NATIONAL COMMISSION ON CHILDREN AND DISASTERS

Hon. Mark Shriver
Chairperson

Michael Anderson, M.D.
Vice-Chairperson

Ernest Allen, J.D.

Merry Carlson

Hon. Sheila Leslie

Bruce Lockwood

Gregg Lord

Irwin Redlener, M.D.

David Schonfeld, M.D.

Lawrence Tan, J.D.

Christopher Revere
Executive Director

Long-Term Disaster Recovery Workshop
February 1, 2010

Report of Findings

1250 Maryland Ave, S.W., 8th Floor East · Washington, D.C. 20447 · (202) 205.9560

I. Introduction

The National Commission on Children and Disasters hosted a Long-Term Disaster Recovery Workshop on February 1, 2010 at the Renaissance Mayflower Hotel in Washington, DC.

The primary goal of the Workshop was to conduct facilitated discussions with attendees on gaps in long-term disaster recovery that pertain to (1) children's access to primary health care, (2) provision of mental health services to children, and (3) barriers to information sharing and data collection. Workshop deliberations were intended to inform further development of the Commission's recommendations for their Final Report to President Obama and the Congress, as well as the forthcoming National Disaster Recovery Framework, which President Obama tasked the Secretaries of Homeland Security and Housing and Urban Development with developing by June 2010.

The Workshop attracted a diverse group of over 110 persons, including representatives from federal agencies (32%), non-governmental organizations (22%), state and local agencies (14%), professional associations (10%), academia (6%), the private sector (5%), and other types of organizations (11%). Eight Commissioners, the Designated Federal Officer (DFO) for the Commission, and two alternate DFOs also attended the Workshop.

This report summarizing the Workshop consists of four sections. First, an overview of the day's activities is provided. Sections 2 through 4 describe the findings and discussions regarding the three topic areas (children's access to primary health care, provision of mental health services to children, and barriers to information sharing and data collection).

Additional information on the Workshop is available on the Commission's web site (www.childrenanddisasters.acf.hhs.gov) including fact sheets developed prior to the Workshop for the break-out sessions, Commission Vice Chairperson Dr. Michael Anderson's opening remarks, Housing and Urban Development Deputy Secretary Ron Sims' keynote address, and PowerPoint documents listing in bullet format briefly summarizing findings and recommendations from the three break-out sessions.

Workshop Overview

After the Commission DFO CAPT Roberta Lavin called the Workshop to order at 9 AM, Dr. Anderson welcomed the Workshop attendees and introduced Mr. Sims. Following Mr. Sims' keynote address, the morning plenary session concluded with Kim Fletcher of Abt Associates summarizing the Workshop's agenda, goals, and objectives.

At 10 AM the attendees moved to the break-out rooms, one for each of the three topic areas. Attendees were pre-assigned to topic areas, based on preferences they expressed at registration, and to tables in the break-out room. Participants were assigned to tables to ensure that each table reflected the variety of organizational affiliations at the Workshop. The two-hour morning break-out session was divided into two segments. During the first segment, each table discussed barriers to implementing specific recommendations from the Commission's Interim Report, or, equivalently and as noted below, achieving the "desired state." Specifically, the table discussions focused on the following:

- Does the desired state need additional clarification or detail?
- What other barriers might there be in reaching the desired state? What is the source of these barriers?
- What is missing in current policy/legislation that may prevent reaching the desired state?
- What other gaps in service delivery regarding this issue can you identify?
- What stakeholders/partners are missing from this discussion?

During the second segment of the morning session, a representative from each table summarized their table's discussion. The breakout room's facilitator then led a room-wide discussion of each table's summary.

Following a lunch break, participants returned to the break-out rooms for a second two-hour session on each of the three topic areas. As with the morning session, the afternoon session was divided into discussions at individual tables and then presentations by table representatives and room-wide discussions. The focus of the afternoon break-out session was on refining the Commission's recommendations and formulating new, related recommendations. The specific questions each table discussed were:

- What recommendations about the desired state can the group make to the Commission for consideration?
- What additional funding sources might there be that could help reach the desired state?
- What other resources are available that might be useful in reaching the desired state?
- What further research needs to be done that might uncover additional stakeholders or resources?
- What action steps should be considered by the Commission in moving toward achieving the desired state?

During the closing plenary session, facilitators summarized the findings of each breakout session and invited questions and further discussion from all the Workshop participants.

Dr. Anderson closed the Workshop by thanking attendees for their participation and inviting them to attend the public quarterly Commission meeting the next day.

II. Breakout Session: Children's Access to Primary Health Care

Workshop participants in this breakout session were asked to consider the following issue:

> What are the gaps in the provision of primary health care to children impacted by disasters, especially in geographic areas where the federal government is providing on-going disaster recovery support and funding for other services? Of particular interest are health care worker shortages, health care-related community capacity building, and training of primary health care providers.

