

DBSA Survey Center

Agitation and Emergency Care Peer & Family Surveys

Summary Report: June 2016

BACKGROUND

DBSA's Agitation and Emergency Care Surveys for peers and family were designed to provide insight into emergency care from the perspective of people who have experienced an agitation episode or crisis and the family members who have assisted them. DBSA conducted these surveys as part of our ongoing efforts to communicate the viewpoints of individuals who are living with depression and bipolar disorder.

Both surveys, one for peers and one for family members, were posted on the DBSA website, DBSAAlliance.org, from November 3, 2015 to April 13, 2016. Participation was solicited from DBSA constituents, people who visit the DBSA website, readers of DBSA's monthly eUpdate newsletter, and followers of DBSA's Facebook and Twitter pages. 147 individuals participated in the peer survey and 90 in the family member survey. Respondents were self-selecting and generally representative of the population that utilizes DBSA's web resources. This report provides a high level overview of responses to both surveys.

It is important to note that the respondents participating in the peer survey have no direct correlation to people who completed the family survey. Additionally, as with all DBSA surveys concerning peer experiences, participants were anonymous volunteers; we cannot determine how closely they resemble the entire population of people who live with mood disorders or their family members. However, this anonymous method has its advantages. With their identity protected, respondents may be more likely to honestly and openly disclose their experiences in Emergency Departments (ED) when in crisis.

RESULTS

TRANSPORT TO THE EMERGENCY DEPARTMENT

Arrival: 17% of peers who responded to "who brought you to the ED and under what circumstances" reported that police were involved in their transport at least one time. 31% of respondents said that they were brought to the ED at least once by ambulance.

INTAKE, INFORMATION SHARING, AND DISCHARGE

Reason for Visit: A significant number peers and family members said in the comments section that they were seeking non-crisis interventions related to ongoing care.

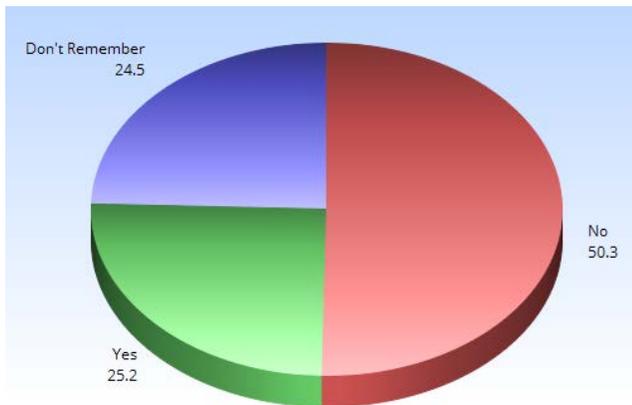
Release Form: 40.6% of peers said they were given an opportunity to complete a Release of Information form. This form allows them to designate who may be informed about their medical condition and treatment. 32.8% of peers said that they were not given this opportunity and 26.6% could not remember.

Opportunity to Share Information: 68.2% of family members indicated they were given the opportunity to share medical knowledge about their family members with medical personnel, including any medication their family member was taking. 29.5% of family members said they were not given this opportunity and 2.3% did not remember. Similarly, 60% of family members indicated they were given the opportunity to share additional medical history and information, 31.8% were not, and 8.2% could not remember.

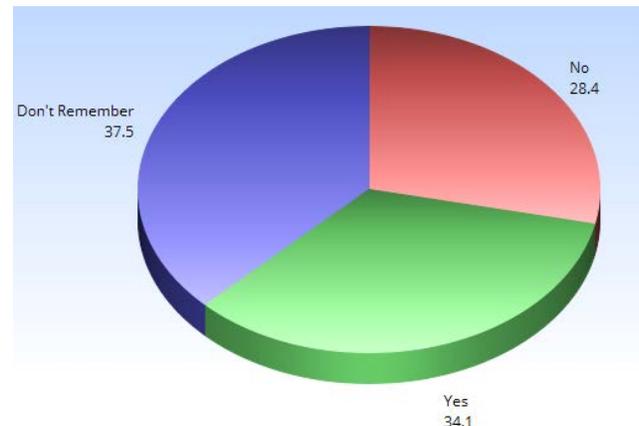
INTAKE, INFORMATION SHARING, AND DISCHARGE (CONTINUED)

