SurveyMonkey© instruments.

The team devised a uniform approach for feedback collection as well. Templates were developed for presentation of the preliminary recommendations via PowerPoint or webinar, or paper versions that could be used in person. Feedback instruments assessing recommendations were developed to include ratings and other quantitative responses, as well as qualitative open-ended responses. A template for documentation of the feedback process was also created to ensure continuity of organization and level of detail of reported findings. This standardization allowed for maximum flexibility and efficiency in reaching expert communities and constituents in a variety of locales, environments and through a range of media to enable field work to occur through in-person, webinar and telephone presentations with individuals and small and large groups.

Protection of Human Subjects

All protocols, procedures and materials were reviewed and approved by the University of Kentucky Institutional Review Board (IRB). Confidentiality and anonymity were privileged as essential components of the data collection process and reporting of findings. All participants in this study were protected by human subject protection regulations and standards in accordance with the IRB requirements. Findings were reported in aggregate whenever possible, and when not in aggregate, specific identifying data was omitted to preserve the confidentiality of the respondents. Geographic locale, professional discipline or

level of expertise was reported only as necessary to inform the finding or recommendation. All study personnel were required to obtain human subject protection training and certification in accordance with the University of Kentucky IRB standards.

All participants were voluntary and agreed to consent for participation either by signing in person or by checking the "I accept or assent" box online (a waiver of signed informed consent was secured from the University of Kentucky IRB for the online surveys). Consent required action be taken by the participant and the informed consent documents were all approved by the University of Kentucky IRB.   Several versions of the informed consent/assent documents were developed as needed for specific populations – professionals, parents and youth and persons speaking Spanish – and approved by the IRB. Translation of the informed consent/assent into Spanish was completed with the approval of and in accordance with IRB requirements.

Sample Phase 1 - Initial Data Collection

Ecological validity was paramount and no *a priori* assumptions were made about the sample at any phase of the project. A "follow the virus" methodology based on the intensity of the H1N1 pandemic for children was used to identify areas for study that experienced high rates of infection. The "follow the virus" sampling strategy identified mortality and morbidity rates in North America based on the MMWR (Morbidity and Mortality Weekly Report) by the CDC. Sampling criteria included the following rates for the first six months of the initial H1N1 outbreak (as of December 2009):

- Highest number of pediatric deaths
- Highest number of overall deaths
- Highest number of confirmed cases of H1N1

Based on this sampling strategy the following states were identified as target sites for data collection: Arizona, California, Florida, New York and Texas (See *Appendix E* for more information). In addition, Mexico was included for its high rates of H1N1 as the epicenter of the initial outbreak, and Toronto, Canada was included for its experience with the SARS pandemic. Kentucky was also a target area, as it served as the pilot study site for the final phase of the project. To maximize ecological validity, local knowledge and practices were given precedence over global definitions of population subgroups, and variations in culture were expected and respected. While the five U.S. states identified from the "follow the virus" method were the focus of respondent recruitment, participants from all over the country were included if their experiences or expertise seemed relevant to the project goals.
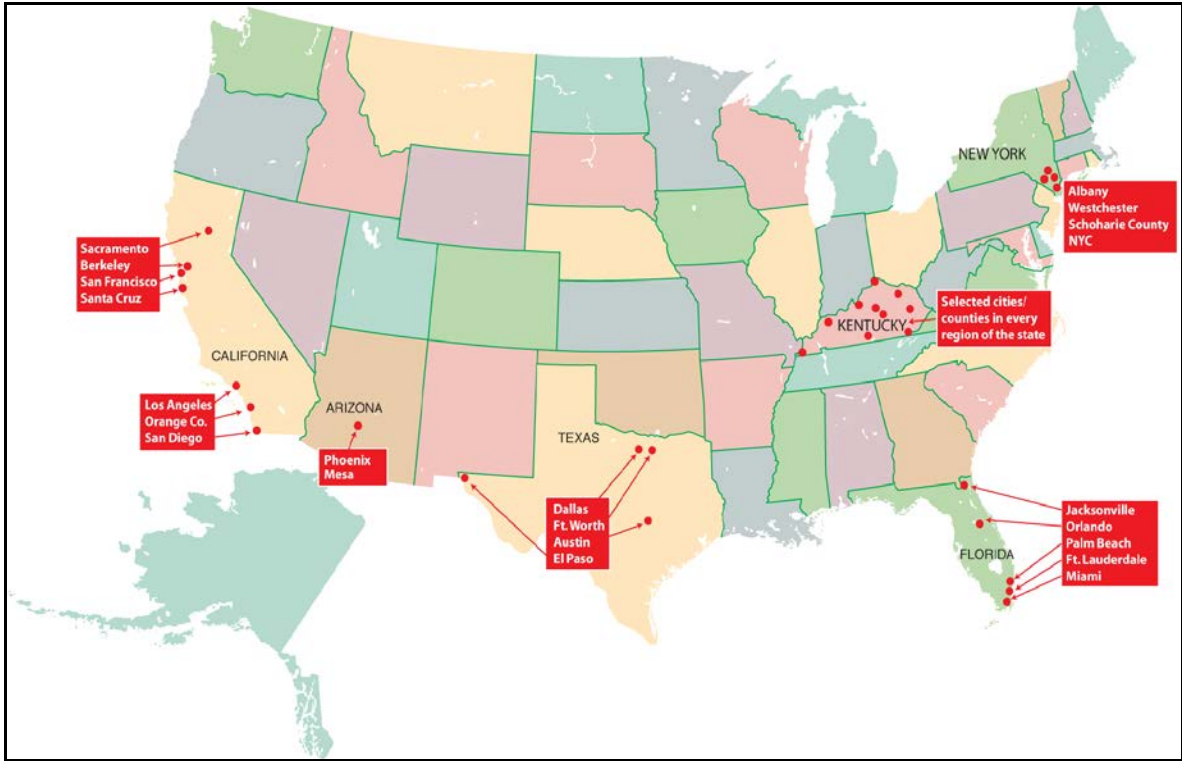
Map of United States Sampling Sites