Workshop participants also reviewed the Commission's relevant Interim Report recommendations:

- Ensure access to comprehensive physical and mental health services for all children during recovery from a disaster, ideally through a "medical home", defined as a source of primary care that is accessible, continuous, and coordinated.
- Accelerate the development of a National Disaster Recovery Strategy with an explicit emphasis on addressing the immediate and long term physical and mental health, educational, housing, and human services recovery needs of children.
- Expand medical capabilities of all federally funded response teams through comprehensive integration of pediatric-specific training, guidance, exercises, supplies, and personnel.

A. Challenges

Participants identified five main categories of challenges to children's access to primary health care during long-term disaster recovery: (1) shortages of health care professionals, (2) systems coordination, (3) barriers to information sharing and patient tracking, (4) changes in eligibility for health insurance, and (5) lack of funding for reestablishing health care practices.

1. Shortages of Health Care Professionals

In general, there is a shortage of health care workers during the response and recovery phases of a disaster. Programs, incentives, and funding to recruit and retain physicians appear to be lacking for disaster-affected regions. Due to the scarcity of doctors with a pediatric specialty, other health care workers are pressed into service without role-specific training. Mechanisms for training health care professionals both pre- and post-disaster are needed. There is a need for Practice Acts for not just for nurses, but for all health professionals, that would facilitate telehealth practices.

2. Systems Coordination

There is sometimes a lack of centralized command and control once disaster response transitions to long-term recovery. Government agencies and non-profit organizations have varying roles in long-term

recovery, and often questions arise concerning management of the recovery effort, the timeline associated with implementation of the response and then recovery efforts, and the period of time for which the federal government provides or supports medical care delivery before transferring the responsibility to local governments or other organizations.

3. Information Sharing and Patient Tracking Capabilities

The ability to share information during the response and recovery phases is critical to operational decision-making. In multi-state disasters, organizations have difficulty sharing logistical information concerning resources and planning. For medical facilities, physicians may not be able to correctly treat patients due to lack of medical records. Electronic online records and back-up servers would mitigate the risk of losing medical records, however many health care facilities do not yet have this capability.

Additionally, there is no central source or mechanism that tracks patient records, supplies, locations of families and children, or volunteer status. This is a challenge given that decision-making processes, credentialing confirmations, and family reunification efforts are critically dependant on this type of information.

4. Eligibility for Health Insurance

When relocated to another state, families face barriers to maintaining their eligibility for a health care payer source (e.g., health insurance, Medicaid). Participants stated that more coverage is needed in such circumstances, whether through flexible eligibility across states, automatic catastrophic coverage, supplemental provisions, or Medicaid waivers.

5. Funding to Reestablish Health Care Practices

Participants noted that the Robert T. Stafford Disaster Relief and Emergency Assistance Act (Stafford Act) does not provide reimbursement for recovery of for-profit primary health care providers. Additionally, these providers often encounter challenges in eligibility or ability to pay back Small Business Administration loans. One participant noted that providing federal funds to for-profit facilities would not be likely to garner political support.

Participants noted that there is no streamlined system that delivers funding to private, for-profit organizations during disaster recovery stages. Consequently, many local primary and secondary care facilities lack resources to serve those in need.

Additionally, recovery assistance processes differ among states. Without a universal recovery plan, standard operating procedures implemented by the federal government may not result in the most effective support for needs experienced at the local level. For example, some citizens may remain underserved because their state lacks minimal standards for medical assistance or coverage.

B. Recommendations

Participants were divided into five groups that proposed recommendations for improving children's access to primary health care following a disaster. The recommendations fell into the categories: (1) improve coordination for the planning and execution of reestablishing health care practices, (2) improve training for professionals and volunteers, (3) improve eligibility and access to health insurance, and (4) establish and streamline funding to support critical infrastructure recovery of health care practice.

1. Improve Coordination for Planning and Execution of Reestablishing Health Care Practices

Participants stated several times that recovery planning and performance could improve if participating agency efforts were better coordinated. Participants offered the following three recommendations: establish a National Disaster Recovery Framework (NDRF) that fully addresses the unique needs of children; develop stronger partnerships between federal agencies and local, state, and tribal organizations, and; improve volunteer credentialing.

Similar to the Emergency Support Functions (ESFs) of the National Response Framework, the NDRF should provide specific authorities or strategies for each agency involved in the recovery process to meet the unique needs of children. Participants stated that children should be integrated throughout the entire framework, not just mentioned as part of "special populations" or the focus of a particular annex. Language throughout the NDRF should assign specific priorities for children and include any relevant stakeholders.

Local success of disaster recovery depends on the transfer of supervision from federal agencies to local governments to ensure revival of community capacities. There should be funding available for local or regional entities to conduct post-disaster needs assessment and use targeted funding to deliver care that addresses the specific needs that are identified. Federal agencies should respond in the short-term, and then empower local organizations to address unmet needs during long-term recovery, so the community can sustain itself in the long run. However, the end of the emergency response phase and the start of the recovery phase is never a definite point in time. Therefore, it was recommended that the federal government should specify to state, local, and tribal governments general guidelines in the NDRF on how to function during this transition period, as well as provide a constant source of resources (e.g., staff, equipment, funding). There should also be ongoing support and funding for public health infrastructure. Several participants also recommended a "one-stop-shopping" help line offering assistance to local health care providers in finding assistance for their own recovery efforts.