Rights and Consent: Approximately half of peers (50.3%) reported they were not informed about their right as a patient to refuse treatments and to give consent before medical procedures were performed, 25.2% reported they were informed, and 24.5% could not remember. 28.4% of family members reported that their family member was not informed of these rights, 34.1% reported their family member was informed, and 37.5% could not remember.

Were you (or your family member) informed of your (their) rights as a patient to refuse treatments and to give consent before medical procedures are done?



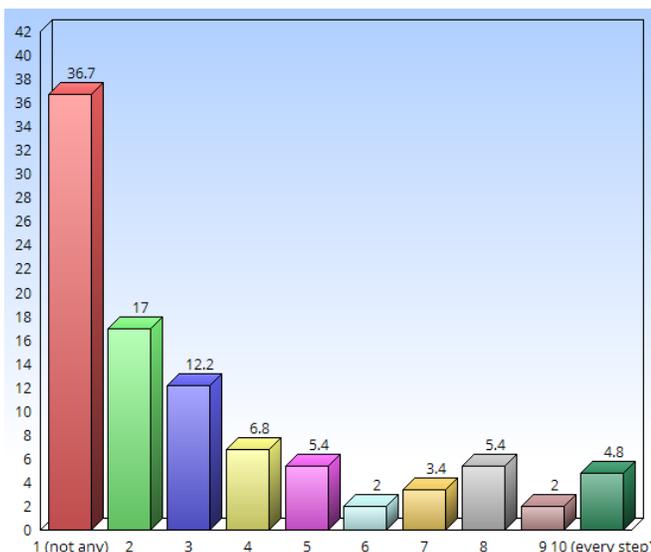
PEER RESPONSES



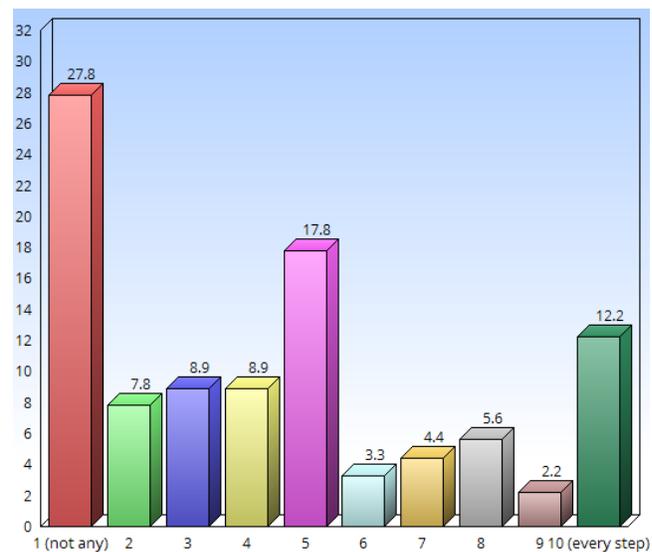
FAMILY RESPONSES

Treatment Information: 65.9% of peers and 44.5% of family members gave a very low rating (1-3 on 10 point scale) when asked how well they or their family members were informed about the protocol—steps taken—of their treatment. 12.2% of peers and 20% of family members gave a very high rating (8-10), indicating they had been informed nearly or every step of the way.

Please rate how you were informed about the protocol of treatment (your family member was receiving) 1=You were not informed about any steps take to care for you (them). 10=You were informed about every step of medical procedure and treatment.



