# Deaf People's Help-Seeking Following Trauma: Experiences With and Recommendations for the Massachusetts Behavioral Health Care System

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Objective: Deaf trauma survivors are one of the more underserved populations in behavioral health care and experience significant obstacles to seeking help. Repeated encounters with these barriers fuel negative perceptions and avoidance of behavioral health treatment. The current study sought to explore Deaf trauma survivors' help-seeking experiences and elicit their recommendations for improving Deaf behavioral health services in Massachusetts. Method: We conducted semistructured American Sign Language interviews with 16 trauma-exposed Deaf individuals that included questions from the Life Events Checklist and the PTSD Symptom Scale Interview and questions about Deaf individuals' help-seeking behaviors. Qualitative responses regarding help-seeking experiences were analyzed using a grounded theory approach. Results: In the aftermath of trauma, our participants emphasized a desire to work with a signing provider who is highly knowledgeable about Deaf culture, history, and experience and to interact with clinic staff who possess basic sign language skills and training in Deaf awareness. Most stressed the need for providers to better outreach into the Deaf community-to provide education about trauma, to describe available treatment resources, and to prove one's qualifications. Participants also provided suggestions for how behavioral health clinics can better protect Deaf survivors' confidentiality in a small-community context. Conclusions: Deaf-friendly trauma treatment should incorporate the components of trauma-informed care but also carefully consider key criteria expressed by our participants: direct signed communication, understanding of Deaf history and experience, stringent practices to protect confidentiality, provider visibility in the community, and reliance on peer support and Deaf role models in treatment interventions.

Keywords: deaf, trauma, help-seeking, trauma treatment, behavioral health care

Deaf<sup>1</sup> trauma survivors are one of the more underserved populations in behavioral health care, even though rates of trauma are higher in the Deaf community than in the general population. Deaf

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We would like to acknowledge the members of the Deaf & Allied Clinicians Consult Group for their consultation and guidance on this project: Gloria Farr, Susan Jones, Lisa Mistler, and Gregory Spera. We would also like to thank Robert Goldberg for his feedback during the preparation of this article. This work was partially supported by the National Center for Research Resources and the National Center for Advancing Translational Sciences, National Institutes of Health (NIH), through Grant KL2TR000160. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

Correspondence concerning this article should be addressed to Melissa L. Anderson, Department of Psychiatry, University of Massachusetts Medical School, Systems & Psychosocial Advances Research Center, 222 Maple Avenue, Chang Building, Shrewsbury, MA 01545. E-mail: melissa.anderson@umassmed.edu people report nearly twice the rates of intimate partner violence and sexual assault (Anderson & Leigh, 2011; Anderson, Leigh, & Samar, 2011; Francavillo, 2009; Porter & Williams, 2011) and may experience more than six unique types of trauma across their life span (Schild & Dalenberg, 2012), although the actual figure may be higher due to unmeasured experiences of *communication abuse* (Mastrocinque et al., 2015) and traumatic events unique to the Deaf population (e.g., corporal punishment at oral/aural school if caught using sign language; Anderson, Wolf Craig, Hall, & Ziedonis, 2016). A recent American Sign Language (ASL) public health survey confirmed these disparities, with Deaf individuals more likely than their hearing peers to have experienced lifetime physical abuse and forced sex (Barnett, Klein, et al., 2011).

Trauma affects multiple domains of Deaf people's functioning, with higher levels of trauma exposure associated with increased depression, anger, irritability, sexual concerns, and substance use disorders (Schild & Dalenberg, 2012). Unfortunately, Deaf people's disparities in trauma are paralleled by severe disparities in

<sup>&</sup>lt;sup>1</sup> The U.S. Deaf community is a sociolinguistic minority group of approximately 500,000 persons who communicate primarily using American Sign Language. Members of this community are unique from other individuals with hearing loss in their identification as a cultural—not disability—group and are delineated by use of the capital *D* in *Deaf*.

their ability to access treatment. Although some attempts have been made to modify evidence-based behavioral health treatments for Deaf clients (e.g., dialectical behavior therapy; O'Hearn & Pollard, 2008), no adaptations or treatment approaches have been empirically evaluated for efficacy within this population. Therefore, trauma-informed, Deaf-accessible treatment services are scarce (Cerulli et al., 2015; Glickman & Pollard, 2013). Similar to other minority groups, Deaf people experience many obstacles to help-seeking: language barriers, low health literacy, and smallcommunity dynamics.

