The 9/11 experience: who’s listening to the children?

Harold S. Koplewicz, MD*, Marylene Cloitre, PhD, Kimberly Reyes, BS, Lena S. Kessler, BA

New York University Child Study Center, 577 1st Avenue, New York, NY 10016, USA

The terrorist attack on Sept. 11, 2001, has the distinction of affecting more children than any other lone act of violence in the United States. In New York City alone, over 5000 children experienced direct exposure to the World Trade Center attack or the traumatic loss of a parent. This sum reflects a collection of incidental facts. The attack occurred at the beginning of the school day, at the beginning of the school year, and in an area dense with schools, thus exposing a larger number of children than otherwise would have been the case. In addition, the average age of the World Trade Center employees who died on 9/11 was early 40s, meaning that an unusually high percentage of those killed were parents of children and teenagers.

In the 2 plus years since 9/11, survey research has indicated that a substantial number of children have developed psychiatric disorders, severe psychological distress, and functional impairment. Despite significant financial support, the availability of mental health services, and the presence of relatively sophisticated mental health providers, a surprisingly large gap has emerged between documented need and service use. This article identifies some of the factors that appear to have contributed to this situation and potential remedies for ongoing difficulties. More broadly, the authors hope that the events of 9/11 and the ensuing efforts to intervene with distressed children will, at a minimum, help identify the factors that are critical to the development of successful mental health programs for children exposed to community disasters and large-scale violence.

* Corresponding author.

E-mail address: harold.koplewicz@msnyuhealth.org (H.S. Koplewicz).

0193-953X/04/$ - see front matter © 2004 Elsevier Inc. All rights reserved.
doi:10.1016/j.psc.2004.04.001
Based on findings from research conducted in New York City following 9/11 and other related child trauma research, the authors propose that effective mental health services planning for traumatized children requires:

- Awareness of the traumatized parent
- Flexibility and diversity in the provision of interventions
- Context sensitivity: programs and implementation plans must have high feasibility and acceptability to the community
- Development and evaluation of alternative programming intended to facilitate community and family engagement

The gap between available services and their use

Unparalleled resources were provided for mental health services to children psychologically affected by the 9/11 terrorist attacks. There was substantial outreach to affected communities through advertisement of available services, and significant efforts to streamline access procedures for these services. Yet, a significant gap emerged and remains between the reported mental health needs of New York City children and the use of available services. Four months after 9/11, a random-digit dialing phone survey found that among New York City children and adolescents (ages 5 to 17), 18% had severe-to-very-severe post-traumatic stress reactions, and 66% had moderate reactions. Only 10% of those sampled, however, had received some type of counseling [1]. Six months after 9/11, traumatic stress reactions among New York City public school children were three times greater than expected based on rates in comparable urban environments; still, approximately two-thirds of those children did not obtain any mental health services [2]. Despite intervening education and media campaigns, 2 years later, the picture remains the same. A recent survey revealed that 70% of parents with children directly exposed to 9/11 were concerned about the psychological health of their children, yet less than half of these parents had accessed mental health services [3].

Awareness of the traumatized parent

One of the most important influences on a child’s experience of trauma is the parent’s health and well-being. The ability of preschool and middle school children to manage stressful situations is strongly contingent upon parents’ behavioral and emotional reactions. The maxim that “the child is only as healthy as the parent” has been supported in several studies. Following World War II, a study [4] assessed the impact of parental distress on children’s response to air raids and evacuations in London. The children, selected from a population receiving services from a mental health clinic, were found to exhibit more behavioral and emotional problems if their parents were distressed as compared with children whose parents were less
anxious. More recently, Sack et al [5] showed that the rates of post-traumatic stress disorder (PTSD) escalated in a sample of Cambodian refugee children from 13% when neither parent had PTSD, to 23% when one parent had a diagnosis of PTSD; if both parents had PTSD, that number almost doubled to 41%.