PEER RESPONSES



FAMILY RESPONSES

INTAKE, INFORMATION SHARING, AND DISCHARGE (CONTINUED)

Physical and Mental Health Information: A great majority of peers and family members reported that vital signs were taken by medical personnel (74.1% peers; 77% family); that personnel asked about current medications (72.3%; 83.7%); and inquiries were made about current and past medical conditions, surgeries, and illnesses (61.3% and 68.6%). A minority of peers (38.7% peers; 39.1% family) reported that medical personnel asked them the name of their or their family members' psychiatrist, therapist, or counselor.

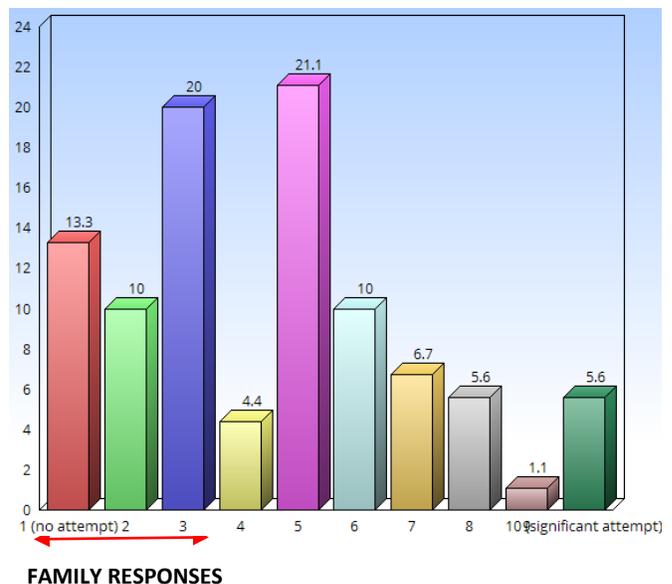
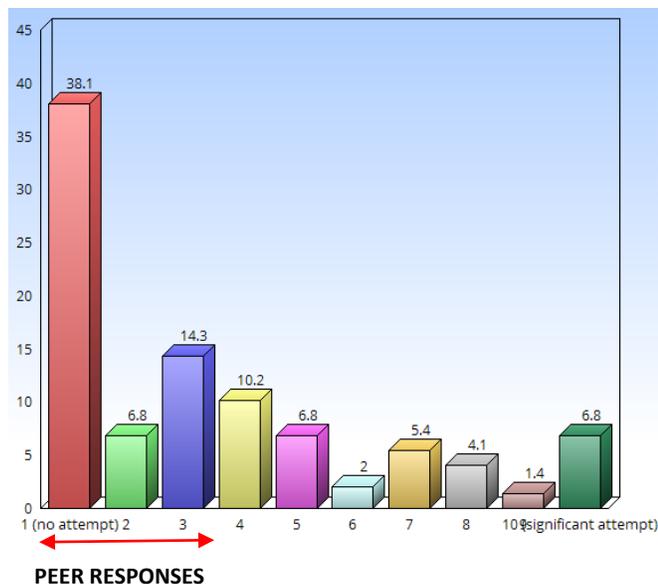
Resource Information Provided upon Discharge: 10% of family members responded to the question "if your family member was discharged to home after your visit to the ED, were they given any information about any of the following resources." (Information included lists of therapists, psychiatrists, community behavioral health centers, social workers, support groups, hotline/warmline information or other resources.) This low response rate may indicate that the majority of individuals were discharged without information. However, many of the comments indicate that it could also be due to many individuals being admitted to the hospital or moved to another facility. Of the family participants responding, there was no significant difference between those who said resource information was distributed and those who said it was not.

Return Rates: 48.2% of peer respondents indicated they had not returned to the ED as a result of a mental health issue. 51.5% did return and of these, 28.8% returned within one year, 5% within 120 days, 7.9% within 60 days, and 10.1% within 30 days. 27.9% of family respondents indicated that their family member had not returned to the ED as a result of a mental health issue. 72.1% said the person had returned and of those, 26.7% returned within one year, 7.0% within 120 days, 15.1% within 60 days, and 23.3% within 30 days.