Map of Mexico Sampling Sites

Map of Canada Sampling Site

The initial sample of professionals was recruited using several methods. Survey respondents in behavioral health and healthcare were invited to participate via e-mail and postcard invitations using addresses obtained from purchased membership lists. Electronic announcements and invitations to participate were sent from professional organizations to their membership after approval from their governing boards or executive committees. Focus group and interview respondents in behavioral health and healthcare were recruited through the survey with a final question asking if they wished to participate in a focus group or interview. If so, they were directed to an unlinked form, where they provided contact information that project personnel used to facilitate a follow-up interview, either face-to-face or by telephone. In addition, behavioral health, healthcare, public health and law and ethics professionals were also invited to participate in focus groups or interviews through direct outreach to identified experts in the areas of pandemic planning, disaster mental health, pediatric disaster response and public health. A snowball approach was utilized and respondents were asked to identify others who might be interested in or appropriate for inclusion in the study.

Parents were adults between the ages of 18 and 99 who had children ranging in age from birth to 22 years old. Parents were recruited for surveys, interviews and focus groups through broad-based advertising in major newspapers (print and online) and through website advertising in all target areas. Flyers recruiting

parents were e-mailed or hand-delivered to local health departments, schools, private and public medical offices, and distributed to attendees at professional conferences. The Kentucky Division of Family Resource and Youth Services Centers also forwarded an e-mail invitation to parents throughout the state. The same process was used to solicit volunteers who completed the survey and wanted to participate in a follow-up focus group or interview to talk more about their pandemic experiences. At the end of each parent survey, respondents were also given the option of nominating their children for participation, and if interested, were directed to a separate form in SurveyMonkey$^©$ where they provided consent for their child to participate, and contact information for the child. These youth were contacted via the e-mail address provided by their parents, and invited to participate. Youth in Juárez, Mexico, were recruited via outreach by the project's cultural consultant who sent written information home to parents with students. Once parental consent was obtained, all youth 7-22 provided an assent to participate at the beginning of each survey, focus group or interview.

All participants, parents, youth and professionals, were eligible to receive a $10 cash incentive upon completion of the survey, focus group or interview.

Sample Phase II - Field Testing

The sample for the feedback stage of the project was drawn from communities of expertise in the fields of disaster preparedness and response, children's mental health, diverse communities, and vulnerable populations. Participants in this stage were included if they were probable consumers of the evidence-informed guidelines. Informants from the original sample provided a check that interpretations of original findings were accurate; new informants provided a critical eye and additional perspectives on the original findings, preliminary recommendations and feasibility of implementation. Two hundred fifty-four (N=254) experts and key informants from professional organizations and in the state of Kentucky were identified based on their roles and responsibilities in pandemic planning and response, as well as nominations from other informants. A snowball method was utilized at this stage as well to enhance identification of expertise in all relevant domains. A breakdown of the field testing sites and the number of interviews and focus groups conducted during this phase of data collection is included as *Appendix F*.

The Kentucky sample provided insights to understanding the unique needs, resources and challenges of adapting the recommendations to a particular locale. Kentucky respondents included parents and youth, and professionals from public health, disaster response, government hospital and medical health delivery, education, child advocacy and protection, business, law and ethics, and representatives of vulnerable populations, including minority ethnic populations and geographically isolated or geographically determined communities. Consideration of the particular needs of vulnerable children in the

Commonwealth was addressed via the inclusion of key informants from Kentucky counties with low ratings in child well-being and health indicators. Vulnerable children were identified as those living in counties with high rates of child poverty, free or reduced meal eligibility, pediatric death, and poor overall citizen health. These indicators were measured based on data from the 2010 Kentucky Kids Count County Data Book (Kentucky Youth Advocates, 2010) and the Kentucky Institute of Medicine's (2007) *The Health of Kentucky: A County Assessment Report*. Based on the findings, counties which were listed among the worst ten counties for three of the four indicators were identified as Lee, Clay, McCreary, Owsley and Wolfe. Parents and youth living in these counties were particularly solicited for inclusion via outreach through the school-based Family Resource and Youth Service Centers.

All participants in the field-testing phase of data collection were eligible to receive a $10 cash incentive upon completion of the survey, focus group or interview.

