

Report on Community Listening Session on Crisis Prevention and Intervention Services
for Individuals with Developmental Disabilities with Severe Behaviors
Held December 10, 2016 in Alameda County

Summary of Process and Activities

An organization of parents, East Bay Parents Housing Network, received a grant from All In Alameda County to hold a listening session on crisis prevention and intervention services for individuals with developmental disabilities who exhibit extremely aggressive, self-injurious or destructive behavior. East Bay Parents Housing Network is a regional support group associated with the Autism Society San Francisco Bay Area and meets monthly to share information resources and explore planning issues of importance to adult family members with developmental disabilities. Discussions have included concerns about the well-being of family members and other individuals whose needs for appropriate crisis intervention services are extreme but for whom services seem to be either denied due to the wrong diagnosis or not effectively targeted to their needs. The goal of the session was to hear from families of individuals with developmental disabilities who have severely aggressive, destructive, or self-injurious behaviors to better understand their experiences of crisis situations, the prevention and intervention services they have utilized, how effective those services have been, and what services or service improvements might be needed.

Prior to the session, outreach was done to many community groups in the county. Potential participants were screened to ensure that all participants were family members of youth or adults with developmental disabilities who have significant behavioral challenges. Before holding the listening session, participants were sent a questionnaire regarding the services they had utilized, the number of times utilized, and whether the services were successful, somewhat successful, not helpful or counter-productive. Many completed the form while at the session. Charts summarizing the survey results are included after this narrative.

The listening session was held on Saturday, December 10, 2016, at a private residence in the afternoon, beginning with lunch. Thirteen participants attended the session, representing twelve families, all with family members who have been either at risk of needing or have used crisis intervention services due to extremely aggressive, destructive or self-injurious behaviors.

Upon arriving at the session, participants put stickers on posted charts to indicate the settings in which their family member had had crisis behaviors (intense aggression, self-injury and/or severe property destruction) and, secondly, what services they had used and how helpful those services were. The two sticker charts are summarized in the first two charts which follow this narrative. The participants became acquainted

and compared situations over a lunch provided by the grant. After lunch, all participants met in one group. During the meeting, each participant described their family member and the behavioral crisis challenges faced, the services used and their effectiveness, and the gaps in services experienced by the family.

Description of Outcomes

The goal of the listening session was to discuss what is working, what is not working, and what is needed to provide crisis prevention and intervention services to individuals with developmental disabilities in Alameda County. The services outlined in the funding proposal as the focus areas were behaviorist support in the home (whether living with family or in outside placement), Regional Center-sponsored crisis intervention services in the home (whether living with family or in an outside placement), 911 calls and police response, medical emergency rooms, psychiatric emergency rooms, psychiatric hospitals, and crisis stabilization housing.

All participants spoke regarding their experiences with crisis situations and the effectiveness of the above services. There were unanticipated outcomes as the criminal justice system had not been listed in the list of services since it is not a crisis intervention service. Yet two of the families had family members whose crises led them into the justice system with its own set of complex issues and long-lasting effect on the family member. Another unanticipated outcome was that participants included in their suggestions some improvements that would be fairly easy to implement, in addition to recommendations about expanding and enhancing the services currently provided.

What Did Community Members Have to Say?

Each community member was asked to describe their family history with crisis situations that brought them to the meeting. They were also asked to describe the services they had utilized and their effectiveness. One parent was scribe and noted major points under service categories on a flip chart which was later reviewed by the group and used for this report.

The following summarizes main points that emerged from participant descriptions of their experience:

Behavioral intervention services provided through health insurance or the Regional Center in the home of the individual have had varied results due to the great variation in training and expertise of the in-home behavioral staff. In addition, hours of services provided in family homes need to be more flexible to complement parents' work schedules. Behavioral services provided in group homes are very limited in hours and in many cases the staff members rarely see the behaviorist. As a result the staff members have little guidance and the behaviorist is not observing frequently enough to adjust behavioral plans or guide staff. In homes that are a "step down" between crisis homes and group homes, the

behavioral intervention services are very effective in some but ineffective in others. Appropriate supports for the transition from a step-down home to a lower level of supported residential service is key to maintaining any progress made during the period in the step-down program. However, this is often lacking and the individual then will likely return to the crisis situations that originally preceded the crisis intervention services.