Looking at both parental and familial characteristics Laor et al [6] found that following SCUD attacks, poor family or maternal functioning predicted negative post-traumatic outcomes for 3- to 4-year-old Israeli children. In a comparison study of the influence of caregiver versus other environmental and social factors on children’s distress, Scheeringa and Zeenah [7] assessed the relative impact of six factors on rates of PTSD in a sample of traumatized preschoolers: proximity to event, duration, injury, age, gender, and caregiver involvement. Higher rates of PTSD were found only if the caregiver had been physically threatened by the traumatic event; the other five dimensions were not related significantly to symptomatology. The authors proposed that the child’s observation of physical threat to the parent may convey a sense of the seriousness of the situation and elicit fear of losing the parent. Alternatively, a parent’s experience of threat may diminish his or her capacity to adequately attend to the child, modulate the child’s feeling state, and promote adaptive coping responses.

Reports concerning the relationship between parent and child psychological symptoms following 9/11 are similar to the World War II and Israeli data. Stuber et al [8] found that parent’s own level of post-traumatic stress strongly predicted children’s enrollment in counseling services. Furthermore children (ages 6 to 11) and adolescents (ages 12 to 17) were 11.1 and 4 times more likely, respectively, to exhibit behavioral difficulties if parents reported difficulties coping with their own emotions [9].

There is also evidence indicating that if either parent or child is psychologically distressed, the risk for negative mental health outcomes for the other is increased. A dynamic can emerge in which both child and parent respond negatively to one another. Scheeringa and Zeenah [10] describe this as a compound effect, where each member of the dyad exhibits symptoms that negatively influence the other, creating worse outcomes for both. For example, if the parents are attending inappropriately to their child’s concerns and feelings, the child may begin exhibiting or increase negative behaviors. In response, the already distressed parents may over-attend to the child (e.g., repetitive inquires about the trauma) or alternatively avoid traumatic reminders and impose excessive restraints on the child’s activities.

To minimize such outcomes, Crockenberg and Leerkes [11] suggest that the parent participate in the child’s treatment and that the parent’s problems be addressed first. Methodologies that involve cognitive–behavioral treatments, infant–parent psychotherapy, touch/massage therapy, and interaction guidance [12–14] have been successful in improving the relationship between child and parent.

More importantly, the inclusion of a parent in the child’s treatment enables the parent to act as a secondary therapist [15]. The goals of parental participation are to assist the child in regaining a sense of security, acknowledge the child’s feelings, and provide appropriate emotional support when needed. Such goals are met through psychoeducation about the consequences of trauma on both the child and the parents. Ideally, this approach facilitates the recovery process in the therapeutic setting and extends its reach to the home and social environment. Parents’ understanding of trauma-related reactions in their child allows them to better anticipate and accurately interpret their child’s behaviors, thoughts, and feelings and respond effectively to them as they occur [16]. In addition, understanding their own traumatic reactions, including perceptions of their child’s functioning, can facilitate parents’ day-to-day coping [11].

**Flexibility and diversity of interventions**

Because disasters are by definition traumatic events, there is a tendency to turn to trauma-focused treatments as a guideline for action. Data suggest that while this approach may be effective for adults, it may not be the most appropriate strategy for children. The largest and most methodologically rigorous study completed on adults in New York City, 6 months after 9/11, revealed substantially high rates of probable PTSD [17], indicating that implementation of PTSD-related interventions would be a priority. In contrast, the largest and most well constructed survey of children indicated much more diverse responses, particularly by age [2].

