# The Perfect Storm

June 1, 2016 By Matthew Zielske

Situated an eyelash above sea level, in the southern pocket of a state mostly known for basketball and the Indy 500, rests lazily in an oxbow of the Ohio River the enigmatic city of Evansville. It's the 3rd largest city in Indiana and synonymous with economic stability and a generous cost of living. A college town of millennials and XYZer's is anchored by a well-established generation of baby boomers. This diversity gives way to a tapestry of voices, interests and opinions stitched together to create the social fabric of the city.

In recent years the Franklin St. Events Association and the Haynie's Corner Arts District has transformed sections of the city into vibrant pockets of restaurants, bars, and nightlife hotspots. Streets, neighborhoods and subdivisions are peppered with reincarnated bohemian souls and well-dressed political elites who have beaten, through sheer will, energy and economic opportunity back into old neighborhoods and parks.

We should appreciate and celebrate these achievements as a positive sign of civic engagement. At the same time we must be cognizant of the fact that Evansville exists as part of a state fast becoming known for heroin overdose, opiate addiction and one of the worst HIV outbreaks in the last 30 years. No city is immune to the ravenous nature of substance use, and the public health crises that follow, not even Evansville.

Vanderburgh County, of which Evansville is the seat, ranks 77 out of 92 counties for over-all health outcomes in Indiana. The county has higher than state average rates of sexually transmitted infections, teen pregnancy and chemical overdose deaths. In addition, 25% of children live in poverty and 41% of households are single parent. I want to be clear that I'm not inferring single parent households are bad households, or that single parents are representative of something that needs to be fixed, but rather, the statistic is important to keep in mind when we consider those households are more likely to have limited resources.

This may result in those households, and the youth living in them, having less access to health care, preventative services and healthy nutrition information. Recognizing these social determinants of health, as well as many others, is imperative as they are indicators of areas where higher incidence rates of HIV/hepatitis C (HCV) may occur.

Also consider that from 2009 – 2013 acute cases of HCV increased 532 percent.  Vanderburgh County has also seen a significant increase in HCV incidence. This sharp increase in HIV/HCV is a direct result of the rise in injection drug use, combined with limited to no access to preventative

services for persons who inject drugs (PWID) where they can obtain sterile syringes and comprehensive health education.

To better understand the precarious position that Evansville and surrounding rural counties are in I need explain why the very thing that is a sign of economic success for Indiana, and the city of Evansville, is also the mechanism that makes us vulnerable to continued HIV/HCV health crises.

For anyone who has ever driven through Indiana on their way to somewhere else, you've likely encountered signs proudly proclaiming we are the "Crossroads of America." As you traverse the main artery of I-64 that runs from St. Louis to Louisville you are greeted with flat farmlands that subtly give way to rolling landscapes, which eloquently turn into the clay cliffs and the fertile soil of Kentucky. The newly completed I-69 corridor that runs North/South to Indianapolis places the finishing touches on a series of inter and intrastate roadways that converge pointedly through Evansville. If viewed from above you would see Evansville in the middle of a directional cardinal of roadways. This makes the city a nexus point within a state that most people hurriedly pass through.

I-69 affords fast transit to and from cities like Nashville and Indianapolis. This increased traffic through Evansville in turn increases the potential for further economic growth. It supplants the city as a midway stop between the four city giants of Indianapolis, St. Louis, Nashville and Louisville. This is a good time to note that Ohio, Kentucky (both in the top 10) and Indiana (15) all rank in the top 15 states in the U.S. for Heroin/Opiate overdose deaths. When you combine the fact that Ohio and Kentucky are states with similar health crises related to substance use, with the frequent intrastate travel that occurs amongst the three states by way of Indiana and Evansville, increased incidence of HIV/HCV begins to make sense.

Inevitably, the direction of key policy change and resource allocation in Evansville has become focused on placing the city in the best possible situation to ensure economic success. This is a larger discussion of city governance and politics, so I'll avoid getting too off track. Suffice it to say that suggesting the decision to declare a state of emergency for HIV/HCV isn't determined by the anticipated economic outcomes would be naïve at best. At worst, such a statement suggests we prefer to remain willfully ignorant and only want businesses to commit to Evansville so that when we are forced to declare a HIV/HCV state of emergency they will find it harder to leave.

This economic mindset helps create an environment where HIV/HCV incidence is much more likely to go unchecked until it's too late. Such a viewpoint has far reaching implications that I will revisit later, but first, let me tell you about Scott County and the lessons we encountered but seemingly don't want to use.

In December of 2014, local health department officials and HIV testing counselors in Scott County began to notice something concerning. In Austin, a city of roughly 4,000 people, where newly diagnosed HIV cases were less than 5 per year previously, public health workers had confirmed 27 people as HIV positive, with 10 preliminary, by the middle of February. In March 2015, when I was dispatched to Scott County to assist with HIV/HCV testing, education and outreach, new HIV

diagnoses were accelerating with as many as 5 people per day being diagnosed.