Regional Center's crisis intervention service was generally considered unhelpful for many situations although had been helpful under certain conditions. Arrival is quite often delayed and the crisis is usually over before the crisis staff arrives. The service does seem helpful for some individuals who respond well to talk therapy during a crisis, especially if the person has engaged with and developed a positive relationship with the intervening crisis staff in the past. The service's documentation of crisis situations can also be very helpful in securing other needed services.

Crisis homes appear to attempt to provide both short-term stabilization and long term services in the same program setting due to the lack of separate long-term services. Individuals stay much longer than needed due to lack of appropriate next placements. Participants concluded that three types of crisis homes are really needed: cool down homes for immediate 48 hours de-escalation; short-term homes for stabilization of a month or two; and long-term residential services that can provide the supports needed to maintain stability. Each of these needs to be tailored to the needs of the individual by staff and managers skilled in working with individuals with developmental disabilities and behavioral challenges .

911 calls and police responses vary greatly in approach and outcomes. Police can be helpful in many situations, depending on the approach of the officers involved. Police can also be very helpful in response to elopement. Police calls often result in a lack of family or caregiver control and jurisdiction which can be helpful in some situations but not in others. Parental rights, even as conservators, are not recognized and the individual in crisis is left without informed individuals to advocate for him or her.

Participants reported family members having negative experiences with police response such as the individual with developmental disabilities being handcuffed due to misinterpretation of their behavior, being threatened with tazers even though sitting on the ground, and responding in fear during subsequent contacts with police. Many participants referenced subsequent "post-traumatic stress" and described how negative experiences with police can inadvertently lead the family member with developmental disabilities to repeat or increase the aggressive or self-injurious behavior that was the cause of the original police call. This can result in the family or caregiver not wanting to make any subsequent 911 calls due to an expected exacerbation of the crisis.

Participants also described experiencing disparities in police response to individuals of different races, whether they were individuals with developmental disabilities or the person's caregiver out in public. This is another factor that can lead families and caregivers to avoid seeking police assistance in a crisis.

One practical recommendation from participants was to train parents and caregivers to determine what key information particular to the individual should be provided to police if they are making a 911 call. This would include a few descriptive words and suggestions to inform the police of how they can respond most effectively to de-escalate the situation. It is difficult for a family member or caregiver to provide succinct, critical information in the heat of the moment so advance planning and practice can help.

Police custody and the criminal justice system was discussed as a very serious outcome even though not considered a crisis intervention service. Participants described the intersection of criminality and disability as being “extremely unhelpful”. Once an individual is accused of a crime, the developmental disability appears to be ignored, the family cannot get information, the individual may well have extremely traumatic experiences in custody and afterward, and any police record can limit admittance to programs, jobs, and housing in the future.

Psychiatric emergency rooms are sometimes used much longer than needed, due to waiting for an appropriate next psychiatric services placement. At other times, individuals are not admitted at all or are discharged the same day.

Psychiatric hospitals usually refuse to admit individuals with autism. Many cannot accept patients with IQ’s under 72, ie. those with developmental disabilities. There is a need for a place for individuals to stay with support and observation when beginning new medications or doing medication adjustments, whether in a hospital or another setting. Without a safe place, medications that might assist the individual cannot be attempted due to the risk of negative behavioral reactions.

Residential treatment programs have very limited availability with wait lists of months or even years. Longer stays are needed and, for some, this high level of support is needed indefinitely.

Other gaps in services were discussed. Many daytime programs, group homes, and supported living services refuse to accept clients labelled as having “behaviors”, creating discrimination and denial of services. Some programs are designated as serving individuals with severe behaviors but there are not enough programs to meet the need. If an individual is lucky enough to be accepted into a non-behavioral program, the program staff are usually not adequately prepared to support the person and the chances of crisis incidents are increased. Several participants had experienced crisis situations arising when the family member was in temporary housing while waiting to have residential living or supported living services arranged.