ED INTERVENTIONS

De-escalation Attempts: 59.2% of peers and 43.3% of family members gave low ratings (1-3 on 10 point scale) for the level of attempt made by the ED staff to verbally help calm down the person in crisis. 12.3% of both peers and family members indicated that medical personnel had made a significant attempt (8-10 on same scale).

Please rate any attempt by ED staff to verbally help you (your family member) calm down. 1=No attempt was made to verbally help you (them) calm down. 10=Significant attempt was made.



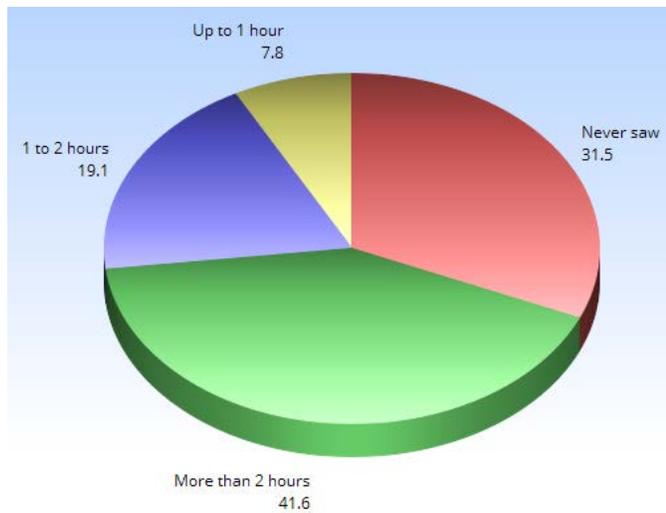
ED INTERVENTIONS (CONTINUED)

Medication Consent: When peers were asked “were you asked to give consent prior to medication being administered,” nearly half (48.9%) reported they were not asked. 24.1% said they were asked for consent and 27% did not remember. When family members were asked “was your family member asked to give consent prior to medication being administered,” 27.6% said medical personnel did not ask the person for consent, 33.3% reported personnel did ask, and 39.1% could not remember.

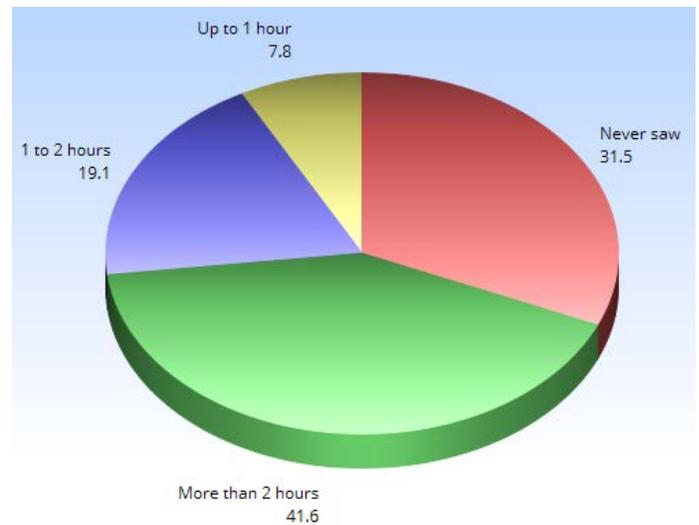
Restraint Consent: When asked “if restraints were used, were you asked for consent prior to use,” 71% of peer respondents indicated this question was not applicable to their situation. For the remaining 29% of peers for whom the question did apply, a high percentage (77.5%) reported that they were not asked for consent, 10% said they were asked, and 12.5% could not remember. When family members were asked “if restraints were used, did your family member give consent prior to use,” 59.8% indicated that this question was not applicable to their situation. For the remaining 40.2%, 65.7% responded their family member was not asked for consent, 14.3% said they were asked, and 20% could not remember.