Measures

Instruments used throughout the initial period of data collection, as well as during the field response phases, were developed by the research team for the project. This development of the University of Kentucky Behavioral Health Pandemic Research Toolkit was a collaborative process with all members of the team contributing. Areas of inquiry were determined based on findings from the literature review and noted gaps in the extant literature. In keeping with project principles, the Toolkit focused on the needs of children and families so as to concentrate on behavioral health responses to pandemic, and to allow for convergence of data from multiple sources (interviews, focus groups, surveys and content analyses). Domains for investigation were determined using a collaborative process involving a series of reductive analyses of findings from the literature review, justification for inclusion based on congruence with project goals and extensive discussion and review by the research team. Standardized instruments were incorporated as appropriate to measure Post Traumatic Stress responses of children (Trauma Symptom Checklist for Young Children – TSCYC© and Trauma Symptom Checklist for Children – TSCC©) and their caregivers (Parent PTSD Checklist, Civilian Version - PCL), and Secondary Traumatic Stress (Professional Quality of Life - R-IV) responses of behavioral health providers and healthcare workers. The final instrument package was designed to be utilized by a range of audiences and populations in a variety of pandemic situations (e.g., H1N1 or SARS). Instruments were adapted as needed for developmental needs (e.g., youth vs. adults), technical literacy (e.g., language used for parents vs. healthcare professionals) and language (Spanish vs. English) as well as pandemic circumstances (quarantine or isolation) and occupational locale (e.g., community-based or hospital-based).

Surveys were translated into Spanish for use in Mexico and with Spanish-speaking participants in the U.S. Cultural consultation by Mexican behavioral

health professionals working in a border area ensured that the intent and meaning of the instruments were preserved through translation. All instruments were field tested for intelligibility and respondent burden with a group of non-vulnerable persons who volunteered and provided feedback using a separate instrument designed by the team. Based on this feedback, modification to the tools was made to increase readability and cultural utility.

The Toolkit included the following instruments by population (See *Appendix C* for complete listing):

- Youth
    - Youth General, Isolation and Quarantine Surveys
    - Youth Pandemic Isolation/Quarantine Focus Group/Interview Schedules (Ages 8 – 18)
    - Trauma Symptom Checklist for Children © (TSCC, Ages 8 – 16)

- Parents
    - Parent Pandemic General, Isolation and Quarantine Surveys
    - Resource Parent General Survey
    - Parent General, Isolation and Quarantine Focus Group/Interview Schedule
    - Trauma Symptom Checklist for Young Children (TSCYC) ©
    - Parent PTSD CheckList, Civilian Version (PCL)

- Behavioral Health Professionals
    - Behavioral Health Professional Pandemic Survey
    - Behavioral Health Professional Pandemic Focus Group/Interview Schedules
    - Professional Quality of Life – R-IV
    - Impact of Events Scale (IES-R)

- Healthcare Workers
    - Healthcare Worker General and Pandemic Surveys (Community-Based and Hospital-Based)
    - Healthcare Worker Pandemic Isolation Focus Group/Interview Schedules (Community-Based and Hospital-Based)
    - Professional Quality of Life – R-IV

- Public Health Officials
    - Public Health Official General and Pandemic Surveys
    - Public Health Official Focus Group/Interview Schedule

- Public Health Preparedness Planners (PHPP)
    - PHPP General and Pandemic Ethics Surveys/Interviews
    - PHPP General and Pandemic Law Surveys/Interviews

- Law and Ethics Experts
  - Law and Ethics Expert General and Pandemic Focus Group/ Interview Schedules

- Pilot Testing Consumer Evaluation
  - Pilot Testing Consumer Evaluation Survey and Focus Group Schedule

- State Plan Review
  - State Plan Review Tool

- Professional Organization Standards Review
  - Professional Organization Standards Review Tool

Instruments used during the field testing phases were also developed in a collaborative and iterative manner, reflecting the feedback provided throughout the process. A template for field response was developed and adapted for each recommendation. The instruments were then created to include the ratings relevant to the specific recommendations being considered by each respondent. The template included Likert scale ratings for each recommendation in three areas:

1) The utility of each recommendation for their workplace or community,
2) How much they believed it would improve pandemic response outcomes for children and families, and
3) How realistic it would be to implement the recommendation.

The Likert scale had five categories; *strongly agree, agree, neither agree nor disagree, disagree* and *strongly disagree.* Feedback instruments included space for comments and sometimes prompted comments with follow-up, open-ended questions about particular recommendations. Respondents completed these ratings following presentation of the recommendations by PowerPoint, printed material or webinar. Webinar participants responded via online polls (generated and delivered via WebEx^{TM}) following each recommendation. As each respondent or group of respondents was presented with only the recommendations germane to their areas of expertise and knowledge, the configuration of the instruments utilized with each set of respondents differed, although the individual questions followed a consistent format.

Analysis

Descriptive and inferential statistical analyses were completed on the data as indicated. All data at all project stages were analyzed for frequency and descriptive characteristics. Initial empirical findings were analyzed using inferential statistical procedures as appropriate and indicated. Qualitative analysis of field notes from interviews and focus groups, open-ended survey

questions, webinar polling answers and feedback responses was also conducted using standard categorization strategies identifying themes and areas of convergence and divergence. Documents and websites were analyzed using standard content analysis approaches. Again, triangulation of findings was sought across respondents, study sites, team members and types of data. High levels of convergence were considered more significant than low levels and in general, if only a single source for a finding emerged after analysis, this data was not included in the findings and did not drive development of any recommendations.

Regular team meetings, review of findings, field notes, analyses and write-ups, and collaborative field work encouraged and supported opportunities for exchange of ideas through shared interpretation of findings, exploration of alternative explanations, varied perspectives and unique expertise. This exchange also facilitated the identification of areas of convergence and ensured an ongoing inclusive and iterative approach to the examination of the findings and development of recommendations.   Ongoing review of the literature continued throughout all stages of the study to identify emerging research and pandemic-related documents to continue to inform the systematic investigation and exploration of evidence about the biopsychosocial responses of children and families during pandemic.