Participants felt that programs and housing services need to be reimbursed at a higher rate for serving this more challenging population.

Participants expressed the need for family caregivers to be provided with crisis intervention training to avoid the need for often ineffective 911 or Regional Center crisis intervention calls.

In addition, the participants described the need for accommodations and supports for individuals enrolled at community colleges.

Also, family overnight respite services provided close to the home are important to help the family caregivers sustain their role supporting the individual in the family home.

Lessons Learned

Participants described various facets of a crisis intervention system that is not effective in preventing or responding to severe behavioral crises such as violent aggression, self-injurious behavior or property destruction often exhibited by individuals with autism or other developmental disabilities. Although many of the crisis services described are helpful in some situations, they can only serve a limited range of abilities and behavioral challenges. An approach truly targeted to the specific emotional and behavioral needs of each individual with developmental disabilities is lacking but desperately needed. In its absence, families live in fear of extreme behavioral incidents and outcomes of physical injury for those involved, mistreatment by police, arrest, incarceration, or homelessness.

Participants found that the lack of appropriate, intensive, skilled supports in housing and daytime program settings leads to repeated behavioral incidents requiring emergency responses. The lack of appropriately trained and implemented emergency responses results in the individual entering one of two cycles of inadequate response, depending on the nature of the emergency and the attitude of the police involved. The individual may be taken through some version of the series of medical emergency room/medical hospital/psychiatric emergency room/psychiatric hospital/crisis stabilization. Or the individual may be arrested, incarcerated, have rights and advocacy access restricted, and go through a series of assessments and hearings while imprisoned, at times for years. When the individual leaves either of these two response paths, the initial reasons for the incident have rarely been changed and it is very likely that the cycle will be repeated.

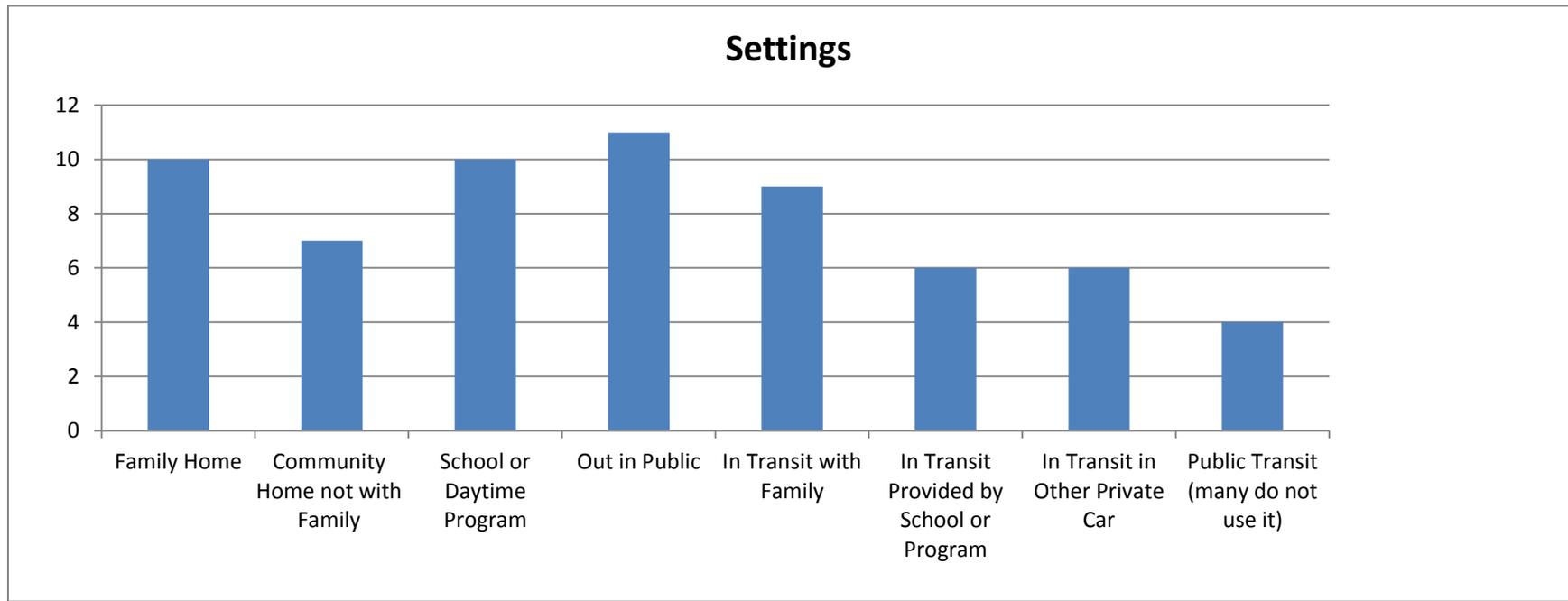
The largest gain by participants in the session was the confirmation that many other families are experiencing similar challenges. When a family is trying to cope with a family member who frequently has severe behavior, the family can be very isolated as members simply try to make it through each day safely. It is extremely helpful to connect with other families with similar experiences, both for the emotional support as well as exchanging resource information.