One participant suggested the federal government support non-traditional approaches to community recovery, such as those used by grassroots groups, culture-specific programs and faith-based and community-based organizations. State planning should include identification of alternate care sites to provide ongoing primary care services including practice in non-traditional settings: mobile units,

schools, faith-based sites, etc. Communities could also access to pediatric expertise through telemedicine.

Similarly, participants noted that improved local case management is needed for children. Integration of services (medical, social, emergency management) from all possible agencies, organizations or facilities would be ideal. Participants noted that the well-being of children affected by disasters must focus not only on medical health but also on physical safety.

Smooth and rapid credentialing processes can promote enhanced services by enabling volunteers and professional responders to immediately begin to work. For example, workers could be accredited before disasters using the Medical Reserve Corps program and the Emergency System for Advance Registration of Volunteer Health Professionals (ESAR-VHP). Because these programs only allow volunteers to work locally within their states, participants recommended a national system which could electronically manage credentials and verify volunteers' qualifications so that they could easily assimilate and work wherever the need is greatest.

2. *Improve Training for Professionals and Volunteers*

Participants agreed that the federal government expand its resources to assist organizations in providing role-specific training for the delivery of health care services and disaster recovery coordination. Oftentimes in a disaster, workers arrive on-site with a set of skills that do not appropriately meet the needs of the affected individuals. By providing training on a wider scope of skills to a wider range of aid groups, the federal government could ensure that these organizations can provide all components of medical care delivery to children.

One participant noted that agencies sometimes "volunteer by circumstance." For instance, a volunteer who specializes in medical services may be asked to perform a communications task. It follows, then, that disaster training should encompass a broad range of skills, functions and capabilities related to and outside of the delivery of children's health care. Participants suggested that the following organizations promote and develop training across disciplines: National Institute of Health (NIH), Medical Reserve Corps (MRC), National Health Service Corps (NHSC), Centers for Medicare and Medicaid Services (CMS), American Academy of Pediatrics (AAP), private practitioners, and community-based and faith-based organizations.

Similarly, training could be provided in the form of a curriculum, or via a clearinghouse of published literature and evidence-based research. Experts in certain fields could provide previous reports or data to establish both the curriculum and literature. Furthermore, the curriculum need not focus exclusively on pediatric health care, but also on community resiliency. As one participant put it, "it's not just how you take care of kids. It's how you rebuild a community… This is both a response and a recovery issue." To achieve this recommendation, national training standards should be established. One

participant suggested the development of a national formulary to standardize practices for providers that aren't familiar with the care of children, such as pediatric drug dosages.
Additionally, incentives, like reimbursements for service or grants, could be provided to recruit members for training and to retain them in disaster-affected areas. Also, more funding could be designated to federal, state, local, and tribal governments to train groups from various disciplines in role-specific areas since acute development of role-specific education and training for health care services is vital to disaster recovery coordination.

One participant noted that groups could use experiences from previous disasters to develop performance measures for organizations. These outcome measures and evaluations could identify the successes and failures of a region's experiences and inform future disaster recovery efforts.

3. *Improve Eligibility and Access to Health Insurance*

Participants agreed that insurance coverage should become more flexible and adaptable to the extraordinary conditions following a disaster. Some of the recommendations that participants proposed included: research private insurance capabilities associated with disasters, consider automatic enrollment for catastrophic coverage, and secure extra support for children with special health care needs.

The most significant issue surrounding access and eligibility concerns the relocation of disaster evacuees. Because insurance policies are not uniform among states, public assistance in one state may not be granted in another. A consistent national policy could encourage portability of health insurance among states. Participants recommended that states familiarize themselves with CMS 1115 and 1135 waivers because they allow states to waive certain original Medicaid requirements and expand eligibility benefits to out-of-state individuals.

Additionally, participants suggested that the CMS perform an internal review of its supplemental provisions for Medicaid-eligible patients. Overall, this evaluation would focus on its ability to grant additional assistance to those affected. In particular though, it would also concentrate on how CMS would function with regional offices to extend eligibility or with local physicians to extend access to care. First, CMS would need to better coordinate with their offices to ensure waiver policies are uniform across regions and educate families on possibilities of coverage. Second, if CMS shortens or waives the state residency requirements due to disasters, physicians would be able to care for patients immediately. Finally, CMS should identify gaps in policies for children with special health care needs.

4. *Improve Funding to Support Critical Infrastructure Recovery*

Participants noted that funding for recovery assistance should be distributed to those organizations that can successfully provide medical services. If medical facilities are damaged or destroyed, the Stafford Act can provide financial assistance, but only to non-profit organizations. The Stafford Act prohibits private, for-profit facilities from receiving reimbursements for critical infrastructure damage.

Participants suggested that the federal government change the Stafford Act to include for-profit facilities and to consider a rescaling of the distribution of funds based on disaster conditions.