In this study commissioned by the New York City Board of Education, over 8000 public school children were surveyed on a range of psychological problems, which were mapped onto diagnostic categories. There was a distinct divide in the rates of disorders by age. Between the ages of 8 and 10, the two most common disorders were separation anxiety and PTSD. In contrast, with the 15 to 18 year olds, agoraphobia and conduct disorder were the most common. A review of the child trauma literature by Lubit et al [18] identified characteristic trauma reactions by age group. Their review found that preschoolers tend to express fear through avoidance of new activities; middle school children avoid school and become preoccupied with danger and reminders, and adolescents engage in new or increased aggression and substance use. The contrasting patterns in frequency of disorders may reflect the specific developmental vulnerabilities of each age group. For younger children, salient developmental goals concern anchoring a sense of personal safety with the parent as a reference point. In contrast, adolescents are exploring and uncertain of their identity; they tend to orient themselves away from the home, experiment with new behaviors, and reference their peers as guides for their behaviors. The teen years are associated with increased risk for depression, irritability, substance abuse,
and risky sexual behaviors, and these risks are increased in the presence of significant traumatic events [19].

These data suggest caution in automatically implementing treatments that focus on PTSD symptoms. Rather, the availability of developmentally appropriate, empirically supported intervention modules, each of which targets the most commonly occurring postdisaster problems (e.g., anger, depression, and bereavement) would accommodate diverse needs better. Although there have been some concerns about the translatability and clinical utility of empirically based treatments whose support rests on their application in academic settings, several studies have found that empirically supported manual-based treatments (ESMBTs) maintain clinical effects when translated to community practices [20–25]. Nevertheless, few of these studies involve children and expenditure of future funds for these adaptations will depend on demonstrating that such treatments are superior to usual clinical practice.

The effectiveness of a flexibly applied modular treatment package compared with “treatment as usual” is underway in a treatment study of children in the downtown New York City area [26]. Further advances might be considered where the process of selecting building block modules is implemented through collaboration between the module developers and representative members of the affected community, including mental health experts and providers in the community, school leaders, and parents. The potential value of this type of program planning is described subsequently.

**Sensitivity to context: programs and their implementation must have high acceptability and feasibility to the community**

The success of postdisaster mental health programs requires that the programs be seen as potentially valuable and therefore likely to be used. In addition, the programs must provide motivation and incentive for participants to complete the assessments necessary to determine the effectiveness of the programs. Under postdisaster circumstances, the concerns of the individual and the community tend, by necessity, to be limited to immediate and personal needs. At best, traumatized communities have little energy to devote to somewhat abstract and far-off gains related to program evaluation. At worst, anger and suspicion emerge toward researchers or relief agencies that appear self-interested and may stand to benefit from others’ pain and difficulty. These problems are exacerbated when programming involves children, as there are acknowledged legal and ethical requirements that adults must protect them from potential harm and exploitation.

Creating a good fit between a program and a particular traumatized community requires that the program be feasible and acceptable to the community. In-school counseling is not feasible if there is overcrowding in classrooms, and hallways are the only free space for counseling.
After-school programming is not acceptable in high-crime neighborhoods where children would be let out after dark, and parents are on their second job shift.

Prefabricated, empirically tested programs inevitably will undergo adaptation as feasibility and acceptability concerns emerge in the community. Issues such as immigration, citizenship, level of acculturation, language, family roles, gender roles and identity, religious beliefs and practices, and community involvement and support must be understood and integrated into assessment and treatment [27,28]. These issues can be addressed best if relief organizations or clinical/research groups initiate partnerships or have a pre-existing relationship with members of the community, particularly those in trusted leadership positions. Community leaders and institutions, particularly those with the same ethnicity, language, and values as the larger share of the community may act as a conduit of information and facilitate the translation process between needs identified by the community and services proposed by a relief organization. The development of trust and mutual respect between the community and the service planners is a prerequisite to the development and implementation of effective treatments.

One increasingly popular way of achieving good fit between program providers and community members is community-based participatory research (CBPR) [29]. In this model, the research process begins with the inclusion of members of the affected community, or stakeholders, to identify the community needs and goals. This fosters an experience of social agency among community members, which is especially important when working with traumatized communities that have experienced a reduction in resources and capacity for self-determination. Although not without difficulties, including community members and community-based service providers as partners in research processes is not only a matter of respect; it also increases the ability of researchers to identify, understand, and effectively address key issues.