There was also a groundswell of energy among participants for working together to create more appropriate services to meet these critical needs. The session was scheduled for four hours but could have continued much longer as there were many related issues and intense emotion involved. All participants expressed interest in further discussions of how they can work to improve approaches to crisis prevention and intervention for individuals with developmental disabilities.

Settings in Which Participants' Family Members Have Had Challenging Behavior as Recorded by Participants on Sticker Charts

Total Families reporting = 11

(Multiple instances in one setting by same family are counted as one)

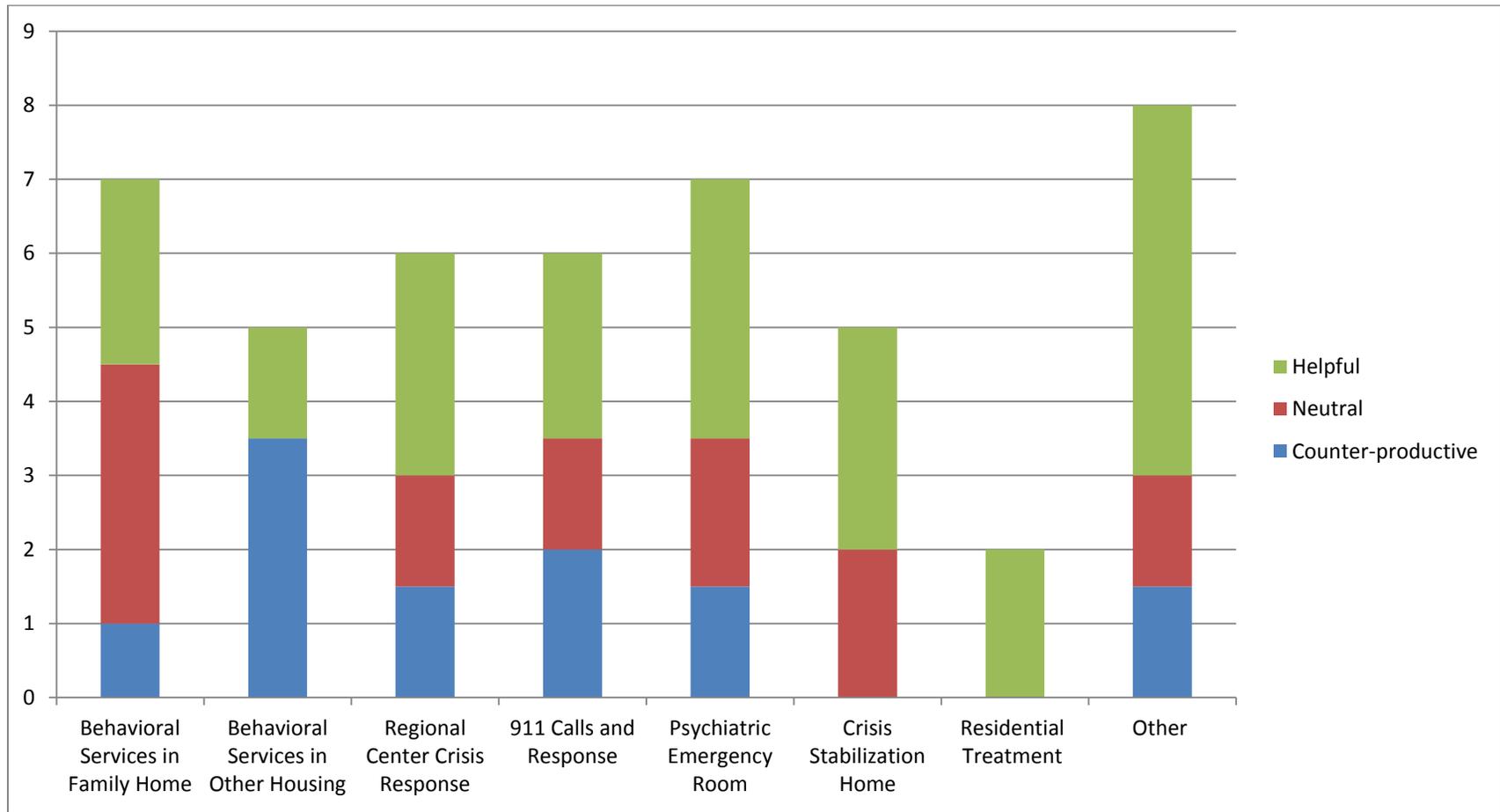


Crisis Prevention or Intervention Services Used

as Recorded by Participants on Sticker Charts

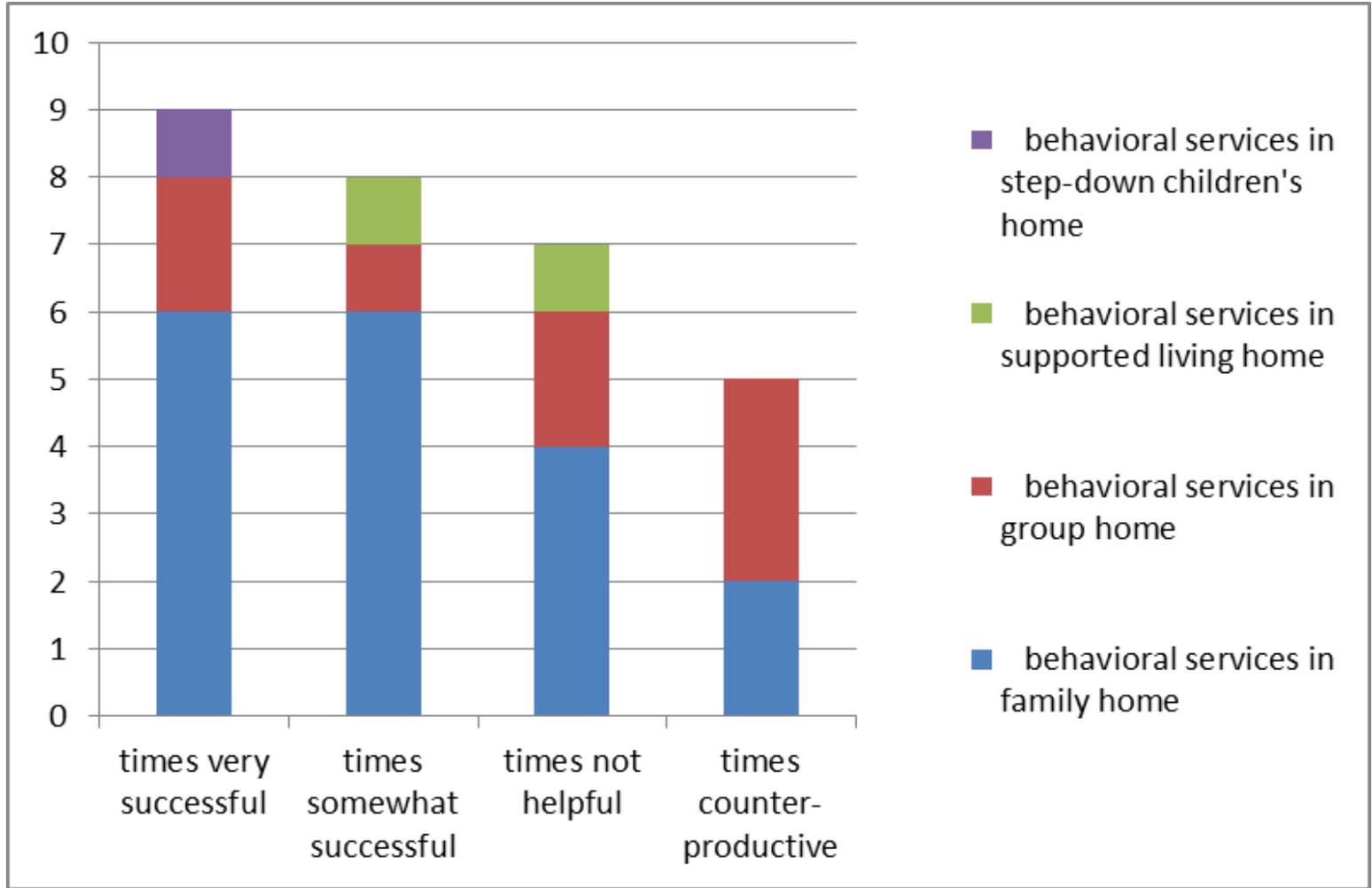
Total families reporting = 10

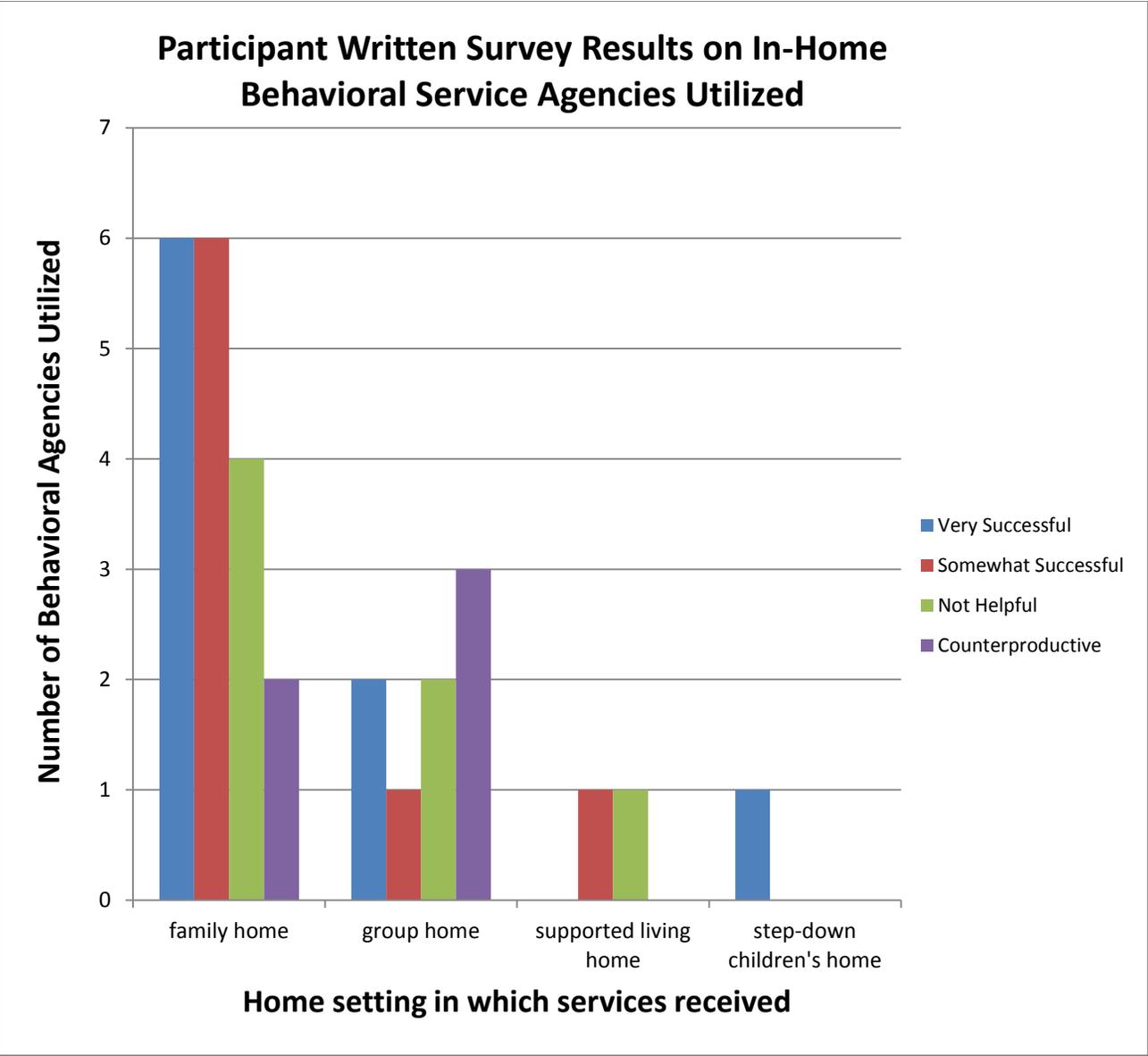
(Multiple uses by same family are counted as 1)