Participants proposed a separate "recovery fund" external to the Stafford Act that would assist all types of health providers including public health agencies, private practitioners, clinics, and hospitals. Further discussion focused on the distribution of funds based on an organization's ability to provide particular medical services. Public and private sector organizations could share these funds, as could response and recovery groups and federal and state governments. Participants acknowledge, however, that issues related to appropriate distribution remain. If such organizations wish to receive funding, participants agreed that they would have to actively participate and integrate themselves into the process of post-disaster medical planning. Local, state, and tribal organizations should coordinate with federal assets which assist the transition from response to recovery, like Disaster Medical Assistance Teams (DMATs) and the MRC.

Participants stated that financial support should be provided to public health organizations as well as private, for-profit facilities since they are both fully capable of delivering medical care to children. Participants also noted that providing financial assistance to for-profit organizations could in fact improve recovery efforts associated with many types of services, not just access to medical care.

Participants suggested implementing a mechanism which could include supplemental Medicaid support. The Stafford Act includes Medicare support, but excludes Medicaid and the State Children's Health Insurance Program (SCHIP). One participant recommended incorporating these two missing funds through "legislation, not regulation, in order to increase access and eligibility of health insurance to all survivors, regardless of their circumstance."

One participant also suggested loan repayment programs to encourage physicians to enter primary care fields and address access to care pre-disaster. There should be incentives for providers to stay or return to disaster-affected areas. For example, the National Health Service Corps, which provides loan repayments to professionals working in a Health Professional Shortage Area, should be established quickly in disaster-affected areas to address health care professional shortages.

III. Breakout Session: Provision of Mental Health Services to Children

Workshop participants in this breakout session were asked to consider the following issue:

> What is and what should be the role of the federal government and its partners in support of the delivery of long-term disaster mental health services to children in congregate care facilities, including schools, child care, Head Start, juvenile justice facilities, etc.? Specifically:
>
> 1. What are some of the limitations of the current federal funding mechanisms and programs that can be used after a disaster to support the delivery of long-term mental health services in schools and other congregate care settings and what changes might be proposed to enhance and expand the delivery of these services?
>
> 2. What are other innovative solutions to support the delivery of mental health services to children in congregate care settings in long-term recovery?

Workshop participants also reviewed the Commission's relevant Interim Report recommendations:

- Encourage initiatives that support and promote training of teachers and other school staff in basic skills in providing support to grieving students and students in crisis through requirements for accreditation, licensure, and recertification/license renewal.
- Enhance pediatric disaster mental and behavioral health training for professionals and paraprofessionals, including psychological first aid, cognitive-behavioral interventions, social support interventions and bereavement counseling and support.
- Ensure access to physical and mental health services for all children during recovery from disaster, including access to comprehensive primary care.
- Enhance the ability of school personnel to support children who are traumatized, grieving or otherwise recovering from a disaster.
- Integrate mental and behavioral health for children into all public health and medical preparedness and response activities.
- Enhance the research agenda for children's disaster mental and behavioral health, including psychological first aid, cognitive-behavioral interventions, social support interventions and bereavement counseling and support.

A. Challenges

Participants identified five main categories of challenges to the desired state of providing basic mental and behavioral health support services to children in child congregate care settings following disasters: (1) training, (2) lack of services and failing infrastructure in normal times, (3) funding, (4) pre-disaster preparedness and planning, and (5) research and information sharing, (6) limited scope of current programs and services.

1. Training

Participants noted a lack of training and curricula related to the provision of disaster mental health services for children, for both mental health professionals and other professionals who work in child-serving systems such as education and juvenile justice. This lack of training contributes to delays in services for children and potentially hinders long-term recovery. Participants suggested that training on the disaster-related emotional, behavioral and mental health needs of children occur at all levels of child service systems and, ideally, take place prior to a disaster.

One participant suggested training the workforce that will interact with children and families in the aftermath of the disaster, including school nurses, daycare providers, and health clinics. He questioned whether it is cost effective to train first responders in mental health services if they will not be there in the long-term recovery stage. Participants noted a gap in the delivery of both services and training not only at child serving government agencies but also at Boys and Girls Clubs, YMCA's and faith-based centers, noting that faith-based organizations can be important centers for promoting trauma resilience and empowerment.

2. Lack of Services and Failing Infrastructure in Normal Times

Participants noted that the day-to-day resources of child-serving systems such as child welfare, schools, and juvenile justice are already stretched extremely thin. Services are often lacking and much of the infrastructure of these systems is already failing in normal times, before a disaster ever strikes. This makes it difficult to provide ramped up services in times of disasters when struggling systems are even more overwhelmed. It was noted that mental health screening is not currently required in juvenile justice facilities in normal times so there is no concrete knowledge of the mental health needs in these facilities prior to a disaster. Other programs, such as No Child Left Behind, do not include provisions for the improvement of the social and emotional well-being of children. The lack of school-based mental health providers as well as after school and faith-based mental health programs was also identified as a challenge.

3. Funding

Although a few current Federal programs exist that could be utilized to provide recovery services in congregate care settings, funding is provided to states by grants with difficult deadlines and application requirements. Participants noted that mental health services must occur in a holistic manner based on individualized timelines, not centered on timelines associated with rigid programmatic funding streams. It was also noted that current federal programs such as the Crisis Counseling Program, do not fund treatment and medication, only basic counseling and outreach. Participants stated that funding for treatment and services is also complicated when families relocate across state lines because of issues with Medicaid eligibility.