Especially salient for Deaf trauma survivors attempting to access the health care system is language access. There are an insufficient number of ASL-fluent clinicians and ASL interpreters trained in behavioral health or trauma-informed care (Cerulli et al., 2015; McKee, Barnett, Block, & Pearson, 2011). Additionally, many Deaf individuals experience obstacles to understanding written health materials due to differences in language and development compared to hearing individuals (Glickman, 2013), with research suggesting a fourth-grade median English reading level among Deaf high school graduates (Karchmer & Mitchell, 2003). Yet, there are few health materials designed specifically for Deaf people or translated into ASL (Graybill et al., 2010; McKee et al., 2011; Pollard, Dean, O'Hearn, & Haynes, 2009).

Low health literacy is also common among Deaf individuals due to limited language access during key developmental periods and "a lifetime of limited access to information that is often considered common knowledge among hearing persons" (Barnett, McKee, Smith, & Pearson, 2011, p. 1). Examples include limited communication with hearing family members, reductions in incidental learning from auditory information in their natural environment (e.g., information typically overheard in public service announcements, news programs, public conversations), and a lack of health education available in ASL (Pollard & Barnett, 2009; Pollard et al., 2009).

When Deaf trauma survivors *are* able to access behavioral health services and resources, they often express confidentiality concerns common among persons living in small communities (Mastrocinque et al., 2015). These concerns include the high probability that ASL interpreters, Deaf-specialized clinicians, or Deaf support group members belong to the same social circles, as well as the possibility that their private information will travel through the "Deaf grapevine" to those in the community who may judge or even harm them (Barber, Wills, & Smith, 2010).

Deaf individuals' repeated encounters with these barriers fuel their avoidance of the behavioral health care system (Steinberg, Sullivan, & Loew, 1998). Recent community-based research with Deaf survivors of intimate partner violence (Mastrocinque et al., 2015) and providers who serve Deaf trauma survivors (Cerulli et al., 2015) echoes these concerns, but it is unclear whether their findings generalize to the population of Deaf trauma survivors in Massachusetts. To better understand current gaps in support for Deaf survivors of trauma in our state, we conducted semistructured ASL interviews with trauma-exposed Deaf individuals to elicit their past experiences with help-seeking and recommendations for improving Deaf trauma services within the Massachusetts behavioral health care system.

# Method

Study procedures were approved by the University of Massachusetts Medical School Institutional Review Board (Docket No. H00003431).

## **Study Population**

We recruited 16 Deaf individuals to the current small-scale, exploratory study. Participants were recruited via online advertisements and through agencies that serve Deaf clients in Massachusetts. Advertisements were disseminated in written English and ASL digital video. Recruitment materials directed interested individuals to contact the principal investigator (a hearing ASL-fluent psychologist) using videophone, a commonly used device that transmits and receives real-time video to allow Deaf sign language users to communicate over the phone.

During this call, the principal investigator screened potential participants for the following inclusion criteria: (a) age 21 years or older, (b) Massachusetts residency (due to the in-person interview requirement and study focus on improving services in our state), (c) self-reported cultural identity as Deaf or Hard-of-Hearing, (d) self-reported ASL fluency, and (e) one or more experiences of trauma at some point in the participant's lifetime. *Trauma exposure* was defined according to PTSD Diagnostic Criterion A in the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; American Psychiatric Association, 2013): "Exposure to actual or threatened death, serious injury, or sexual violence in one (or more) of the following ways:

Directly experiencing the traumatic event(s); 2) Witnessing, in person, the event(s) as it occurred to others; 3) Learning that the traumatic event(s) occurred to a close family member or close friend;
 Experiencing repeated or extreme exposure to aversive details of the traumatic event(s).

Only adults unable to provide informed consent and prisoners were excluded.

# **Interview Instrument**

Eligible participants were scheduled for an in-person study session during which the principal investigator obtained informed consent and conducted a 45-min semistructured interview in ASL. The interview included questions about basic sociodemographic information, questions from the Life Events Checklist (Blake et al., 1995) and the PTSD Symptom Scale Interview (Foa, Riggs, Dancu, & Rothbaum, 2000), and questions about Deaf individuals' help-seeking behaviors. In the present study, we focus primarily on participants' experiences of help-seeking after trauma and report here on our findings from only the Life Events Checklist and questions about Deaf individuals' help-seeking behaviors.

The Life Events Checklist queries each participant's level of exposure (i.e., *happened to me, witnessed it, learned about it, not sure, doesn't apply*) to 16 events that commonly result in post-traumatic stress disorder (e.g., natural disaster, physical assault, sexual assault; Blake et al., 1995). It also includes a final item about exposure to any "other very stressful event or experience" not represented in the previous 16 items. For the current investigation, we focused primarily on events that participants had di-

rectly experienced in their lifetime (i.e., *happened to me*). We did not query participants for the approximate date of the trauma event. The Life Events Checklist has demonstrated acceptable psychometric properties as a stand-alone trauma assessment tool with hearing individuals, including adequate temporal stability and good convergence validity with other measures of trauma (Gray, Litz, Hsu, & Lombardo, 2004).