Participant Written Survey Results on Usage of Home-based Behavioral Services in Different Home Settings

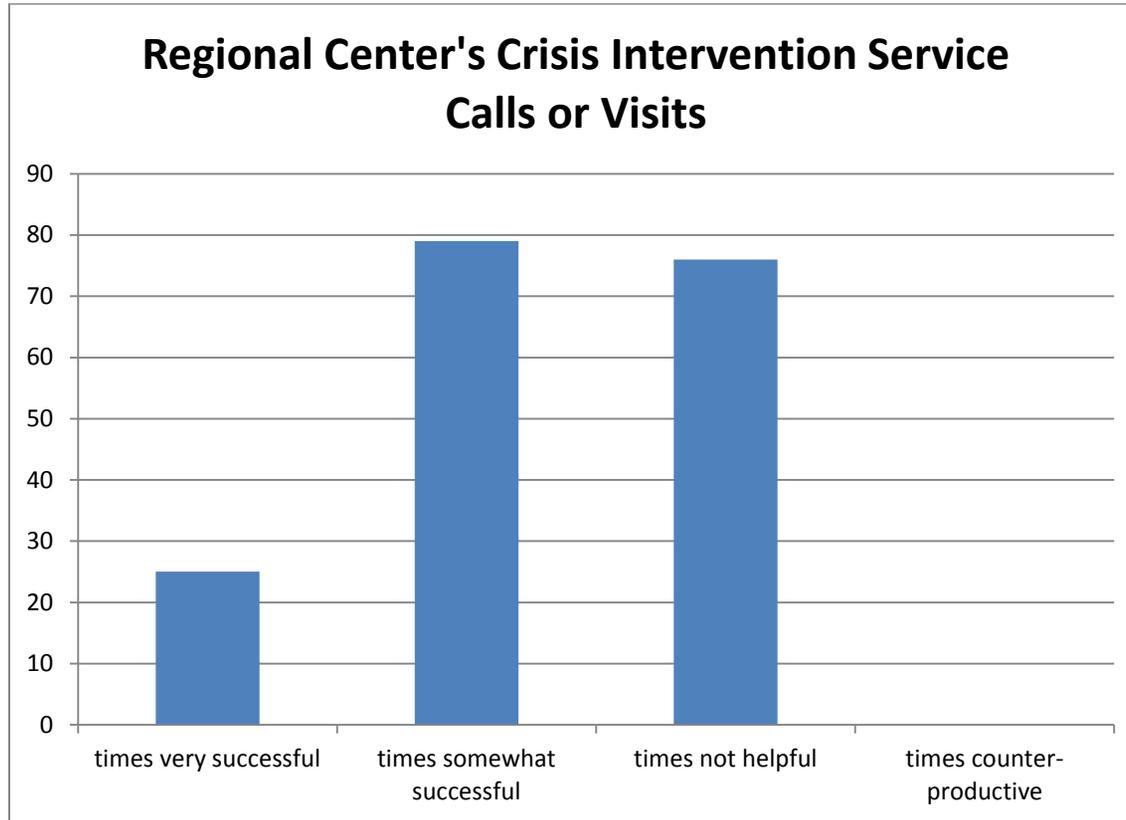
(one instance indicates the usage of one agency)