One participant noted that it is unclear what federal funding and support is available, especially in the pre-disaster planning phase, and consequently few local professionals have the requisite institutional knowledge about possible funding options to develop pre-disaster plans that adequately address services in long-term recovery. The participant suggested that a group convene to identify funding sources. The group could sponsor annual conferences for local and private organizations that will develop preparedness plans.

4. Pre-Disaster Preparedness and Planning

Participants noted that day-to-day infrastructure gaps need to be addressed prior to a disaster, and that plans should be in place to provide relevant services in an emergency, and even during a non-emergency period. Additionally, participants noted the current lack of pre-disaster planning among schools, non-profit, and faith-based organizations that have the capabilities to provide disaster mental health services.

5. Evaluation and Information Sharing

Participants decried the inability to research and monitor outcomes for individuals served by the Crisis Counseling Program as a result of the limitations of the Stafford Act. It was noted that funding for this type of evaluation and research is needed in order to improve programs and services. Participants also noted the lack of capacity and capability to share lessons learned and best practices among service providers and professionals who work with children, citing the absence of a centralized platform. Participants mentioned that there is no technology in place to support or enhance the system of care, including communication and education tools.

6. Limited Scope of Current Programs and Services

Participants noted that at the most basic level, providers and policy makers must consider mental health equal in importance to physical health. In addition, participants observed that it is important to recognize that children will need broader services than just those related to trauma, such as services that include bereavement support. These factors are not considered in the current state of federal programs, where rigid programmatic guidelines prevent the broadening of services. In addition to a broader continuum of care, it was stated that there must be continuity of care from the pre-disaster period, to post-disaster, to long-term recovery in order for mental health services to be effective. Finally, participants mentioned that sensitivity to cultural competency often remains absent from the provision of mental health services to children and family in the aftermath of disasters. Specifically, it was noted that different populations have different needs, including issues related to language and the cultural acceptance of mental health care outside of the family.

B. Recommendations

Participants were divided into five groups and focused the following five recommendations: (1) enhance capacity and planning, (2) develop flexible funding mechanisms, (3) reform current programs, policies and authorities, (4) focus on the family, and (5) enhance and standardize training.

1. Enhance Capacity and Planning

Participants discussed how to improve the capacity of child serving systems in order to achieve the desired state of fostering emotional well-being in the recovery phase of disasters. Participants recommended that the Commission examine the federal laws and regulations that have authority related to the systems and programs that impact children, for example, grants addressing education, juvenile justice, child care and child welfare. The federal government should clarify who should have specific roles and responsibilities in delivering mental health services in the recovery phase of disasters. Participants recommended that federally funded programs to states should require state plans to include disaster plans that meet children's mental heath and emotional and social well-being following a disaster. One example of this would be to require state juvenile justice agencies to have such plans in connection with the funding they receive pursuant to the Juvenile Justice and Delinquency Prevention Act. Participants also recommended there be a requirement for states to create a single unified plan for children in disasters spanning the whole continuum from preparedness, to post-disaster, to long-term recovery, rather than by individual agency or organization. This would help to ensure a holistic approach to all aspects of care for children during disasters, including mental health care for children in congregate care facilities.

Participants also noted there should be a more coordinated effort among federal agencies in the delivery of mental health services. This could be achieved by forming a formal organization or interagency workgroup to enhance coordination among individual agencies. Participants recommended that federal partners offer training and technical assistance to states and their partners that incorporate evidence-based and promising approaches to mental health services in schools, juvenile justice facilities, and other congregate care centers. It was noted that in order to be successful, programs must be culturally competent and sensitive to the populations that they serve.

Regarding schools specifically, participants suggested that funding for school psychologists, social workers, and other mental health care providers who are part of the school infrastructure in normal scenarios and in disasters be included in the reauthorization of the Elementary and Secondary Education Act. Participants also recommended that the Office of Safe and Drug Free Schools, which has been successful in taking an all hazards approach for school safety, institutionalize the availability of interdisciplinary teams for post-disaster consultation and just-in-time training.

Finally, participants recommended that the National Incident Management System (NIMS) include behavioral health as a component of all disaster preparedness activities and integration of disaster

behavioral health in all disaster preparedness grants. In addition, the National Disaster Recovery Framework must include long-term disaster mental and behavioral health as a core component.

2. Develop Flexible Funding Mechanisms

Participants developed the following issue statement around the need for flexible funding mechanisms for services in long-term recovery:

> *"Funding for long-term mental health services for children after disasters is not adequately prioritized or funded, nor effectively integrated within broader community recovery efforts. Furthermore, funding regulations and mechanisms need to be flexible to adapt to the full range of services required to ensure long-term recovery*."

Participants stated that in order to justify funding, the Commission should highlight and underscore the desirability, feasibility, and efficiency of delivering mental health services for recovery of children within congregate care settings, including those facilities that support infants and toddlers such as Early Head Start Programs, early child care, and early intervention services. It was noted that the rationale for providing services in these settings is supported by the fact that several congregate care sites, such as juvenile justice and child welfare systems, are characterized by pre-existing high rates of mental health issues that place children at particularly high risk in the aftermath of a disaster.