Interview questions regarding help-seeking were developed by the principal investigator and the Deaf & Allied Clinicians Consult Group (hereafter, Consult Group), a consultation group including professionals from the University of Massachusetts Medical School, the Massachusetts Department of Mental Health, and other-affiliated professionals who work with Deaf clients. The Consult Group meets regularly to provide ethical and cultural consultation to group members and collaborate on research, writing, and needs analysis projects about Deaf behavioral health services in Massachusetts. At the time of the current study, the Consult Group included two Deaf and three hearing members with professional backgrounds in psychology, psychiatry, mental health counseling, mental health case management, and social work. All members had prior didactic training and direct clinical experience treating traumatic stress disorders with Deaf clients.

The principal investigator and Consult Group created this series of three nested questions that explored participants' receipt of support after trauma:

- "After your experience(s) of trauma, did you get help from friends/family/peers? If yes: Who? What did you find most helpful? What was not helpful? What could they have done to better support you?; If no: What prevented you from getting help from friends/family/ peers? What could change to increase your likelihood of seeking their help in the future?"
- 2. "After your experience(s) of trauma, did you get help from a professional? If yes: Who? What sort of treatment did they provide? What did you find most helpful? What was not helpful? What could they have done to better support you?; If no: What prevented you from getting help from a professional? What could change to increase your likelihood of seeking their help in the future?"
- 3. "How likely are you to seek professional trauma treatment at the current time?" This was rated on a 5-point scale ranging from 0 (*extremely unlikely*) to 4 (*extremely likely*).

All interview questions were adapted from written English into ASL in collaboration with the Consult Group. Item adaptation focused on preserving linguistic equivalency and psychological conceptual equivalency. A typical three-stage procedure was used (i.e., translation, back-translation, equivalence comparison), similar to the translation of other psychological measures into ASL (Brauer, 1993; Graybill et al., 2010). In addition to the principal investigator's conducting all interview questions directly in ASL, Certified Deaf Interpreters<sup>2</sup> were provided to any participants who specifically requested this accommodation to access the research study.

# **Data Analysis**

Interview responses were entered into a Research Electronic Data Capture (REDCap; Harris et al., 2009) database. Quantitative data regarding participants' sociodemographic information, rates of informal and formal help-seeking, and likelihood of seeking trauma treatment were exported to SPSS Statistics Version 22, where descriptive analyses were conducted. Additionally, we conducted chi-square tests of independence to determine whether rates of formal and informal help-seeking varied on the basis of participants' sociodemographic characteristics.

Qualitative data were exported to ATLAS.ti (2013), where interview responses were analyzed for recurring themes and perspectives using a grounded theory approach (Glaser, 1992; Glaser & Strauss, 1967). We relied on two major techniques: (a) content analysis, where the number of similar responses to questions were tallied and described, and (b) a summary of the answers to the questions outlined by Casey (as cited in Krueger, 1998). Such questions included "What are the participants saying?" "What are they feeling?" "What is really important?" "What are the themes?" "Are there any comments said only once but deserve to be noted?" "Which quotes really give the essence of the conversation?" "What ideas will be especially useful for intervention?"

#### Results

We enrolled and obtained complete data from a total of 13 female and 3 male participants between March and September 2014. Most identified as culturally Deaf, White, and heterosexual (see Table 1). Most were middle-aged, had attended at least some college, and were employed.

Participants most commonly endorsed these trauma items from the Life Events Checklist (Blake et al., 1995): "physical assault" (n = 14); "sudden, unexpected death of someone close to you" (n = 13); "transportation accident" (n = 10); "assault with weapon" (n = 9); "sexual assault" (n = 9); "other unwanted or uncomfortable sexual experience" (n = 9); and "other' very stressful event" (n = 13). Although some "other" events overlap with traumas in the general population (e.g., 9/11 evacuations, extreme family poverty, severe verbal abuse), many were unique to Deaf people (e.g., corporal punishment at oral/aural school if caught using sign language, utter lack of communication with hearing parents that participants reported caused lasting emotional or psychological injury, being sent to Deaf residential school at a young age and fearing that they were being permanently aban-

<sup>&</sup>lt;sup>2</sup> As defined by the National Consortium of Interpreter Education Centers (NCIEC), [a] Deaf Interpreter is a [Deaf] specialist who provides interpreting, translation, and transliteration services in ASL and other visual and tactual communication forms used by individuals who are Deaf, hard-of-hearing, and Deaf-Blind. As a Deaf person, the Deaf Interpreter starts with a distinct set of formative linguistic, cultural, and life experiences that enables nuanced comprehension and interaction in a wide range of visual language and communication forms influenced by region, culture, age, literacy, education, class, and physical, cognitive, and mental health. These experiences coupled with professional training give the Deaf interpreter the ability to successfully communicate across all types of interpreted interactions, both routine and high risk. NCIEC studies indicate that in many situations, use of a Deaf Interpreter enables a level of linguistic and cultural bridging that is often not possible when hearing ASL-English interpreters work alone. (National Consortium of Interpreter Education Centers, 2016)