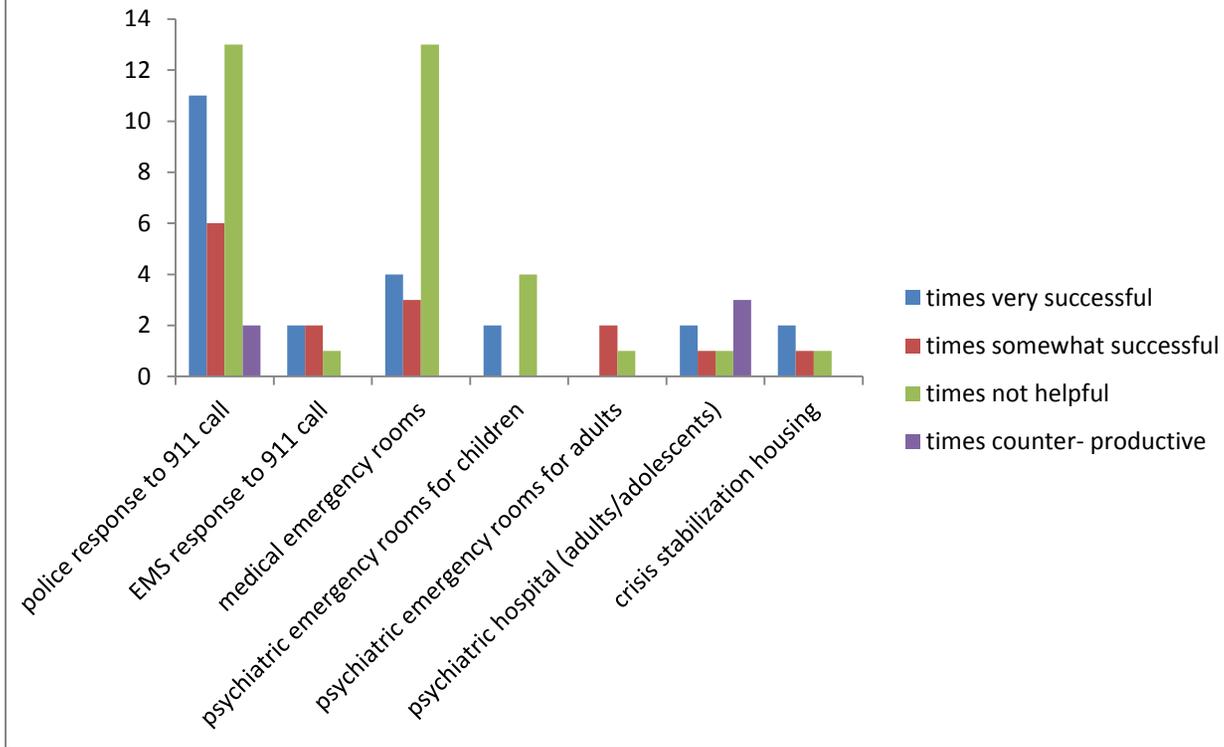


Participant Written Survey Results on Usage of Regional Center Crisis Response Services

(one instance indicates one crisis)



Participant Written Survey Results on Usage of Police and Subsequent Intervention Services



For more information, please contact Irene Litherland at EastBayParentsHousingNetwork@gmail.com.