As summer was coming to a close approximately 175 people had been diagnosed as HIV+ in Scott County; a figure that would have been 35% of the total HIV diagnoses for Indiana the previous year. For comparison, in roughly 7 months Indiana had more HIV positive diagnoses that identified injection drug use as a primary risk factor than all of New York City did for the 2014-year. A startling fact when you consider Scott County has a population of 40,000 and New York City has a population of 8 million.

I still vividly recall the first person I screened for HIV/HCV in Scott County. They told me in an exasperated and helpless tone, “When they stopped selling syringes over the counter, we knew they wanted us to get sick.” A heartbreaking statement of despair and hopelessness that would be echoed in the days, weeks and months that followed. Unless you’ve experienced it there isn’t any effective way to describe what happens in the moments after you tell someone they are HIV+.

I was asked once by a newly trained testing counselor what the first thing I said was after telling someone they were HIV+. My response was then, and still is, I don’t usually speak first. I mean what can you really say in those moments that seem to stretch on forever? Nothing really. So, after some time has passed and their breathing has relaxed, if they haven’t spoken, I simply ask them if they want a hug, because the truth is, far too often the compassion of others is what they’re most afraid of losing.

Austin is the unfortunate example of how isolated you can be as a community despite being perfectly situated between the two cities of Indianapolis and Louisville. The majority of those diagnosed as HIV positive were PWID, who were also co-infected with HCV. What unfolded in Scott County, and in many ways is still unfolding, is unfortunate and saddening because we allowed it to happen. It doesn’t have to be all for naught though. If we look close enough we will find information that allows us to predict where HIV/HCV is going and carry out effective disease prevention to try and avoid what happened in Scott County occurring again.

I didn’t know it at the time, but I was witnessing a shift in the organic trajectory of HIV prevention. In the 35 years since the HIV pandemic began we have learned a lot about the virus and how to treat it. People are living longer and healthier than ever before. AIDs diagnoses both nationally and on a state level are decreasing, a direct result of advanced antiretroviral therapy.

Unfortunately, new HIV infections are increasing among certain populations. Being outpaced by HCV incidence that a few years ago would have seemed inconceivable. A recent snap of shot of Epidemiology data for 2015 from the Indiana State Department of Health shows that 32% of all new HIV infections were among PWIDs, and 40% were among 20-29 year olds. A sign that in our certainty of how to handle HIV we became overly confident and forgot about its pernicious nature and determination to adapt.

The HIV outbreak in Scott County didn’t suddenly manifest out of thin air. For some time the social determinants of health were working to make an environment conducive to large scale HIV/HCV transmission. We simply didn’t notice them, in part because we weren’t looking, but also because

we weren’t encouraged to look.

Epidemiology is a complex field that is vital to tracking the progression of communicable disease while also giving us a trove of data to reference when allocating and maximizing resources. As with all tools, epidemiology data is only as effective as the ways it’s used and by the people who use it.

As I see it, the danger of epidemiology data is twofold. First, it can reinforce tunnel vision and limit innovation in the field of HIV/HCV prevention. This occurs most often when viewing culture through a singular lens as a static variable, using macro data trends on a micro level, and as a direct result of only going where the numbers lead.

As an example, if the national incidence and prevalence data on HIV infection tell us that we should be focusing on young men who have sex with men and African Americans, then we tend to do so because our grants are constructed in ways that force our hand.

Yet, allowing this epidemiology data to take precedence and ignoring local demographic and risk information simply does not make sense. If the racial composition of Evansville is 86% white, with a high prevalence of persons who inject drugs, this would suggest, and encourage, that those are the populations we direct the bulk of resources to. Ignoring that information because it doesn’t fit the messages of national health campaigns is reckless and lazy.

HIV/HCV does not disproportionately affect populations simply because of their cultural variable.

I would hope this goes without saying, but by chance that isn’t the case let me explain. African Americans are not disproportionately affected by HIV incidence simply by proxy of being African American. Rather, they exist within structural systems of policy and social norms that limit their agency and lead to social determinants of health that indirectly increase risk. The same can be said for men who have sex with men. In prevention we have a phrase you may be familiar with, “It’s not who you are, it’s what you do,” a nice sentiment that we don’t truly let guide us as often as it should.

This distinction is important because the narrative that is projected through health campaigns inadvertently leads the general public to ignore their risk as a result of “othering.” If the highest risk group is men who have sex with men and African Americans, then what health information would regularly be encountered to lead heterosexual women to be aware their risk of contracting HIV/HCV is also high? None. Not until you tell them that over 50% of all new HIV infections are among heterosexual women. There is a very real possibility that targeted outreach and health information as a direct result of macro epidemiology data contributes to a cycle of HIV/HCV incidence by way of limiting peripheral vision.

The second danger of epidemiology data is that it takes a while to verify and compile. Rightly so, we want this data to be valid and statistically significant. Yet, this is all the more reason to keep in mind most publicly available epidemiology data is a year old.

Which means, more often than not, we are working on an information delay.  So when people present the argument to me that, “we need the numbers,” to support the declaration of an HIV/HCV state of emergency, my response is usually an exasperated one.