Table 1						
Sociodemographic	Characteristics	of the	Study	Sample (N	= 16)	

Sociodemographic characteristics	n	%
Age (years)		
21-34	3	18.8
35–44	2	12.5
45+	11	68.8
Ethnicity		
Not Hispanic or Latino	13	81.3
Hispanic or Latino	3	18.8
Race		
White	16	100.0
Black or African American	1	6.3
American Indian or Alaska Native	1	6.3
Sexual orientation		
Heterosexual	12	75.0
Gay or lesbian	3	18.8
Bisexual	1	6.3
Cultural identity		
Deaf	14	87.5
Hard-of-Hearing	1	6.3
Not sure	1	6.3
Preferred language		
American Sign Language	14	87.5
Spoken English	1	6.3
Other	1	6.3
Parental hearing status		
Both hearing	13	81.3
Both Deaf	3	18.8
Parental communication method (select all that apply)		
Spoken English	9	56.3
American Sign Language	4	25.0
Home sign <sup>a</sup>	2	12.5
Signed Exact English	1	6.25
Other (e.g., gesture)	7	43.8
Education level		
Some high school	3	18.8
High school diploma	3	18.8
Some college	4	25.0
4-year college degree or above	6	37.5
Employment status		
Collecting SSDI/SSI	7	43.8
Employed full-time	6	37.5
Employed part-time	3	18.8

<sup>a</sup> Home sign is a system of basic manual gestures that a Deaf child uses to communicate with other household members. Such communication often develops within a household where the Deaf child does not have access to a formal language system.

doned by their parents). For an in-depth discussion of these findings, please see Anderson et al. (2016).

Following these experiences of trauma, 44% (n = 7) of the sample sought help from informal sources (e.g., family, friends, peers), and 63% (n = 10) sought help from formal sources (e.g., clinicians, other professionals, authorities). Compared to participants with hearing parents (n = 13), those with Deaf parents (n = 3) were more likely to seek support from informal sources following trauma,  $\chi^2(1, N = 16) = 4.75$ , p = .029, and none sought support from formal sources,  $\chi^2(1, N = 16) = 8.12$ , p = .004. Similarly, participants who were raised using ASL (n = 4) were more likely to seek informal support than were those raised in a non-ASL-using household (n = 12),  $\chi^2(1, N = 16) = 6.86$ , p = .009; those who were raised using spoken English (n = 9) were more likely to seek formal sources of support,  $\chi^2(1, N = 16) =$ 

9.35, p = .002. Compared to participants below the age of 45 (n = 5), older participants (n = 11) were less likely to seek support from informal sources,  $\chi^2(5, N = 16) = 12.39$ , p = .030.

Qualitative results are described in the next section using an ecological systems framework (Bronfenbrenner, 1979; Mastrocinque et al., 2015; Smith & Chin, 2012), with reported themes organized across individual, family or friend, provider, intervention, community, and systems levels. Select quotes are translated into English and included here to elucidate our findings.

### Informal Help-Seeking

**Individual-level barriers and facilitators.** Participants reported that they struggled to seek help from friends, family, and peers due to feelings of fear, shame, embarrassment, fear of not being believed, or because they felt "not ready" (see Table 2). They did not indicate any facilitators that would have increased their internal motivation for seeking help from informal sources.

Family- or friend-level barriers and facilitators. The most commonly reported barrier to seeking help from informal sources was limited shared communication ("I need an interpreter for my family. We have no communication"). Additional barriers reported were mistrust of family or friends, often fueled by experiences in which these individuals showed little empathy, provided little emotional support, minimized the participant's problems, or blamed the participant. Isolation and distance from family or friends also acted as a barrier to seeking help, but others described the positive influence of technological advancements to bridge these distances in recent years ("Out of state friends were hard to connect with. Now we have videophone").

The primary facilitator to seeking help from family, friends, and peers was "shared communication"; "Sign!" and "They should learn ASL, have a soft heart." Participants also emphasized the need for family and friends to share resources or connect them with services ("My mom talked with the Department of Mental Health and helped me get a restraining order. My friend suggested that I call the cops"; "My sister helped me find an apartment, pay my bills, and get set up with Supplemental Security Income"; and "[My friend] picked me up from the hospital, checked up on my medications, checked in on me, kept in touch").