In order to help direct funding priorities and support local and state efforts to effectively plan for recovery, it was suggested that the Commission should clearly define what constitutes holistic mental health recovery for children and families and how long-term mental health needs, services, and recovery are both conceptualized and operationalized. This definition could be incorporated into the National Disaster Recovery Framework currently under development.

Participants also noted the need for clarification of potential uses and capacity for funding of long-term mental health services for children in congregate care sites. Such information should be readily available, easily comprehensible, unambiguous, and well-known prior to a disaster to inform preparedness planning at the local, state, and tribal levels for mental health recovery services for children and families. This clarification should not restrict the flexibility that is still required for addressing unanticipated but critical needs for long-term mental health recovery.

Finally, participants suggested that funding be designed to ensure a seamless transition without interruption of services from response through long-term recovery, and from federally-funded to state or locally supported mental health recovery services. Changes in the nature and extent of services provided would be dictated by the evolving needs of clients, rather than the funding mechanism or source.

3. Reform Current Programs, Policies and Authorities

Participants suggested that federal policy and programs related to the delivery of mental health services to children in recovery should reflect research and evidence-based practices. It was recommended that changes should be made to allow for treatment in long-term recovery to address pre-existing mental health conditions, as these may be exacerbated following disaster-related trauma. Currently, counseling services must respond only to event-specific trauma, operating under the assumption that every child had the same mental condition prior to the event. Another suggested change was to allow for the timeline for the provision of services to be more flexible and not tied to the date of the Presidential disaster declaration. Currently, counseling programs expire (without an extension) 18 months following the declaration of the disaster. This does not consider that there may be a delayed response to the disaster or enduring struggles in long-term recovery. Participants mentioned that current programs focus too much on trauma and should expand their scope to include bereavement support and resiliency building. Participants also recommended that authorities be created to allow for the funding of outcome assessments that measure program effectiveness. This would inform and improve future efforts. To enhance the ability to learn lessons from past efforts, participants recommended creating a website for historical information that would allow for information sharing with respect to best practices and lessons learned so that states have examples of successful initiatives.

4. Focus on the Family

Several participants recommended providing relationship-based behavioral services that focus on the well being of the entire family unit, including children and their caregivers. Participants developed the following issue statement around the importance of targeting the family unit when delivering behavioral health services in long-term disaster recovery:

> *"A child's mental health well being and recovery is dependent upon the well being and recovery of the family, defined to include caregivers. It is in the best interest of children that the Commission recognizes and targets the family/caregiver as the conduit for the delivery of all services in a holistic and integrated approach to long-term disaster recovery."*

Participants recommended identifying how services in congregate care sites for children can interface with and support complementary services for adult family members and ensuring that funding mechanisms promote and support such integration. One strategy to ensure that behavioral health services target the family unit would be to support the inclusion of family/caregiver-centered services in Medicaid funding. It was noted that family-focused care is particularly critical for children ages 0-3, when it is important for mothers to form healthy relationships with infants and young children, especially following disasters.

5. Enhance and Standardize Training

Participants suggested implementing specialized training and technical assistance for professionals who work with children including teachers, early child care providers, pediatricians, and others to promote awareness and capacity building in addressing the psychological, behavioral and educational impact of disasters on children. Participants identified the need to fund and support professional education programs as part of continuing education requirements that focus on disaster mental health and social and emotional needs to endow these professionals with necessary skills.

Participants crafted the following issue statement around the development of training standards for professionals who work with children in congregate care systems:

> *"What is the role of the federal government and its partners in creating a broad-based coordinated system of mental health disaster training that addresses the full continuum of services for children of all ages, and their caregivers?"*

In response to the above stated question, participants suggested that incorporating language into the National Disaster Recovery Framework regarding the importance of providing training on basic disaster behavioral health issues to professionals who work with children in congregate care settings would be an important first step. Participants suggested that disaster mental health training for child care staff could be a component of the accreditation of child care centers, such as the voluntary accreditation system of the National Association for the Education of Young Children. Other suggestions included revising the Head Start regulations to include a requirement that all staff receive training on the full continuum of mental health disaster services (e.g., from preparedness to long-term recovery, including loss). Participants suggested that schools receiving Safe and Drug Free Schools funding should require teacher training in the full continuum of mental health disaster services, and that the Community Emergency Response Team (CERT) program and Medical Reserve Corps (MRC) expand training to include child disaster behavioral health components. At the state level, participants suggested that language mandating training be included as part of grant requirements.

IV. Breakout Session: Barriers to Information Sharing and Data Collection

Workshop participants in this breakout session were asked to consider the following issue:

> What policy changes are needed so that the federal government can effectively collect and share data on children with state and local government agencies and voluntary organizations to facilitate evacuee tracking, family re-unification, disaster case management, and the delivery of social services? Specifically:
>
> > 1) What type of information should be collected and shared and who should information be shared with?
> >
> > 2) What are the barriers to information sharing under current laws and policies, and what modifications are necessary to improve sharing of personal information for purposes such as evacuee tracking and delivery of services?