Written Documents Produced to Date

Each phase of the study has produced a final report, documenting in detail the process and findings for that phase. The documents produced to date that culminate in the development of *Evidence-Informed Guidelines for Child-Focused Pandemic Disaster Planning and Response* are as follows:

1. *Best Practices Guidelines for Pandemic Disaster Response: A Social Behavioral Evaluation. A Comprehensive Analysis of Pandemic and Quarantine Responses for Families and Children* (September 2009)
2. *University of Kentucky Behavioral Health Pandemic Research Toolkit: An Analysis of the Child and Family Experience* (November 2009)
3. *University of Kentucky Best Practices Guidelines for Pandemic Disaster Response Expert Database, Phase 1* (July 2010)
4. *A Comprehensive Analysis of Pandemic and Quarantine Responses for Families and Children: Integrative Report of New Evidence (Preliminary Findings)* (August 2010)
5. *New Directions in Pandemic Response: A Roadmap to Resilience* (August 2010)
6. *Best Practice Guidelines for Pandemic Disaster Response: Response from the Field (Part 1)* (December 2010)
7. *Best Practice Guidelines for Pandemic Disaster Response: Response from the Field (Part 2)* (March 2011)

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Appendices

Appendix A.   Expert Database: Surveys, Focus Groups and Interviews
Appendix B.   Demographic Description of Expert Database
Appendix C.   Tools/Instruments by Population Category
Appendix D.   Key Documents Reviewed
Appendix E.   National Field Testing Sample
Appendix F.   State and National Field Testing Sample
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                  the Field
Appendix H.   Recommendations for Brief Trauma Screening Tools
Appendix I.   Ethical and Legal Resources for Practitioners

Appendix A
Expert Database: Surveys, Focus Groups and Interviews

Role	Survey Respondents	Focus Group Participants	Interview Participants	Total
Public Health Officials	151	27	69	247
Healthcare Professionals	653	54	29	736
Behavioral Health Professionals	705	19	26	750
Law and Ethics Experts	------	66	16	82
Parents	596	-----	4	600
Youth	156	6	6	168
Other		*25*		*25*
Total Participants in Study	*2261*	*197*	*150*	*2608*

Appendix B
Demographic Description of Expert Database

Gender	N	Percentage
Female	1855	71.1%
Male	692	26.5%
Unknown	61	2.4%
State or Country		
Arizona	136	5.2%
California	273	10.5%
Florida	228	8.7%
Kentucky	565	21.7%
New York	293	11.2%
Texas	453	17.4%
Other state	284	10.9%
Canada	129	4.9%
Mexico	247	9.5%
Race		
White	1693	64.9%
African-American	229	8.8%
Asian	76	2.9%
Indian/Alaska	12	.4%
Hawaiian/Pacific Islander	5	.2%
Hispanic	359	13.8%
Multiple	5	.2%
Other	26	1.0%
Unknown	203	7.8%
Population Subgroup		
Behavioral Health	750	28.8%
Healthcare Worker	736	28.2%
Public Health	247	9.5%
Law and Ethics/Multidisciplinary	82	3.1%
Other	25	1.0%
Parents	600	23.0%
Youth	168	6.4%
Total Participants	**2608**	

Appendix C
Tools/ Instruments by Population Category

Population	Instrument
Behavioral Health Professionals	*Behavioral Health Professional Pandemic Survey* *Behavioral Health Professional Pandemic Interview/Focus Group* *Professional Quality of Life – R-IV (ProQOL – R-IV)* *Impact of Events Scale-Revised (IES-R)*
Healthcare Workers	*Healthcare Worker General and Pandemic Surveys (Community-Based and Hospital-Based)* *Healthcare Worker Pandemic Isolation Interview/Focus Group (Community-Based and Hospital-Based)* *Professional Quality of Life – R-IV (ProQOL – R-IV)*
Law and Ethics Experts	*Law and Ethics Expert General and Pandemic Interview/Focus Group Schedules*
Pilot Testing Consumer Evaluation	*Pilot Testing Consumer Evaluation Survey/Focus Group Schedule*
Public Heath Officials	*Public Health Official General and Pandemic Surveys* *Public Health Official Interview/Focus Group Schedule*
Public Health Preparedness Planners (PHPP)	*PHPP General and Pandemic Ethics Surveys/Interview Schedules* *PHPP General and Pandemic Law Surveys/Interview Schedules*
Parents	*Parent Pandemic General, Isolation and Quarantine Surveys* *Resource Parent General Survey* *Parent General, Isolation and Quarantine Interview/Focus Group Schedules* *Parent PTSD Checklist- Civilian Version (PCL)* *Trauma Symptom Checklist for Young Children© (TSCYC)*
Professional Organization Standards Review	*Professional Organization Standards Review Tool*
State Pandemic Plan Reviews	*State Pandemic Plan Review Tool*
Youth	*Youth Pandemic General, Isolation and Quarantine Surveys* *Youth Pandemic Isolation/Quarantine Interview/Focus Group Schedule* *Trauma Symptom Checklist for Children© (TSCC, Ages 8-16)*

Appendix D
Key Documents Reviewed

Documents Reviewed and Evaluated

Over the course of this project, over 1,200 relevant documents have been examined. A broad range of resources were analyzed from a plethora of domains. Some examples are listed below.