Other factors that facilitated informal help-seeking were being given the space to express oneself, feeling listened to and understood, receiving emotional support, receiving honest feedback, feeling empowered, and being believed by family and friends ("They helped me by just being there"; "They asked how I felt, listened to me, took me on trips"; "They provided emotional support, were very lovable"; "My best friend let me express myself, gave me opinions and feedback"; "They supported me to solve problems myself"; and "They should believe me").

**Community-level barriers and facilitators.** Participants reported issues with stigma surrounding trauma in the Deaf community ("We did not talk about domestic violence at that time"). They reported feelings of mistrust and fear that private information would gossiped about, spread through the "Deaf grapevine," and tarnish their reputation ("People still gossip about my mental illness to my boyfriend. People never forget—they think in the past"). They also reported a lack of available mentors in the Deaf community to support survivors in their own recovery from trauma ("I needed a leader in ASL, but there was no model there ... I

Level	Qualitative theme		
Individual	Barriers	•Fear •Shame, embarrassment •Secrecy •Fear of not being believed •Limited readiness for change	
	Facilitators	•None reported	
	Barriers	<ul> <li>Lack of or limited communication ability with family members</li> <li>Mistrust</li> <li>Lack of empathy or understanding</li> <li>Lack of or limited emotional support</li> <li>Minimization of the survivor's problems</li> <li>Blaming the survivor</li> <li>Family mental health problems</li> <li>Isolation</li> <li>Distance</li> </ul>	
Family or friends	Facilitators	<ul> <li>Shared communication, ASL</li> <li>Case management support</li> <li>Listening and talking</li> <li>Empathy</li> <li>Emotional support, "soft heart"</li> <li>Honest feedback</li> <li>Providing distractions</li> <li>Empowerment</li> <li>Believing, not blaming, the survivor</li> <li>Use of technology to bridge distances</li> </ul>	
Community	Barriers	<ul> <li>Stigma, taboo, myth acceptance</li> <li>Deaf grapevine, gossip, reputations</li> <li>Mistrust</li> <li>Lack of Deaf role models, mentors, or sponsors</li> </ul>	
	Facilitators	•Deaf peers, shared experiences, empathy	

Table 2Barriers to and Facilitators of Informal Help-Seeking for Deaf People

Note. ASL = American Sign Language.

needed someone like me to show up. Someone who had lived it, to recognize it quickly, but there was no one").

Despite these concerns, participants still emphasized the importance of seeking help from other Deaf community members in the aftermath of trauma ("They had shared experience"; "I sought help from friends and Deaf Women United—among Deaf peers, I didn't feel so alone"). This peer-support theme also emerged from formal help-seeking experiences, outlined next.

## Formal Help-Seeking

**Individual-level barriers and facilitators.** Many participants reported that they did not seek formal help after trauma, because they were unaware of treatment options or how to access these options ("I didn't know about treatment because I was Deaf"; see Table 3). Others reported that feelings of pride, fear, shame, or embarrassment held them back from seeking professional support ("We don't like to admit our problems; we feel like we always have to prove that we can do it").

Participants felt strongly that awareness of treatment options and better understanding of the purpose of treatment are key facilitators to formal help-seeking ("Realizing how treatment could help would have helped me. Before, I thought, 'What's it for? What's the point?"" "[Therapists should] go to Deaf events and workshops because many Deaf people don't know about available services"; and "Go to events to meet people—someone there needs treatment or knows someone else who needs treatment").

Provider-level barriers and facilitators. The most commonly reported barriers to seeking formal help in the aftermath of trauma were the provider's lack of shared communication with the participant, failure or refusal to provide ASL interpreters, and lack of awareness of Deaf culture and history. Many participants also reported negative experiences with providers who struggled to remain supportive or neutral in client encounters ("Some staff have negative attitudes, bad facial expressions, and act inappropriately. This triggers clients to blow up, but it's really the staff person's fault. They need to take trainings on how to use better facial expressions"). Others reported mistrust of providers due to harmful experiences of being overdiagnosed or misdiagnosed ("She decided to diagnose me as Borderline. I received many wrong labels"; "Diagnoses, labels, medications-lousy!"), not being believed, provider dishonesty, violations of confidentiality, and severe violations of boundaries or ethical principles.