Community-based participatory research often includes stakeholders, such as community and research administration members, and participating families in the advisory board to the research program plan. In some CBPRs, collaboration is sought on program objectives and services, and data interpretation, while design, execution, and data collection lie solely in the hands of the researchers. Other programs use more full-spectrum participatory models in which stakeholders share responsibility in problem-solving implementation issues, choice of assessments and instruments, ownership of data, and choice of a research institution. Negative reactions to certain aspects of research, which for some programs are unchangeable (eg, random assignment or nationally based assessment measures), can be diminished by preemptively introducing general principles of research and researcher roles and interviewing and data collection activities. Additional aspects of this collaborative approach that lead to its success include:
employment of community residents as research staff; sharing of preliminary findings with program/community (if appropriate to study design and goals); and having focus groups with staff, family, and researchers at every step of the research process.

The school as an example of community: treating children where they live and work

There are a few short-term mental health programs that have been implemented in schools following significant traumas that have reported successful outcomes [30–32]. There are several benefits to implementing such programs in schools. First, schools provide the largest concentration of children of any community environment. Second, schools also represent the setting in which children spend the largest portion of their day. It is the environment in which they socialize, make friends, evaluate themselves, and learn about the world. Schools are where children live and work. The implementation of postdisaster services in the schools provides an opportunity to reach a large number of children in a relatively rapid and streamlined way. Furthermore, the availability of mental health services at schools may reduce logistical barriers to accessing care (eg, no travel costs) and destigmatize the use of mental health services, as it is more likely to be viewed as part of the natural landscape of the children’s world.

School-based programming also provides a way of connecting with the hard-to-reach, primarily minority and impoverished children who otherwise would have very few resources to access care in more traditional mental health settings. The success of trauma programming in schools has significant implications for enhancing the psychological and social well-being of children. The number of students across the country who experience a traumatic event, including community or domestic violence or some type of interpersonal abuse, is significant and continues to rise [32]. These experiences are related significantly to impairment in all domains of functioning. In addition to identifying and resolving acute post-traumatic psychological disturbances, trauma programming that includes psychoeducation about stress, violence, and trauma has the potential to decrease the risk of violence-triggering events (eg, bullying, hazing activities) and interrupt the development of long-term sequelae such as substance abuse, increased impulsive behaviors, and sexual misconduct.

The process of implementing trauma interventions in the schools requires the partnership efforts similar to those described previously. Such projects require trust among partners, additional time commitments by school staff, adaptation to the logistics of the school day and its structure, maintenance of confidentiality, identification of space, and equitable distribution of funds [20,29]. Specifically, school counseling staff need to be open to learning new techniques for identifying and treating traumatized children, and committed to spending time on being trained. School staff need to be agreeable to the
notion that the treatments being used are evidence-based and accept an adherence or intervention monitoring system. Conversely, program administrators, research clinicians, or outside mental health professionals need to adapt to the limits of time and space and pre-existing programs that already work well for staff and students. It is inevitable that the transition of an intervention program “from the manual” to the classroom will not work point-for-point. Typical adjustments involve providing shorter treatment sessions, less time for client and clinician feedback and clinician supervision, and ongoing adaptation to real-world variables such as varying cognitive abilities within grades, presence of comorbidities, caregiver involvement, and the possibility of ongoing traumatization and associated safety concerns.

The success of a trauma treatment program can be enhanced by providing support to the teachers, parents, and school community in generating interest and positive reactions for the program. This includes satellite activities such as psychoeducation and dissemination of relevant materials to clinicians, teachers, and administrative staff through workshops, provision of lectures in community venues, and mailing materials about the program to parents, students, and community leaders. In addition, those implementing the programs should be prepared to serve as a referral source for needs that go beyond the expertise of program staff.