Examples of the types of documents reviewed include, but are not limited to:

- National pandemic preparedness plans
- State-level pandemic preparedness plans (50 states and the District of Columbia)
- Peer-reviewed academic articles and reports in the fields of medicine, public health, behavioral health, social sciences, law, and ethics
- Books and book chapters
- Official and governmental publications (e.g., Commission Reports, Agency Reports, Public Policies and Protocols, Recommended Guidelines, Research Findings)
- White papers
- Conference proceedings and papers
- Newspaper and magazine articles (features, fact pieces, opinion pieces, etc.)
- Working papers
- Relevant databases
    - Using EBSCOhost, OVID, or WebSPIRS, the following databases were searched:
        - Academic Search Premier,
        - America: History and Life
        - CINAHL
        - Cochrane Databases
        - Communication and Mass Media Complete
        - ERIC
        - Health Source –Consumer Edition
        - Historical Abstracts
        - MEDLINE
        - Newspaper Source
        - Psychology and Behavioral Sciences Collection
        - PsychINFO
        - Sociological Collection
        - TOPICsearch
    - Google and Google Scholar were also used as search engines
- Web sites and internet forums, including online support groups and resources such as
    - U.S. Department of Health and Human Services Website (www.flu.gov or www.pandemicflu.gov)

- Ready America (www.ready.gov)
- SARS Support Centre (http://www.sarssupportcentre.net/)
- Hastings Center Bioethics Forum (http://www.thehastingscenter.org/bioethicsforum/default.aspx)
- Law and Ethics Documents including
  - Case law
  - Court decisions
- Federal and State Legislation
- Disaster Response Organization Documents and Websites:
  - American Red Cross
  - Department for Homeland Security (DHS) Disaster Preparedness Centers
  - Federal Emergency Management Agency (FEMA)
  - National Center for Disaster Preparedness (NCDP)
- Health Organization Documents, including
  - *Trust for America's Health*
  - United Nations documents
- Professional Organizations Documents and Standards of Care
  - American Academy of Pediatrics
  - American Medical Association
  - American Psychological Association
  - Council on Social Work Education
  - National Association of School Psychologists
  - National Association of School Social Workers

Areas for Inquiry include but are not limited to the following domains, organizations and entities:

- Public Health and Pandemic-Related Policy, Documents and Literature:
  - State Pandemic Plans United States)
  - Provincial Pandemic Plans (Canada)
  - Public Health Pandemic Plans (City, County and Regional Level Plans)
  - Centers for Disease Control and Prevention (CDC)
    - *Crisis and Emergency Risk Communication (CERC)*
    - *Morbidity and Mortality Weekly Report (MMWR)*
    - *Building Community Resilience for Children and Families*
    - Mental Health Workgroup
  - Institute of Medicine (IOM)
  - Association for State and Territorial Organizations (ASTO)
  - National Institutes of Health (NIH)
  - US Department for Heath and Human Services (DHHS)
    - Office of Minority Health (OMH)
    - Agency for Healthcare Research and Quality (AHRQ)
  - Homeland Security Council
  - Public Health Agency of Canada -- Center for Infectious Diseases Prevention and Control (CIDPC)
  - State-level
    - *Helping to Heal: Behavioral Health Planning and Response to Public*

- *Health Emergencies* (Virginia)
    - *Emergency Preparedness Oversight Council, Vulnerable Populations Workgroup* (Arizona)
    - *Community Conversations on H1N1 Vaccine: A Public Engagement Project Conducted by Public Health Seattle and King County* (Washington)
  - City-level
  - County-level
  - Other
- International Pandemic Planning and Response documents including, but not limited to those by
  - World Health Organization (WHO)
  - United Nations
  - World Bank
  - National Collaborating Centre for Methods and Tools (Canada)
- Public Health and Healthcare Literature, Documents and Guidelines
  - Robert Wood Johnson Foundation (RWJF)
  - Center for Infectious Disease Research and Policy (CIDRAP)/*Promising Practices: Pandemic Influenza Tools*
  - National Association of City and County Health Organizations (NACCHO)
  - Center for the History of Medicine (CHM) University of Michigan Medical School
- Behavioral Health Literature, Documents and Guidelines
  - Substance Abuse and Mental Health Services Administration (SAMHSA)
  - Center for the Study of Traumatic Stress (CSTS)
  - National Child Traumatic Stress Network (NCTSN)
  - Professional BH Organizations Documents and Standards of Care:
    - American Psychological Association
    - Council on Social Work Education
    - National Association of School Psychologists
    - National Association of School Social Workers
- Social Sciences Literature including Social Psychology, Social Work, etc.
- Law and Ethics Literature including Case Law, Court Decisions
  - Health Lawyers Public Information Series
  - University of Toronto Joint Centre for Bioethics
  - *Congressional Research Service Report for Congress: Federal and State Quarantine and Isolation Authority*
  - *National Academy of Sciences Workshop: Ethical & Legal Considerations in Mitigating Pandemic Disease*
- Disaster-Focused Commissions and Agency Documents and Guidelines
  - National Commission on Children and Disasters
  - National Consensus Panel on Emergency Preparedness for Racially and Ethnically Diverse Communities
  - The SARS Commission
  - National Biodefense Science Board – Disaster Mental Health Subcommittee
- Disaster-Focused Scientific Research