Participants reported that a major facilitator to formal-help seeking was if providers could communicate with them in "direct ASL,

Table 3	
Barriers to and Facilitators of Formal Help-Seeking for Deaf People	

Level		Qualitative theme
Individual	Barriers	•Unaware of treatment options or how to get help •Pride •Fear, shame, embarrassment
	Facilitators	•Awareness of treatment options •Understanding the purpose and value of treatment
Provider	Barriers	<ul> <li>No shared communication, no interpreters provided</li> <li>Lack of awareness of Deaf culture or history</li> <li>Bad attitude, bad facial expressions</li> <li>Misdiagnosis, labeling</li> <li>Not believing the survivor</li> <li>Dishonesty</li> <li>Mistrust</li> <li>Lack of firmness</li> <li>Confidentiality violations</li> <li>Boundary or ethical violations</li> <li>Inexperience</li> </ul>
	Facilitators	<ul> <li>Direct communication, ASL</li> <li>Willingness to work with certified Deaf interpreters</li> <li>Understanding of Deaf culture or history</li> <li>Shared experiences, empathy, peer support (Deaf)</li> <li>Honesty, bluntness</li> <li>Friendly personality, "soft heart," compassionate, calm</li> <li>No attitude, no bad facial expressions</li> <li>Open-minded</li> <li>Confidentiality</li> <li>Community involvement but with boundaries (hearing)</li> <li>Experience</li> </ul>
Intervention	Barriers	<ul> <li>Lack of trauma focus</li> <li>Lack of substance abuse focus</li> <li>Lack of case management support</li> <li>Lack of contact between treatment sessions</li> <li>No availability of crisis sessions</li> <li>Lack of structure</li> <li>Overfocus on diagnoses and labels</li> <li>Disempowerment, one-up approach</li> <li>Lack of education or provision of information</li> <li>Group therapy (due to confidentiality concerns)</li> </ul>
	Facilitators	<ul> <li>Skill-building (behavioral)</li> <li>Future orientation, goals</li> <li>Case management</li> <li>Comorbid substance abuse treatment</li> <li>Use of appropriate self-disclosure</li> <li>Feedback, confrontation</li> <li>Space for storytelling and self-expression</li> <li>Flexible support</li> <li>Follow-up, check-ins</li> <li>Availability between sessions</li> <li>Sufficient education or provision of information</li> <li>Peer support</li> <li>Individual therapy (to avoid embarrassment)</li> <li>Group therapy (to feel validation and support)</li> <li>Long-term treatment</li> </ul>
Community	Barriers	<ul> <li>Small-community dynamics</li> <li>Confidentiality violations, gossiping</li> <li>Lack of anonymity in group therapy</li> <li>Lack of privacy with ASL interpreters</li> </ul>
	Facilitators	Hearing provider who knows ASL     Spaced-out appointment scheduling

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(table continues)

Level	Qualitative theme		
	Barriers	<ul> <li>No ASL interpreters provided, or interpreter issues</li> <li>Limited services, wait lists for available services</li> <li>Travel distance to treatment</li> <li>Insurance problems</li> <li>Financial problems</li> </ul>	
	Facilitators	<ul> <li>Employ Deaf or signing professionals</li> <li>Hire interpreters</li> <li>Advertise via community outreach</li> <li>Accept insurance</li> <li>Ease of scheduling appointments</li> <li>Maintain Deaf-friendly services even within larger hearing agencies</li> <li>Provide awareness training and basic sign language training for staff and medical personnel</li> <li>Safe, homey environment</li> </ul>	

Note. ASL = American Sign Language.

no interpreter" and if they "know Deaf culture through and through" and "They can see the 'real me,' not through an interpreter." They indicated a preference for providers who are also willing and able to work with certified Deaf interpreters (see footnote 2) if additional communication facilitation is necessary. Some specifically prefer to work with a Deaf provider, who has shared experiences and could more easily empathize ("A therapist who is not hearing is my preference. It feels like home"). Others reported that they preferred to work with a hearing provider with less involvement in the Deaf community ("I'm more comfortable with a hearing provider who knows sign because I won't see them at Deaf events"). Additional provider-level facilitators to helpseeking reported by most of our participants were the provider's ability to be "honest"; "direct, blunt"; "friendly"; "calm"; "not close-minded"; and "have compassion," which some participants attributed to duration of professional experience ("I want someone who is more experienced than other newer therapists, who suck").

**Intervention-level barriers and facilitators.** Participants reported limited success with clinical interventions that lack a trauma focus ("Bad programs deny trauma"; "Some therapists never talked about domestic violence. I thought the abuse was my fault. I thought that I was not nice, that I was a bitch. I was angry, not innocent. I believed that abuse only happens to innocent people"), lack sufficient case management support, lack appropriate education or provision of information (e.g., "The therapist never explained my diagnosis"), and lack structure. They also expressed frustration with approaches that prohibited betweensessions contact or crisis sessions.