Psychiatrist Availability: After being admitted to the ED, 51.8% of peers said that they never saw a psychiatrist and 34.5% reported waiting for more than two hours to see one. 6.5% waited one to two hours and 7.2% waited less than one hour. A large percentage of family members reported similarly, indicating that their family member never saw a psychiatrist (31.5%) or waited more than 2 hours (41.6%).

How long did you (your family member) wait to see a psychiatrist after being admitted to the ED?



PEER RESPONSES



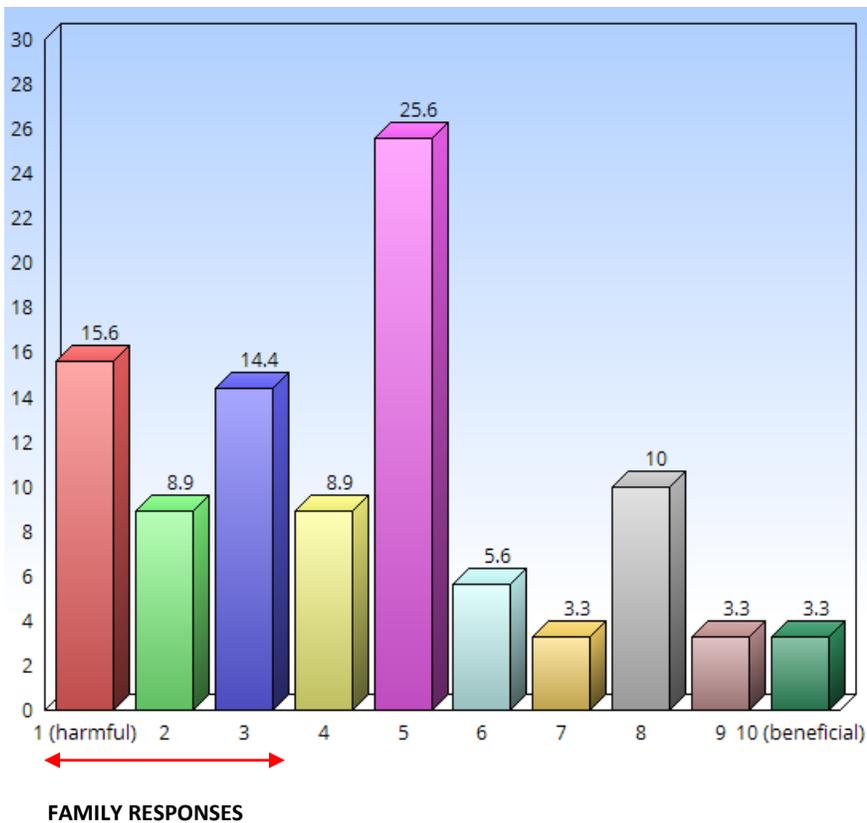
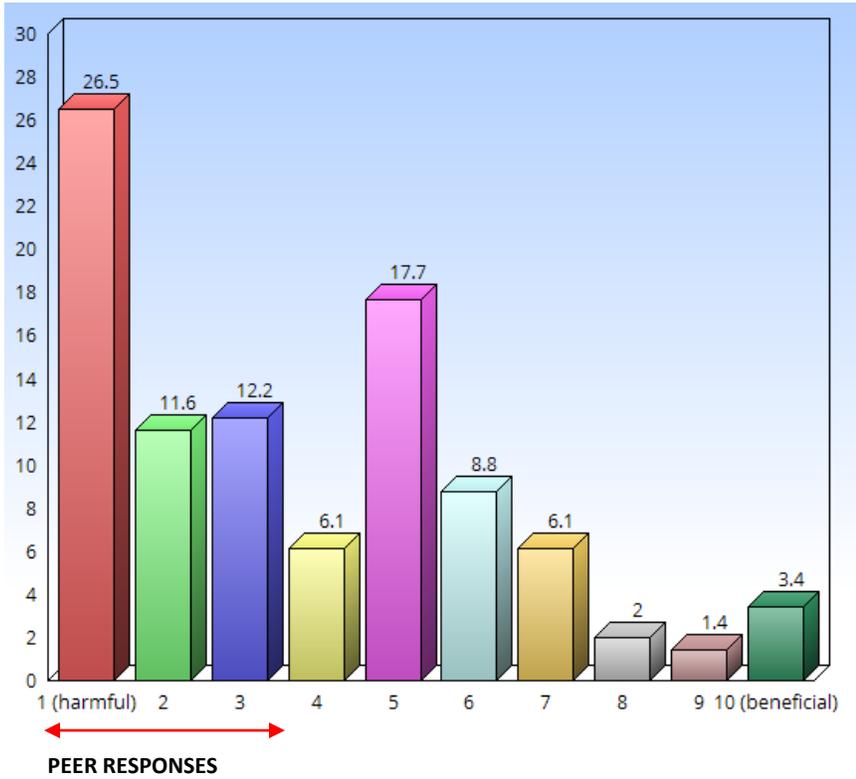
FAMILY RESPONSES