- *Redefining Readiness: Terrorism Planning through the Eyes of the Public*
- Consumer/Patient Memoirs
  - *Pandemic Influenza Storybook*
  - SARS memoirs
- Disaster Response Organization Documents and Websites
  - American Red Cross
  - Department for Homeland Security (DHS) Disaster Preparedness Centers
  - Federal Emergency Management Agency (FEMA)
  - National Center for Disaster Preparedness (NCDP)
  - Center for Biosecurity of UPMC
  - Emergency Medical Services for Children (EMSC)
  - Center for Public Health Readiness and Communication at Drexel University
- Professional organizations documents and standards of care
  - American Academy of Pediatrics
  - American Medical Association
  - American Psychological Association
  - American Public Health Association
  - Council on Social Work Education
  - National Association of School Psychologists
  - National Association of School Social Workers
  - National Association for School Nurses

Appendix E
National Field Testing Sample

Target Groups Part 1	Sector/ Discipline/ Profession	Method	Region/ Geographic Area
	National behavioral health Disaster/terrorism	Interview	All regions
	National behavioral health Trauma related	Presentation and feedback	All regions
	National behavioral health Disaster/terrorism	Interview	All regions
	Public health – National disease control	Focus Group	All regions
	Healthcare expert systems of care	Interview	All regions
	Children's healthcare Disaster focus	Focus Group	All regions
	Child Life specialists	Focus Group	All regions
	Healthcare and public health expert	Interview (webinar)	All regions
	Healthcare, behavioral health, parents, children and vulnerable groups	Focus Group (webinar)	California
	Parents, children, vulnerable groups	Focus Group	All regions
	Law and ethics center	Interview	Canada
	Hispanic healthcare, parents, children and vulnerable groups	Focus Group (webinar)	All regions
	Public health - Well-designed preparedness plan	Interview	Washington
	Public health - National organization	Interview	Canada
	Public health - Infection control	Presentation and survey	All regions
	Law and ethics - Public health	Interview (webinar)	All regions
	Behavioral health providers	Focus Group	All regions
	Public health professionals	Presentation and discussion	All regions
	Public health organization	Interview and/or Focus Groups	Mexico

Target Groups Part 2	Sector/ Discipline/ Profession	Method	Region/ Geographic Area
Consumers			
	Parents	Focus Groups (5)	Kentucky
	Youth	Focus Groups (2)	Kentucky
	Children and families in communities	Interview	Kentucky
	Children and families in communities	Focus Groups (4) (face-to-face and webinar)	Kentucky
	Behavioral health consumers – Advocacy organization	Interview	Kentucky
Diverse Populations			
	Vulnerable populations – City government	Interview	Kentucky
Schools			
	School disaster response – School safety organization	Interview	Kentucky
First Responders			
	National community disaster response	Interview	All regions
	National pediatric disaster response	Interview	All regions
	Community crisis response	Interview	Kentucky
	Pediatric disaster response	Interview	Kentucky
Community and Faith-Based Organizations			
	National faith-based disaster response	Focus Group (webinar)	All regions
	State faith-based disaster response	Interview	Kentucky
Public Health			
	Public health	Interview	Kentucky
	Public health – Preparedness planning officials	Focus Groups (2)	Kentucky
Healthcare			
	Hospital disaster response – Hospital professional interest group	Focus Groups (2) (webinar)	Kentucky
	Hospital and community disaster response – Health preparedness	Focus Groups (2) (webinar)	Kentucky

Professional Groups			
	National behavioral health organization – all disciplines	Interview	All regions
	National behavioral health organization – Social Work	Interview	All regions
	National behavioral health organization - Psychology	Interview	All regions
	National behavioral health organization - Pediatrics	Interview	All regions
	National behavioral health organization - Psychiatric Nursing	Interview	All regions
	National pediatric health organization	Focus Group (webinar)	All regions
	Behavioral health – marriage or family therapy	Interview	State
Business			
	Community crisis response – Business guild	Interview	Kentucky
Legal and Ethical			
	National legal issues – Court system	Interview	All regions
	Kentucky legal issues - Judiciary	Interview	Kentucky

Appendix F
State and National Field Testing Sample

State	Interview	Focus Groups	Webinar
AZ		1 group, 6 participants	
CA	1	1 group, 2 participants	1 webinar, 15 participants
CO		1 group, 19 participants	
DC	4	2 groups, 16 participants	1 webinar, 4 participants
GA		2 groups, 22 participants	
MI	1		
NY	1	3 groups, 24 participants	
OK	1		
TO	1		
VA	1		
WA	1		
KY Breathitt, Carlisle, Clay, Fayette, Floyd, Franklin, Fulton, Hopkins, Jefferson, Laurel, Madison, Magoffin, Muhlenberg, Murray, Ohio, Owsley, Perry, Pike, Pulaski, and Warren Counties	11	10 groups, 86 participants (57 parents, 9 youth, 20 professionals)	3 webinars, 17 participants
U.S. States (miscellaneous)			3 webinars, 21 participants
Total	**22**	**20 groups, 175 participants**	**8 webinars, 57 participants**

Responses from the field were sought to review of preliminary recommendations by a range of experts, professionals and consumers, throughout the country. These reviews occurred during individual interviews, focus groups and webinars. Preliminary recommendations were presented as written documents, PowerPoint presentations or webinar presentations and respondents provided feedback via discussion and response using a rating instrument. The presentation and rating instrument was adapted for each respondent based on domain of expertise and experience, but utilized the same materials to ensure consistency of presentation across domains and respondent populations. Webinar participants responded using an online polling system with the same content as written or online tools. All participants consented to participation in research via signature or online acceptance of the consent form.