Participants reported that the ideal trauma intervention would teach them skills to manage trauma symptoms (e.g., "I learn how to use skills, like art, knitting, painting"; "Meditation, relaxation, talking, less stress and emotions"; "Good therapists suggested yoga, healthy food, walking"), focus on setting and achieving goals, case management support, treatment for comorbid addiction ("Good programs link trauma with addictive behavior"), and education or provision of information ("They should give more resources and education, so that Deaf people do not remain ignorant"). They expressed a preference for flexible intervention approaches that allow for clinician self-disclosure ("She was open about herself;" "She shared her own experiences, felt like a peer"), honest feedback and confrontation, space for clients to express themselves and tell their story ("Let them tell their story—don't interrupt!"), between-sessions check-ins, peer support, and long-term treatment if needed.

**Community-level barriers and facilitators.** Many participants reported that they did not seek professional help after trauma due to small-community dynamics, fearing that their providers, ASL interpreters, or group therapy members would violate confidentiality ("The Deaf community is so SMALL"; "All the therapists know my mom—it's a small Deaf community. I didn't want people to gossip. I didn't want my ex to find me"; "I didn't want to work with interpreters—there's no privacy"). A few participants reported preference for individual treatment over group treatment, to avoid embarrassment and shame ("If Deaf people know each other, they are ashamed to share"); others reported a preference for group intervention, to receive validation and support from other Deaf community members.

Recommended facilitators included training hearing providers who are fluent in ASL, so that Deaf clients can select between Deaf or hearing clinicians, and to adequately space therapy appointments with Deaf clients ("Don't schedule back-to-back appointments with Deaf clients. They pass each other or see each other's cars—this breaks confidentiality").

**Systems-level barriers and facilitators.** The most common systems barrier reported by participants was difficulty requesting or receiving ASL interpreter services. Also salient were participants' concerns about the limited availability of Deaf-specialized services and long wait lists for the services that do exist ("There are not enough services in the whole state"; "I prefer a Deaf provider, but I'm currently on waitlist for counseling"). Other barriers were long distances to treatment, as well as insurance or financial problems.

Regarding pragmatic facilitators, participants recommended that insurance and scheduling procedures be more transparent and easier to navigate and that the clinical environment feel safe and "homey, not cold or institutional." Behavioral health care systems should strive to maintain Deaf-friendly services, even within large systems geared toward serving the general population. Specific recommendations included employing Deaf or signing professionals, hiring staff ASL interpreters, and providing awareness training and basic sign language training for all personnel ("The hospital should be aware of the needs of Deaf people. They should be good with interpreters"; "They need awareness training for medical doctors. They need training on bad facial expressions. They think Deaf people are stupid").

Participants also strongly suggested that available trauma services be advertised via outreach into the community ("Therapists need better outreach and advertisement. They need to be visible—on Facebook, the Internet, through independent living workers, host a Deaf Expo table . . . ."; "Deaf people prefer to see you in person, hear about your experience and qualifications in person"; "They should get exposure at health fairs, booths with the therapist there. If I meet you, I might be more motivated to open up").

## Discussion

The current study explored the help-seeking experiences of 16 trauma-exposed Deaf individuals and elicited their recommendations for improving Deaf trauma services in the Massachusetts behavioral health care system. In the aftermath of trauma, 10 of 16 participants sought help from formal sources and seven of 16 sought help from informal sources, suggesting a slight preference for reaching out to clinicians, other professionals, and authorities. This trend, however, did not hold true for the three participants who identified themselves as Deaf children of Deaf parents and who were raised in an ASL-using household-in other words, those who had been exposed to Deaf culture from birth. These individuals were more likely to seek help from informal support sources, with none reporting that they sought support from professionals or authority figures. This finding aligns with a recent qualitative study that investigated Deaf people's experiences with recovery-oriented mental health services, in which many participants "noted a desire to receive peer support from another Deaf person. They felt that there was a deeper level of understanding and trust present when working with another peer, partly due to sharing a similar language and culture" (Cabral, Muhr, & Savageau, 2013, p. 654). On the other hand, participants in our study 45 years and older were less likely to seek informal support compared to younger participants, perhaps due to a generational effect and the relatively recent shift toward peer support within the behavioral health care system (Davidson et al., 1999). Qualitative results further clarified these theories, and are summarized next.

Facilitators for formal support generally aligned with principles of trauma-informed care as applied in the hearing community (Herman, 1992). Participants stated a desire for a qualified provider who exemplifies characteristics of honesty, compassion, care, composure, and appropriate use of self-disclosure. The ideal trauma intervention is flexible, allowing for varying lengths of treatment, between-sessions contact, and peer support. Intervention foci would be on building coping skills and thinking toward the future, as well as providing case management and supplemental education or resources to fill fund of information gaps (Cerulli et al., 2015).