OVERALL EXPERIENCE

Helpful or Harmful: Survey respondents were asked how positive their experiences at the ED had been. 50.3% of peers and 38.9% of family members gave the experience a low rating (1-3 on 1-10 scale with 1 indicating a belief the experience was harmful to their or their family member’s well-being). 6.8% of peers and 16.6% of family members rated their experience as beneficial (8-10 on same scale). *See charts on next page.*

Please rate your overall experience at the ED for agitation (PEERS). Please rate the overall experience at the ED (FAMILY).

1=You consider the experience to be harmful to your (family member's) well-being. 10=You (feel your family member) benefited from the experience.



DETAILED RESPONSES

Selected Comments and Suggestions by Peers and Family Members for Staff Regarding ED Procedures

RESPECT

- *Give them the same respect you would if someone was having a heart attack.*
- *I deserved to be treated with respect and informed just like someone without a mental health condition. I know I was delayed in my recovery because of the trauma I experienced during my ED visit. Even though the person you are treating isn't well at that moment, your words and actions can have a HUGE impact on how quickly they rebound and come to terms with the experience. Please show compassion and respect. We need it most then.*

HEALING ENVIRONMENT

- *Be calm and empathic. Ask people what they think would help them.*
- *We are human beings who are in pain. It would be helpful if we were treated as such. You may not have the skills to help us but you can, through both attitudes and actions, make the experience of being in the ER much less painful for us.*
- *If we need a sitter, rather than having the sitter just guard the door, please introduce yourself, make sure we are comfortable, give us food and drink, ask us about things we like when we are well.*

PROCESS IMPROVEMENT

- *All ED staff should be trained specifically in dealing with mental health. It would also be very beneficial for hospitals, clinics, fire and police departments to consider training and bring certified peer specialists into the mix as I found that to be a great help.*
- *Staff also needs to be trained in how to work with the families of individuals that are in the ED for mental health-related issues as the families struggle to understand as well. The use of peer specialists can bridge the gap.*
- *Have a psychiatrist [available] who is current and up-to-date on mental health.*
- *Have my records available to you so you know me and what meds I'm taking.*
- *Have a separate room to wait for evaluation and treatment.*
- *Just listen and don't leave the patient—I had meds in my purse and I took more of them as I was suicidal!*
- *Do not medicate and leave alone in a room for hours.*
- *Reduce stimuli. ERs are noisy, bright places and this serves to increase agitation. Some suggestions are to turn off the lights in the patient's room, give us a warm blanket, give us our prescribed medications, speak in a soft, low voice, and let us know you care and are concerned.*
- *Don't make diagnoses when you have no idea what's wrong, in spite of all the tests run.*
- *Treat mental illness like an emergency, just like you would a heart illness; they both kill.*