Feedback instruments were all called ***The Behavioral Health Impact of Pandemic on Children and Families: Some Preliminary Recommendations*** and included a standardized format for every recommendation. The recommendation was summarized and respondents were asked to rate the need, viability and benefit to children of the recommendation in their community or sphere of functioning. The rating scale utilized a Likert scale of degree of agreement and was presented as follows after each recommendation:

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
There is a need for this in my community					
This is a realistic strategy for my community					
This will improve care for children and families					

Instructions for the rating tool read as follows:

> Please provide a rating and your initial impressions. *Your opinions will help us shape the recommendations we will submit to the National Institute of Hometown Security.*

Recommendations were summarized as follows, each with the rating scale following the statement. Not all recommendations were presented to all respondents.

Pandemic Preparedness Communication and Collaboration:

1. Create the role of **child-focused pandemic boundary spanner** to coordinate a community network to address the needs of youth and families during pandemic disaster.

    Tell us what you think about the idea of a boundary spanner and pandemic network? Is the network a good idea? Is a boundary spanner necessary for the network to succeed? Will it work? What is needed to make it work? What might get in the way of it working?

Behavioral Health:

2. Include **behavioral health screening** of youth and families **by trained professionals** as a routine component in **all** pandemic response protocols (e.g., in clinics, hospitals, doctors' offices, public health departments), peri- and post-pandemic, utilizing an integrated care model.

3. Develop strategies for **identification and utilization of evidence-based behavioral health assessment and intervention protocols**.

4. Support **behavioral health screening by professionals most suited to the role**, (e.g., child life specialists and social workers in hospitals, pediatricians and primary care providers in outpatient settings), and provide adequate training and updates in recommended protocols.

5. Support protocols requiring **follow-up behavioral health screening** of **family members** of patients who screen positive for pandemic-induced behavioral health stress responses and follow-up for **anyone meeting traumatic stress response levels.**

6. Include and support reimbursement for **alternative ways of delivering mental health and human services** to youth and families during pandemic, (e.g., using web-cam, telephone, internet communication) in place of face-to-face meetings.

    What types of **technology** would you like to see used for delivery of mental health or human services if face-to-face is not available?   What would the challenges be to using those technologies?

7. Ensure the biopsychosocial needs of children and families during pandemic are a part of the **national agenda**:

- include strategies to address the behavioral health and human services needs of families and children during pandemic in the National Disaster Recovery Framework
- include pandemic preparedness in the Concept of Operations component of disaster mental health if adopted by Congress.

8. Include the behavioral health needs and responses of children and families during pandemic in the **national research agenda** of children's mental health.

9. Require **state pandemic plans to have a Behavioral Health Appendix** to include:
   - requirements for psychoeducational information for parents and youth
   - resources for families and children
   - clearly outlined and pre-determined behavioral health screening strategies
   - use of evidence-informed and protocol driven assessment and intervention approaches, and
   - development and utilization of child-focused pandemic boundary spanner.

10. Support a **coordinated and collaborative approach** to pandemic preparedness by **professional organizations** to:
    - develop guidelines and standards of care for biopsychosocial needs of children and families
    - identify roles and responsibilities during pandemic
    - develop contractual agreements with disaster gatekeepers
    - specify educational and training competencies for pandemic disaster responders
    - develop ethical guidelines for pandemic response to children and families.

Risk Communication:

11. Make sure **pandemic messages** and **communication** are **child-focused, family-targeted, developmentally appropriate** and **culturally sensitive**.

12. Include **input from special and vulnerable populations** in risk communication development and **pretest messages** with special and vulnerable populations.

13. Feature and include input from **pediatricians and other primary care providers** in developing effective peri- pandemic risk communication and messages

14. Utilize **existing community structures, including schools**, for communication of information and ensure community-targeted messages minimize potential for stigma.

Professional Risk Communication/ Information Dissemination:

15. Promote **professional communication** that is **timely, evidence-based, utilizes a "push" methodology** and utilizes a **range of media**.

Family-Centered and Continuity of Care for Children and Families:

16. Promote **family-centered care and responses** for pandemic planning to keep families together as much as possible including during periods of hospitalization, quarantine or isolation.

17. Promote **family-centered care with comprehensive pre-pandemic training** of all pandemic first responders and medical responders, especially physicians, nurses and direct service medical providers.

18. Promote continuity of care **through advance training, cross-training** and **adequate staffing coverage plans** (e.g., three-deep), especially in areas of specialty services for children (e.g., PICU, NICU, pediatric oncology, etc.).

19. Establish, evaluate, and prioritize family-centered care practices for quarantine and isolation that maintain connection between child and parent.

Family Support and Community Resiliency:

20. Include strategies for **meal distribution** or **food replacement** of free or reduced cost meals for youth during periods of school or child care closure.

21. Include strategies for **job security** or **income replacement** for work time lost due to pandemic (e.g., illness, ill family member, quarantined based on exposure, school closure, etc.)

22. Include strategies to **protect** special populations from **stigma or stereotyping**.

Professional Training, Support and Resiliency:

23. Address psychosocial needs of pandemic responders through recommendations for establishment of non-stigmatizing, non-punitive opportunities for individual and group support and intervention for pandemic-related stress responses.

24. Ensure mental health **providers from different professional groups work together** and **work with other professionals** to address the needs of youth and families during pandemic.