Many preferences for formal help-seeking, however, were distinct to Deaf trauma survivors. Participants reported a desire to work with a signing provider who is highly knowledgeable about Deaf culture, history, and experience and to interact with clinic staff who have received training regarding basic sign language skills and cultural sensitivity. Some participants described a preference for a Deaf provider (e.g., "feels like home"), as well as the importance of seeking help from Deaf peers after experiencing trauma. Yet, similar to findings in Deaf persons with mental illness (Cabral et al., 2013), they noted significant stigma toward trauma and traumatic stress disorders within the Deaf community (Mastrocinque et al., 2015) and a lack of visibility of Deaf trauma survivors to serve as role models for recovery. Conversely, other participants reported that they would opt for a hearing, signing provider, whom they would be less likely to encounter on a regular basis at community events (Mastrocinque et al., 2015).

Despite this desire for privacy, most participants stressed the need for providers to make more outreach efforts into the Deaf community—to provide education, to describe available treatment resources and their intended benefits, and to prove one's qualifications and level of signing skills. This visual presence allows members of the community to "hear about your experience, qualifications" and "trust what [they] see for [them]selves." Overcoming mistrust is not unique to Deaf people but is a common thread that weaves itself through culturally sensitive work with any historically marginalized or oppressed group (George, Duran, & Norris, 2014).

Participants also provided concrete suggestions for how behavioral health clinics can better protect Deaf survivors' confidentiality, a concern frequently expressed by other consumers from small, highly connected communities (Damianakis & Woodford, 2012; Mastrocinque et al., 2015). Our participants recommended that clinics hire both Deaf and hearing signing providers from whom clients can choose, hire only certified ASL interpreters who are highly trained in mental health and confidentiality law, and allow adequate time between appointments so that Deaf clients do not cross paths in waiting rooms or parking lots. This last suggestion, however, may present a challenge to the sustainability of clinics, because insurance reimbursement relies on direct face-toface time with clients; creative approaches, therefore, are crucial to better meet the needs of Deaf clients within the constraints of the current behavioral health system.

#### **Study Strengths and Limitations**

A key strength of our study was the use of Deaf-accessible methods (e.g., recruitment materials, informed consent, and interviews provided in ASL; provision of certified Deaf interpreters as needed). This is largely attributable to consultation with Deaf colleagues throughout each step of the research process, including when designing methods, selecting and translating trauma assessments, interpreting study findings, and preparing the article.

Our primary study limitation was small sample size. Additionally, our sample was primarily White, female, middle-aged, and heterosexual. Inasmuch, the results of this small exploratory study should be generalized with caution. A second limitation was that we did not collect data regarding the date of participants' trauma events and subsequent help-seeking behaviors, nor the age at which these experiences occurred. As such, it is possible that some of the reported trauma experiences and barriers to help-seeking occurred in the remote past, when both the general population and the Deaf community were relatively unaware of issues of trauma and how to access trauma services. Therefore, some of the barriers and facilitators reported by participants may not necessarily be applicable in the present day. A third set of limitations is related to the use of a semistructured interview instrument, a portion of which was a researcher-created measure. As such, the exact psychometric properties of our instrument when completed by a Deaf population is unknown; however, we attempted to reduce the impact of this limitation by administering all measures in ASL and providing additional communication accommodations (i.e., certified Deaf interpreters) as needed. An additional limitation was that our interview focused on participants' experiences of help-seeking from only family, friends, peers, clinicians, other professionals, and authorities. We did not investigate the helpfulness of alternative sources of help-seeking (e.g., self-help books, Internet-based resources).

# **Study Implications and Future Directions**

Despite these limitations, our findings provide important information to avoid common pitfalls and guide the development of Deaf-friendly trauma treatment and peer support services. The approaches that are developed should begin with essential components of trauma-informed care (Herman, 1992) but should also carefully consider the following key criteria expressed by our participants: signed communication, understanding of Deaf history and experience, stringent confidentiality practices, provider efforts to outreach into the community and be more visible, and reliance on peer support and Deaf role models in treatment. Until those serving Deaf people are better able to listen to them when designing clinical services for them, some Deaf trauma survivors will continue to avoid the behavioral health care system, seek support elsewhere, or not seek help at all.

Future clinical services research should engage Deaf individuals at the early planning stages; apply community-based participatory research principles throughout the research process (Barnett, Klein, et al., 2011; Leung, Yen, & Minkler, 2004); and aim to recruit a larger, national sample of Deaf individuals who better represent the U.S. Deaf community at large. Additionally, these investigations should differentiate between help-seeking behaviors of Deaf adults, Deaf children, and Deaf families; investigate alternate pathways of help-seeking not investigated in the current study; and explore the ebb and flow of Deaf services over time and the impact of this evolution on the health and well-being of Deaf trauma survivors.

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Received October 28, 2015 Revision received September 26, 2016 Accepted September 28, 2016