STIGMA

- *Try to act and speak like the staff doesn't think psychiatric patients are, at best, an annoyance. For example, I have on several occasions overheard staff complain about having "those crazy psych patients" to deal with.*
- *It seems that ED staff sees anyone with a mental illness as a threat, not as a sick individual.*
- *Do not treat me as a criminal!*

COMMUNICATION

- *Keep me better informed as to what is happening.*
- *Don't threaten the patient with calling security or the police or calling for restraints.*
- *Tell us what you are going to do and give us information.*
- *Take the time to verbally talk to them to help them calm down so you can better understand and order appropriate treatment.*
- *Talk calmly to me and reassure me that I'm safe.*
- *De-escalate! Mental health patients are human beings who are suffering. Don't escalate their suffering through seclusion and restraints. Help them to de-escalate it humanely.*

SUMMARY AND DISCUSSION

The results of these two surveys clearly suggest that increased attention must be paid to patient rights regarding consent to treatment and treatment options. More than half of peers (50.3%) reported they were not informed of their right to refuse treatment and to give consent before medical procedures were performed; 40.6% said they were not given the opportunity to complete a Release of Information form; 48.9% said they were not asked for consent before medication administration; and 77.5% were not asked for consent when restraints were used.

Peer responses indicated that restraints were used nearly a third of the time (29%) in the ED, a disturbing proportion. Attempts at verbal de-escalation by staff was rated very low, with 59.2% of peers indicating no or very little attempt was made to verbally help them calm down. The recognized effectiveness of verbal de-escalation techniques, compared to forced medication and restraint, indicates that greater staff training and adoption of these techniques is warranted and will improve care and ensure greater safety for both the patient and ED staff.

Peer and family members' comments consistently reflected the need to better train staff on how to treat mental health conditions and the people who live with them. There was an overwhelming number of pleas for increased compassion, respect, preservation of dignity, and appropriate care, as well as use of restraints as a last resort. The significant number of instances where police and ambulance personnel were reported to be involved in a person's transportation to ED further demonstrates the need for training on how to best handle mental health-related calls.

More than half of peers (51.8%) reported that they never saw a psychiatrist in the ED; 34.5% waited more than two hours to see one. This delay accessing—or non-existence of—psychiatric care in ED's is of tremendous concern. Mental health conditions are not as visible as a gushing flesh wound but they are no less critical. Delays in proper treatment can have a profound impact—they can worsen a crisis and have long-term effects on a person's ability to manage their condition as well as their willingness to seek help in the future. There are also challenges surrounding medical personnel soliciting information from peers regarding their therapists, psychiatrists, or counselors. Only 38.7% of peers indicated they had been asked for this information.

Of greatest concern is the alarming number of peers (50.3%) and family members (38.9%) who felt that their experience at an ED was actually *harmful* to their or their family member's well-being; only a small number felt the experience was beneficial (6.8% peers; 16.6% family members). These low rankings are reflective of the impassioned comments of survey participants.

Given the large number of behavioral health users known to use the ED; that the ED is often the only avenue for admission to in-patient care; that alternative resources for off-hour and/or ongoing mental health care are not

available within most communities; and the high return rate to EDs within a year of discharge reported by both peers and family members, it is clear EDs must seek out new ways to address this population.

Several areas to explore include

- increased staff training on how to treat mental health conditions and the people who live with them;
- greater use of de-escalation techniques;
- enhanced processes for addressing urgent care for people with mental health conditions both within and outside of the ED;
- improved design of ED facilities so that people in crisis are not overwhelmed;
- integration of peer providers into the ED; and
- better knowledge of and closer collaborations between community mental health resources and EDs.

Additionally, greater availability of co-located or independent crisis intervention facilities, urgent care centers for people with mental health conditions, and mental health respite facilities would increase the potential for enhanced care as well as provide significant relief of behavioral health patient loads in EDs.

NEXT STEPS

The information collected by these surveys will both inform DBSA programs and contribute to the training of health care professionals, ultimately improving emergency department services for people with mental health conditions.