What about Hep C? Time to dispel myths, misperceptions

By Richard Baker

Just how serious is Hepatitis C? It kills more Americans than the next 60 infectious diseases combined, and nearly 70 percent of those living with it are unaware of their status. With prevalence estimates ranging upwards of 200,000 people in the Commonwealth, the need for a robust, multi-stakeholder response is critical.

We've seen the ads: "Were you born between the years 1945 and 1965? Have you been tested for Hepatitis C?" But what puts an entire generation collectively at risk for this infection – and where is the connection to injection drug use? The answer: blood. Hepatitis C is an insidious virus that began its rapid transmission long before we ever studied it or learned how to prevent it. Without proper blood screening or universal precautions in clinical settings, thousands were exposed to infected blood as viral transmission peaked in the 80s. As a result, we face two epidemics of equal concern: chronic Hepatitis C among the Baby Boomers and an exponential rise in acute Hepatitis C incidence among people who inject drugs. While national awareness campaigns continue to press the urgency for testing and treatment among the former, stemming the epidemic will require an equally concerted effort to test and treat people who inject drugs.

With the national spotlight focused on the opioid epidemic, the rising rate of acute Hepatitis C receives far less attention. It is critical that we see these two epidemics as intrinsically connected. The Hepatitis C virus is unique in its ability to survive for extended periods outside of the body, and for its resistance to bleach as a disinfectant. Without proper training, the challenges faced by people who inject drugs to prevent HCV transmission can be daunting, and bear serious consequences to their health. With the rise in short-acting illicit fentanyl, individuals are injecting more frequently – increasing the likelihood of syringe sharing and virus transmission. Recent data from the Department of Public Health show alarming increases in injection drug use and concurrent Hepatitis C infections in the population of youth and new users in Massachusetts. Unfortunately, this is also the population least likely to engage with harm reduction or treatment services – placing them at elevated susceptibility to both overdose and Hepatitis C infection.

Noting the rise in Hepatitis C cases within our residential treatment programs, Victory Programs made the decision to launch the Viral Hepatitis Prevention Project in November 2016. Our prevention work employs a harm reduction philosophy to empower those at risk or living with Hepatitis C with the skills and resources to safeguard their health. Group-based education, individualized service navigation, and provision of safe injection supplies and resources are all key elements of this project. Clients enter treatment with a variety of risk comprehension levels, many learning of their risk factors for the first time. Anxiety and unease are common as people learn that even sharing used razors or toothbrushes can place them at risk for Hepatitis C transmission, or that continued substance use can rapidly advance liver damage.

As we learn more about the virus and the treatment landscape becomes more nuanced, more than ever community education is necessary to dispel the myths and misperception. This is where our community health workers play the most significant role. With restrictive insurance policies behind us, the most effective way to get people tested and cured is through education and building self-efficacy.

So what can you do? Join the advocacy effort toward the elimination of Hepatitis C in Massachusetts. In 2016, Victory Programs began coordinating the EndHepC-MA Coalition, a multi-stakeholder collaborative of advocates, providers and consumers working to build capacity, expand treatment and change policy. Thus far the Coalition has successfully changed insurance regulations, trained community health workers and is currently working to expand screening requirements and better incorporate Hepatitis C care in the clinical guidelines of addiction medicine. While we've made progress with the elimination of treatment restrictions, there are still significant barriers preventing Massachusetts from reaching its goal of elimination. As providers we play a key role in seeing this goal realized, and it's our responsibility to get there.

Richard Baker is the Viral Hepatitis Coordinator for Victory Prevention, a division of Victory Programs.

Connecting communities, families through universality of music

By Meredith Pizzi

On this Friday night, a group of adults who live together with staff support were prepping for their night out on the town at the Project Harmony: Karaoke/Open Mic Night. One town over, a family prepared for the evening by gathering their children, dressed in their stage-ready clothes, and talking about the songs they would sing. For a professional working in the field of disability services, it was a long, stressful week and on the way home from work she decided to stop in as well. Despite the various motivations for going out to the karaoke night, it became clear that everyone was looking for something similar: a chance to be part of something bigger than themselves.

As the end of 2017 approaches, it is safe to assume that many of us know what it is like to feel disconnected or isolated. Whether we are looking in our neighborhood, at digital social networks or the national landscape, the main headlines are often filled with themes of division and disagreement. No matter where you find yourself on the political spectrum, it can be an isolating experience. Those of us working to improve the lives of people with disabilities have not forgotten for one moment how vitally important it is for everyone to feel like they belong.

As committed human service organizations, Providers' Council members continue to be on the front lines of bringing people together: building bridges of social capital and personal connection. At Roman Music Therapy Services, we believe that community music therapy addresses the needs we all share – to belong, to feel included, and to be part of meaningful, shared experiences. As I have been writing and presenting more on our community-based services, I have come to define community music therapy as a reflective and responsive philosophy of music therapy that focuses on the two-way connections between individuals and communities. Authentic friendship, inclusive communities and mutually beneficial activities are universal needs that can be addressed through music therapy services that promote and reinforce interpersonal connections.

Looking around the room of 100 people in attendance for our first Project Harmony Karaoke Night, you could see connections happening within the groups that came together and among people who only met that night. These magical musical moments were a measurement of the success of the evening: a performer selling his CD promoting rights for people with disabilities, a young man taking the stage to beatbox with a music therapist he had just met, housemates cheering each other on when they took the stage, a mom performing to encourage her daughters to take their turn.