25. Support a **coordinated and collaborative approach** to pandemic preparedness by **professional organizations** to:
    - develop guidelines and standards of care for biopsychosocial needs of children and families
    - identify roles and responsibilities during pandemic
    - develop contractual agreements with disaster gatekeepers
    - specify educational and training competencies for pandemic disaster responders
    - develop ethical guidelines for pandemic response to children and families.

26. Promote **professional resiliency** through:
    - availability of non-stigmatizing, non-punitive peri-pandemic behavioral health services for pandemic responders and their families
    - peri-pandemic outreach and education; regular professional opportunities for self-screening, peer assessment and supervisory screening
    - regular opportunities for individual and group support or intervention
    - collaboration with professional organizations, unions, work-place safety, etc.

27. Overcome stigma directed at healthcare providers who care for those quarantined or isolated.

28. Address healthcare provider anxiety re: "bringing disease home," especially for non-infectious disease healthcare providers.

Additional comments on the preliminary recommendations:

Thank you for your feedback!

Appendix H
Recommendations for Brief Trauma Screening Tools

Child Instruments

- *Child Stress Disorders Checklist – Screening Form (CSDC-SF)*
  A four-item scale; assesses traumatic stress reactions in youth ages 6–18.
  www.nctsnet.org/nctsn_assets/acp/hospital/CSDC-Screening%20Form2.pdf

- *Child Trauma Screening Questionnaire (CTSQ)*
  A 10-item version of the Trauma Screening Questionnaire (TSQ), reworded for child comprehension.
  www.psid.org.au/.../Child-Trauma-Screening-Questionnaire-for-children.pdf

- *Impact of Events Scale – 8 (IES-8 or CIES)*
  An eight-item child and adolescent self-report scale; measures intrusion and avoidance responses to a specific identified event.
  www.childtrauma.com/chmies8.html

Adult Instruments

- *Short Form of the PTSD Checklist – Civilian Version*
  A six-item screening instrument derived from the original 17-item PTSD Checklist-Civilian Version (PCL). http://www.pdhealth.mil/guidelines/appendix3.asp

- *Short Screening Scale for PTSD*
  A seven-item scale, suitable for all ages, that contains five avoidance and two hyperarousal items. (This is a subset of items from the DIS/Composite International Diagnostic Interview PTSD section).
  http://www.ptsd.va.gov/professional/pages/assessments/short-screen-ptsd.asp

- *PTSD-8*
  An eight-item tool derived from the first 16 items of the Harvard Trauma Questionnaire (HTQ) and assesses both DSM-IV symptoms and culture-specific symptoms associated with PTSD.
  www.benthamscience.com/open/cpemh/articles/V006/101CPEMH.pdf

- *Trauma Screening Questionnaire (TSQ)*
  A 10-item screener created to use with survivors of a variety of traumatic stressors. It is based on items from the PTSD Symptom Scale-Self Report (PSS-SR) and contains five re-experiencing items and five arousal items.
  www.completepractitioner.com/assessment/PSD.pdf

- *Primary Care PTSD Screen (PC-PTSD)*
  A four-item screening scale designed for use in primary care settings.
  http://www.ptsd.va.gov/professional/pages/assessments/pc-ptsd.asp

Appendix I
Ethical and Legal Resources for Practitioners

Planning and Responding to Pandemic Influenza: Ethical Considerations Checklist
This checklist was developed by the Ethics Subcommittee of the Advisory Committee to the Director, Centers for Disease Control and Prevention (CDC) and should be used by public health officials when developing or approving plans that will have a substantive impact on policy, practice or the public. It is intended to enhance ethical decision-making. Topics covered include general ethical considerations, and ethical issues relating to data collection, liberty limiting measures, and allocation of scarce resources. The checklist is available at:
http://www.cdc.gov/od/science/integrity/phethics/Pan_Flu_Ethics_Checklist.3-15-07.final.doc

The Centers for Disease Control and Prevention Public Health Law Program
The CDC's Public Health Law Program website includes material and links on the law of public health emergency legal preparedness.
http://www2.cdc.gov/phlp/

The National Action Agenda for Public Health Legal Preparedness
The first national summit on public health legal preparedness sponsored by the Public Health Law Program at the CDC and 19 multidisciplinary partners. Findings presented in *The Journal of Law, Medicine & Ethics* (2008, Vol 36:1)
http://www2a.cdc.gov/phlp/docs/Journalpdf.pdf

The Centers for Law and the Public's Health: A Collaborative at
Johns Hopkins and Georgetown Universities
A primary resource on public health law, ethics, human rights, and policy for public health practitioners, lawyers, legislators, judges, academics, policy makers, and others.
http://www.publichealthlaw.net

Public Health Law Checklists
Together with colleagues at CDC's Public Health Law Program, the Association of State and Territorial Health Officials [ASTHO], and the National Association of City and County Health Officials [NACCHO], the *Center*s developed checklists on three major topics for use by public health agencies in assessing their legal preparedness for public health emergencies, including emerging infectious disease epidemics.

Interjurisdictional Legal Coordination for Public Health Emergency Preparedness
http://www.publichealthlaw.net/Resources/ResourcesPDFs/Checklist%201.pdf

Local Government Public Health Emergency Legal Preparedness and Response
http://www.publichealthlaw.net/Resources/ResourcesPDFs/Checklist%202.pdf

Civil Legal Liability Issues and Public Health
http://www.publichealthlaw.net/Resources/ResourcesPDFs/Checklist%203.pdf