Workshop participants also reviewed the Commission's relevant Interim Report recommendations:

- Develop a standardized, interoperable national evacuee tracking and family reunification system that ensures the safety and well-being of children, and
- Review and modify current privacy policies and laws to permit the timely sharing of relevant disaster victim information among federal, state, local, tribal and non-governmental agencies and organizations engaged in supporting children and families affected by disasters, when it is clearly in the best interest of children to do so.

A. Challenges

Participants identified four main categories of challenges: (1) scope and type of data for collection, (2) tracking system design, management, and maintenance, (3) consistency in interpreting regulatory materials, and (4) outreach and funding.

1. Scope and Type of Data for Collection

Most participants noted that it is necessary to identify and define what types of data need to be collected and shared, identify the sources for such data, establish standards for data collection to ensure relevant information is being collected, determine any overlap of data collection efforts and needs across entities to reduce redundancy, and determine if data needs change based on the type and/or level of disaster. Similarly, ensuring uniformity and quality in data collection was an expressed concern, as was the need to ensure interoperability with the array of existing systems that currently track relevant data. It was also noted that because of issues like budget restraints and varying technical abilities, the capacity to collect quality data varies widely. Some participants noted that an entity's data needs vary depending on a

child's needs, contact time, and other conditions. Related to this is the question of whether data will be used solely to track individuals, or rolled up for interpretation and use at an aggregate level.

Many participants noted that data collection for use in disaster response and recovery should start before a disaster occurs, though authority would be needed to do this. It was widely agreed upon that data collection should be built into planning efforts. Thought should be given to how to capture information on all children (in schools, child care centers, etc.) that may be in a disaster area. Additional topics recommended for consideration included when the data could be made available, who enters the data, and the level of access to this data afforded to a variety of entities.

Finally, several participants noted a need for a clearly defined trigger allowing for information sharing to begin, and a way to cover liability for the person "pulling the trigger." Associated with this, there is a need for better understanding of the point at which a child's safety and well being (potentially requiring information exchange) becomes more important than privacy concerns.

2. Tracking System Design, Management and Maintenance

Participants stressed the need to carefully define all aspects of a tracking system itself and the importance of creating and defining a common lexicon.

Participants noted that in developing a system, leaders should take care to include all organizations that deal with children. It is extremely important to consider the potential for integration of existing systems of information collection – including schools, courts, health care providers, welfare, law enforcement, and other relevant entities – with a national tracking system. Several participants expressed concern as to whether a single platform could exist that catered to the varying technical abilities of entities at the state and local levels, and questioned who determines what sort of system is adequately standardized and interoperable. One participant noted that the Health Insurance Portability and Accountability Act (HIPAA) mandated standard/interoperable claims processing, and to review lessons learned associated with its implementation.

Participants also noted that issues related to system accessibility need to be detailed, including who has access to the system, when it can be accessed and for how long, the process for gaining access, and identification of system safeguards. Additionally, some participants stressed that there needs to be contingency plans for when systems are not available, an alternate means of providing service, and a review and implementation of IT capacity and system redundancies.

In regards to management of a tracking and reunification system, the primary concern revolved around what agency or entity would be responsible for system operation and management. Many participants noted that there should be an agency or organization that can be held accountable for the system and system management, and that support for a system would require full funding and staffing. However,

other participants noted that there would likely be less of a Federal presence than a state, local, and non-governmental presence in system maintenance and perhaps even overall management.

3. Consistency in Interpreting Regulatory Materials

Participants acknowledged challenges for information collection associated with existing laws and policies meant to protect the individual's right to privacy, and the need to identify any potential missing policy regarding relevant authority, clearance, and access issues. However, participants also noted that it is important to determine if there are true barriers in the law or if there are simply perceived barriers due to interpretation of the law, and to discriminate between law, policy, and guidance. If there are true barriers, it will be necessary to address these challenges, and potentially gaps, in the law.

Some participants also noted potential conflicts between Federal privacy laws and policies and state laws, with the Family Education Rights and Privacy Act (FERPA) being cited as a primary example. Many participants agreed that there is a need to understand the varying nature of state laws with respect to disaster tracking and reunification, information sharing, and privacy rights.

4. Outreach and Funding

Participants agreed that outreach aimed at improving public awareness of the need for data collection and sharing for the purpose of evacuee tracking and reunification of children with caretakers/families following a disaster is necessary and should be a priority. Funding was also identified as a key challenge, particularly if states view development or use of a tracking system as an unfunded mandate.

B. Recommendations

Participants discussed recommendations for improving information sharing in four areas: (1) define the scope and type of data for collection, (2) detail the design, management and maintenance of a tracking system, (3) review all relevant laws and policies and establish guidance on their application, (4) conduct outreach efforts and address funding needs.

1. Define the Scope and Type of Data for Collection

Participants suggested that articulation is needed on the type of data to be collected and data sources need to be identified. Suggestions for data collection included information on physical characteristics, digital photographs, and possibly DNA-based identifiers. Some participants stressed that the scope of data collection should be focused on information related to family tracking and reunification only. Other participants stated that limiting the scope to reunification was too narrow, as in certain events, there might not be anyone to reunify with.