"Musicking," a term developed by Christopher Small, describes the act of taking part in a group music experience, as a performer, active listener or other contributor. Regular participation in music therapy leads to increased feelings of trust, reciprocity, belonging and attachment because everyone has a voice. Everyone has a part to play.

In Community Music Therapy, it is the music therapist's job to carefully structure music experiences to ensure that everyone has an opportunity to make progress on their personal goals and outcomes. I have seen this happen in our large Universal Music Therapy events, but also in our small group home or Community-Based Day Support environments, when residents are laughing, playing and sharing together in music. Although each individual comes to musicking with different needs, everyone can find connection and belonging in music therapy. In our new Project Harmony Intergenerational Chorus, members are increasing decision making, teamwork and communication skills as we rehearse for the Showcase Performance on Dec. 18th. More importantly, they belong. They have a voice in the chorus and are excited to be heard.

As we put our words and our values into action with Project Harmony, we hope you will join us. Your organization can get involved by spreading the word to participants, families and staff members that our Project Harmony music experiences are open to everyone who wants to gain the mutual benefits of musicking. If your organization wants to play a bigger role in supporting friendships with other adults or building bridges across various agencies, we hope that you will consider sponsoring a Project Harmony program to help bring musicking to more individuals.

Music-making is a great common denominator. We truly believe that to counteract the isolation and divisions in our communities, we can come together in communal music experiences. By making music together and supporting community music therapy, we can create a social capital resource that can be utilized and drawn upon immediately. Music therapy can be a uniting force to connect families and communities, big and small.

Meredith Pizzi, MPA, MT-BC, is Executive Director of Roman Music Therapy Services.

Deaf Survivors Program breaks down barriers to help

By Kim Dawkins and Stephanie Reynolds-King

Looking back over our history as we prepare to celebrate our 45th anniversary in 2018, Pathways for Change has established a long standing record of accomplishments and a commitment to reaching the diverse communities within Central Massachusetts. Our mission is to address the impact of sexual assault and abuse by providing quality and multicultural services to all persons whose lives have been impacted by sexual violence and education geared toward the prevention of violence. Pathways is proudly one of the leading rape crisis centers in Massachusetts and has served as an example of promising practices nationally.

Of all the agency's many successful and groundbreaking programs, one that I am most proud of is our Deaf Survivors Program (DSP). DSP is the only culturally and linguistically accessible program for d/Deaf, hard of hearing, late deafened and deaf/blind survivors of sexual violence in the Commonwealth. Originally focused on Worcester County, DSP currently operates with a service area that includes Franklin, Hampshire, Hampden, Middlesex, Worcester and parts of Norfolk County.

To date, there are no definite statistics available on the exact number of deaf individuals in Massachusetts. However, using the application of reliable prevalence rates to state population data, estimates of the number of deaf individuals residing in our service area can be determined. According to the 2010 U.S. Census, our service area contains a population of 2,266,594 individuals. The MRC Disability Fact Sheet, released by the Massachusetts Rehabilitation Commission in 2016, estimates the percent of Massachusetts. residents who are d/Deaf and between the ages of 18-64 living in the community at 1.8 percent. It can, therefore, be safely estimated that there are roughly 40,798 d/Deaf individuals living within our service area. Similarly, using the most recent prevalence rates for sexual violence, we can conservatively estimate there are approximately 19,583 d/Deaf survivors of sexual violence in this same area.

Recent research on sexual violence in the d/Deaf community, however, suggests that d/Deaf individuals are significantly more likely to experience sexual assault than their hearing counterparts. For example, previous studies demonstrate that although sexual assault rates among college students are high, among the d/Deaf community, these rates are nearly double. Similarly, in a 2010 study, d/Deaf undergraduate students were found to be 1.5 times more likely to be victims of sexual harassment and sexual assault than hearing undergraduates at the same university. According to a statistics put out by the Washington Coalition of Sexual Assault Programs, 54 percent of boys who are d/Deaf have been sexually abused, compared to 10 percent of hearing boys. And 50 percent of girls who are d/Deaf have been sexually abused, compared to 25 percent of girls who are hearing.

As one of the most significant barriers to d/Deaf survivors seeking help is the lack of accessible communication in sexual violence support agencies, the provision of sexual assault counseling and advocacy by individuals who are fluent in American Sign Language (ASL) is critical to eliminate the need for interpreters and assuage concerns regarding confidentiality. Low rates of health literacy in the d/Deaf community and lack of linguistically accessible health materials emphasize the need for medical advocacy services. In addition, the lack of communication accessibility in the legal system highlights the importance of legal advocacy services provided by advocates fluent in ASL. Finally, workshops held in the d/Deaf community to educate individuals are viewed as essential. At the same time, d/Deaf culture workshops with hearing service providers are viewed as equally important to improve the experience of d/Deaf survivors. Knowing how to communicate, how to find an interpreter and how to protect the rights of d/Deaf individuals are primary areas to be stressed.

Today DSP employs three full-time staff (two members of the d/Deaf Community and 1 ASL-fluent hearing individual) to provide culturally and linguistically accessible services to d/Deaf survivors of sexual violence. From Pittsfield to Boston we have provided individual and group counseling; hospital, court and police station accompaniment; educational workshops; case consultations and technical assistance in order to ensure that every d/Deaf Survivor seeking assistance has access to the same high quality services that others enjoy. If your agency or clients could benefit from these services, contact the DSP Outreach Specialist Carly Achilles at 508.852.7600 or DSP Coordinator, Stephanie Reynolds-King (via Videophone) at 508.502.7681.

Kim Dawkins is the Executive Director and Stephanie Reynolds-King is the DSP Coordinator at Pathways for Change.