Engaging the community, families, and children

Despite documented high rates of psychiatric disorders and the best efforts by program developers, a substantial portion of a traumatized community may remain uninterested in, unaware of, or resistant to mental health programs. This may reflect the perception of mental health services as stigmatizing to children or irrelevant to the immediate needs of children and their families. Identified needs often relate to desire for increased safety, the return or securing of material resources (ie, housing, food, or transportation), and mechanisms for rapid information dissemination about safety and resources. Community initiatives after 9/11 have included collections of needed items for other community members, childcare and child transportation schedules, development of Web sites, and fund-raising events Litz et al [33] have noted that such actions are an effective means of facilitating physical and economic recovery. Such efforts are based on principles of solidarity and assistance among those in the community. Accordingly, these attitudes and actions may serve as an excellent antidote to the lost or diminished sense of competence, mastery, and safety that community disasters engender.

Substantial benefits could emerge if mental health service providers consider partnering in these initiatives as a regular feature of post-trauma
programming. To the authors' knowledge, there has been no systematic research on the mental health benefits of grassroots community programs. Such information would be useful in organizing future mental health plans and outcome assessments. Minimally, mental health partnerships with community programs could allow for the development of positive relationships with a community and act as a bridge between the community and traditional mental health services, increasing the number of families willing to consider mental health services and increasing the number of pathways to the services.

Some types of community initiatives lend themselves easily to functioning as bridges or common ground between the community and mental health providers. These include the community initiatives such as the creation of murals, quilts, and parks as commemorative activities (eg, November 2001 Rally for Recovery, available at http://www.columbia.edu/cu/news/01/11/rally_recovery.html) [34]. For children and adolescents, community or school-based art and theater programs can function as an effective portal of entry into the mental health system. These activities attract youth, as they are more familiar, interesting, and potentially more comforting than cognitive–behavioral interventions or supportive counseling. In addition, such activities may initiate the process of recovery. Given the nature of these programs, namely self-expression in the context of a structured environment, children can begin organizing and articulating the often fragmented memories, confused thoughts, and conflicting emotions that are intrinsic to traumatic reactions [35]. Reduction of these difficulties may lead to greater interest, acceptance, and confidence in the potential value of focused attention to the emotional aspects of trauma recovery (ie, traditional mental health services). Systematic empirical investigation would require the assessment of the relative mental health benefits of each component (community programs and psychotherapy) in sequence, alone, or in combination.

**Looking toward the future: growing resilience**

The ability to adapt well to surroundings and to changes occurring in those surroundings is spoken of as competence. The term resilience refers to the ability to retain competence after an adverse event [36]. Interest in resilience increased after 9/11, following the realization that the threat of terrorism and other large-scale violence may become part of the ongoing American experience, joining that of many other nations around the globe. Focused effort to enhance resilience in children is seen as one way to effectively prepare for, respond to, and perhaps reduce the presence of political, community, and other forms of violence.

Resilience has been identified as emerging from at least three sources: internal or personality attributes, family structure, and extrafamilial support.
systems. Individual characteristics associated with resiliency are easy temperament, social competence, ability to problem-solve, optimism, self-directedness, sense of humor, intelligence, and emotional/behavioral adaptability [37,38]. Environmental or social characteristics include the presence of responsibilities and tasks for children that are developmentally appropriate, the presence of boundaries in the family and community in regards to role development, and a community that supports children as integral members of society [39].

Many characteristics that are thought to help with resilience are considered to be outgrowths of self-regulation. Children’s ability to control their emotions, actions, and attention has been associated with characteristics such as effective social adaptation [40]. Self-regulation is influenced strongly by parenting behaviors and the interactions between parent and child [41]. Indeed, a central task of parenting in the early years involves the creation of emotion-regulating experiences for the child. Because of the importance of the parent–child relationship on the development of emotion regulation, some have suggested that preventative interventions should focus on strengthening these skills in parents among whom there is risk of traumatic exposure, or the presence of parental distress, poor parenting skills, or attachment difficulties [40].