Participants suggested that information collection begin before a disaster occurs, though authority would be needed to do this. Some participants proposed implementing a universal identifier for children assigned during school enrollment and activated upon declaration, with a release secured during school registration, to ensure that all children can be tracked. Participants also suggested that similar releases could be signed at other places that come into contact with children, including day care centers, doctor's offices and courts.

Participants suggested identifying a trigger that would allow for information sharing during catastrophic events, and a way to cover liability for the person "pulling the trigger." There was also wide agreement that the trigger should not solely be a Federal disaster declaration, as most emergencies that may require information sharing do not reach the level of a Federally-declared disaster.

Participants also expressed concern about data quality, when data can be made available, who enters data, and the level of access to this data afforded to a variety of entities, though specific recommendations to address these challenges were not formulated. Several participants suggested access to information should be based on need, though this also must be defined further.

2. *Detail the Design, Management and Maintenance of a Tracking System*

Participants suggested developing a common lexicon to describe a tracking system – including creating standard definitions of relevant terms like "tracking" and "safety and well-being" – and to carefully define all aspects of the system itself. They also noted that in the development process for a tracking system, leaders should take care to include all organizations that deal with children.

Participants also suggested researching the feasibility of integrating multiple platforms to create one system for sharing information related to children during disasters. Along these lines, participants noted that it would be most efficient to develop a system that integrates existing systems and data collection points. It will be important to identify the entity or group of entities that determines or deems systems adequately standardized and interoperable. Additionally, the system would also need to detail the direction of information sharing (e.g., federal to state, state to state, government to NGO, public to private, etc.).

Some participants noted that the National Crime Information Center (NCIC) may provide a good model for a tracking and reunification system, albeit with limited access. Other participants suggested implementing a pyramid model of data sharing. At the top of the pyramid would be agencies and entities that need less and less specific information, including aggregate data, with more specific information shared further down the pyramid. An increase in the level of contact with children and families would correspond to an increased quantity and specificity of information required, and therefore be associated with organizations represented toward the base of the pyramid.

Participants noted that system accessibility should be detailed to protect sensitive information. Specifically, details related to who has access to the system, the process for gaining access, when it can be accessed and for how long, and identification of system safeguards should be developed. Additionally, some participants stressed that IT capacities and system redundancies need to be reviewed and alternate plans must exist for when systems are down.

Similarly, some participants suggested that there needs to be an ability to transfer in and out of lower bandwidths to preserve the ability to communicate, especially if systems go down. Furthermore, several participants noted that some localities have implemented paper forms that are easily scanned into an electronic database, with the hard copy serving as the redundant receipt. Participants also underscored the importance of maintaining data in multiple locations to ensure business continuity.

Participants noted that responsibility for a system should not rest within a single federal agency, suggesting an overarching body representing multiple agencies and entities with knowledge on information sharing be established. This body would oversee operations, management, and maintenance of a system. Furthermore, it could serve as a national level leader or advocate, pushing this agenda (i.e., the need for a cohesive information sharing system) forward.

This council would also need to be supported by a well-represented advisory body, consisting of public and private representatives, government (Federal, state, local and tribal) and non-government entities, and all other organizations that have responsibility for children. All roles must be well-defined and balanced.

3. Review All Relevant Laws and Policies and Establish Guidance on Their Application

Many participants felt a major impediment to information sharing occurred in interpretation of privacy laws and policies, and on several occasions suggested a full review of these laws and policies. Participants felt this review will help distinguish any true barriers and gaps that exist in the law from perceived barriers that can actually be addressed by unified guidance on application of the law.

One participant suggested contacting major education associations (e.g., National School Board Association) to discuss what government guidance would help school districts apply the health and safety emergency exceptions of FERPA. Likewise, each privacy law could be discussed with a relevant or corresponding national association whose members are familiar with the laws.

Some participants suggested creating a government portal that presents guidance and outreach related to all relevant privacy issues (e.g., privacy.gov). This one-stop-shop would present all privacy-related information and guidance, identify data fields that are tracked in the standardized system, and be a valued resource in situations where protection of privacy and sharing of information are dual, and potentially conflicting, concerns.

4. Conduct Outreach Efforts and Address Funding Needs

Participants recommended conducting outreach to ensure buy-in to information collection and sharing efforts. A public relations effort explaining the need for information collection and sharing during calm periods, explaining the roles FEMA, schools, child care, child welfare and other entities that interact with children and families will help parents embrace these efforts. Some participants also suggested leveraging the knowledge of school superintendents to supplement development of trainings and guidance on children and disasters related to information sharing. Another recommendation was to establish incentives to promote information sharing, so local entities already collecting information would be less likely to view this as an unfunded mandate.

Several participants noted the need to detail the necessary funding and identify sources of funding to support development of an integrated tracking system. It was suggested that while the effort must be staffed, overall cost could be reduced if information does not have to be collected outright, but can be attained from existing entities, to develop the initial database.