The presence and effective use of social systems for support, such as healthy peer relationships and natural/programmatic mentoring, also contribute to enhanced resilience. Programs that advance peer interactions that highlight conflict resolution, teamwork, and appreciation for cultural diversity can enhance pro-social skills. Athletic activity, promoted and supervised by naturally occurring mentors such as coaches and trainers integrally involves teamwork and problem solving, and may add to a child’s resiliency and provide a sense of accomplishment, self-worth, and competency [42].

Many recent studies have confirmed the protective influence of caring and competent adults who are not parents, particularly to youth in high-risk environments [43]. A study examining the use of natural (eg, neighbor, store owner) and structured mentors (eg, volunteers from a mentoring program) reported that resiliency among youth in mentoring programs increased as a result of the relationships created [44]. Mentoring relationships exert their influence in part as compensatory mechanisms that act to reduce or neutralized negative behaviors such as drug use and delinquency. In addition, mentors have been shown to promote healthy behaviors such as selection of positive peer groups and known to facilitate in redirecting attention to activities centered around healthy behaviors [21,42,45,46]. Mentoring appears to be an excellent match to the needs of children who have lost a parent or experienced significant trauma. In the best case scenario, mentoring can compensate for some of the material and emotional losses that occur with a parent’s death, including the presence of a role model for life skills development, an objective third party presence to problem-solve day-to-day
hassles, and emotional solace when none other is available. Although it is likely that many children and adolescents now participating in mentoring programs are indeed traumatized youth, little systematic evaluation has been conducted to determine the value of mentoring in alleviating the consequences specific to trauma that are known to derail social and emotional development.

Summary

This article has identified barriers to and difficulties in the implementation of mental health efforts for children following 9/11. It also has suggested characteristics of program and implementation plans to reduce these difficulties. Recognition of the role of the traumatized parent and parental involvement in the child’s (and their own) recovery has been highlighted. Treatments need to be flexible and address the many possible manifestations of psychological disturbance resulting from trauma, with sensitivity to age, ethnicity, and community setting. Treatments need to be accessible and offered in places that parents and children know and in which they feel comfortable. The role of the relationship between the traumatized community and the relief agencies has been emphasized throughout. Traumatized communities need to have equal say, if not take the lead, in determining the help they need and when and how they should receive it. Program planning should, from its inception, emerge from a dialog between those who need help and those who wish to and are able to give it. Lastly, the article identified the critical need to create programs that build bridges to acute post-trauma mental health services and the importance of evaluating the effectiveness of each of these program components in regards to their relative contributions in reducing distress and enhancing resilience.

Large-scale acts of violence such as the attack on the World Trade Center are community traumas, and as such, the unit of analysis is the community. With this in mind, as a final caveat, the authors note the observations made by Wallerstein [47] in her synopsis of innovative community mental health provisions in “Helping the Helpers Not to Harm: Iatrogenic Damage and Community Health.” This synopsis describes the way in which she, a historian, and her father, a Harvard psychiatric researcher involved in the 1950s preventative programs for youth at risk, retrospectively view these efforts and their presence today. The translation of innovative programming into community practices went awry. “Now in his late eighties,” the abstract describes, “he returns to take a long second look at how the models of preventative interventions that were designed to rescue vulnerable children from serious sequelae have become the mundane bread-and-butter interventions for child protective agencies.” The description goes on to note how the undifferentiated application of findings from social research to clinical settings has had a significant negative impact on programs. The material and financial resources directed to those suffering from the effects of 9/11 have been astounding and at times overwhelming. Indeed, the high, driving
energy behind good intentions occasionally has road rough-shod over real but unheeded needs, particularly those of children, who are often the silent and under-represented members of the community. There is no substitute for compassion, good judgment, and interest in listening to those psychiatrists seek to serve.

References