You see, we can only get the data if there are large numbers of people infected with HIV/HCV, which is what the entire field of prevention is trying to avoid. In addition, the subtle message that accompanies such a statement is that in order to take action there is only one statistic that will allow it.  Again, this ignores the possibility of using peripheral epidemiology data such as other social determinants of health to predict the possible occurrence of an increase in HIV/HCV incidence.

Sometimes I like to think of myself as a weatherman. I’m not as crazy as that sentence reads. Just hear me out. Instead of looking at humidity, weather patterns and air streams to predict storms, I look at social determinants of health to predict spikes in HIV/HCV incidence before they happen. I have found this process to be further complicated by the differences of importance people place on chronic HCV incidence versus acute HCV incidence. There appears to be a persistent mindset that chronic HCV numbers are the only ones that matter.

Roughly 75% of people who are exposed to HCV develop chronic infection, liver complications and are likely to require treatment. The other 25% of people will virally suppress HCV on their own resulting in no long-term complications or need for treatment.

This focus on chronic HCV likely comes from the cost of treatment. In 2016 the Medicare system will incur costs of 9 billion dollars to treat all U.S. persons living with chronic HCV. Some economic models predict the cost to treat all chronic HCV persons living in the U.S. would exceed 300 billion dollars.

These economic projections are all the more reason to pay close attention to acute HCV incidence rates. Ultimately, acute cases of HCV are signs of risk occurrence. They indicate the sharing of injection equipment and continued exposure to possible HIV contraction. They indirectly tell us where we need to be. Ignoring them simply doesn’t make sense.

Epidemiology data is crucial; vital in fact, but we should not, and cannot, allow that data to limit our creativity and innovation in prevention.

Prevention is about limiting, slowing, or eradicating the incidence, morbidity and prevalence of illness. In order to do this effectively we need to be predictive, not reactive. I understand, and support, the need for statistically valid data to be successful with grant funding and policy change. I am not refuting the necessity of it.

The truth is, however, that even though epidemiology data is sound in methodology and objective in the information it reveals, how it is used can be highly subjective when trying to advocate for policy change. My issue isn’t with the tool, but with the arguably intentionally incorrect fashion by which that tool is used.

There is no better example I can think of to highlight the consequences of improperly using epidemiology data than what can occur in the process of Senate Bill 461 (SB 461). SB 461 is a law signed & approved by Indiana Governor Mike Pence that authorizes an emergency syringe exchange program (SEP) in Scott County. Additionally, the law allows individual counties within Indiana to approve and operate an SEP as long as they complete required steps.

The approval of SB 461 was intended to project a sense of urgency and empathy for those affected by the HIV outbreak while pragmatically addressing the health crisis. A message that I could have gotten on board with had the legislation not been signed until well into the HIV outbreak. If we are being honest, Governor Pence more than likely signed SB 461 at the behest of the CDC than his own volition.

I'm sure somewhere in the hallowed halls of a dysfunctional Indiana legislature feelings of urgency and empathy can be found. Keep in mind, however, that over the course of the previous few years this is a State Government that has shown a lack of emotional intelligence and flexibility in regard to broader social concerns. A lack of self awareness that has landed it in the national spotlight on more than one occasion. I would never suggest a part is representative of the whole, I know Indiana government officials and policy makers can be found who are rational, pragmatic and empathetic of the HIV/Hepatitis C and substance use epidemic. I've talked to them myself. I am grateful that they've fought hard, and continue to fight, for an effective and comprehensive approach to this growing public health concern.

The truth is though, SB 461 is really just a half measure designed to placate the public and abdicate responsibility, more than pragmatically address the crisis. Ultimately, the legislation gives the appearance of autonomy for individual counties to approve an SEP, but in reality the law is laden with a key barrier that can make it difficult to get approval.

Some would say that at least SB 461 is a step in the right direction, and that we are making progress. I agree with that sentiment, in part, but in the time that elapses while counties try and navigate the process of approving SB 461 people are still contracting HIV/HCV at unprecedented rates. It is true that the door has been unlocked for us, but an unlocked door is only as advantageous as the person standing in front of it.

For a SEP to be approved and operated within an Indiana county a series of steps need to be completed. First, the county has to declare a public health emergency of HIV/HCV. This declaration has to come from the county health commissioner who is likely to make the decision, in part, using epidemiology data that is outdated and/or only representative of chronic HCV incidence. This power of the county health commissioner to turn the first lever can be a very difficult step in the process to navigate. After a state of emergency for HIV/HCV is declared, a vote must take place among the local legislature, and then only after that can a SEP legally operate under SB 461.

The successful navigation of all of those steps, which can take months, only ensures the opportunity to run an SEP. The funding, staffing and housing resources of the operation have to come from somewhere else. These requirements are a tall order to fill, especially in rural parts of Indiana where resources range from limited to nonexistent.

Gauging public opinion and engaging in civil discussion about SEPs so that concerns are addressed, and law enforcement is supportive, is important to the long-term health of individuals who access SEPs. I firmly believe that transparency is key. I also firmly believe that in dire situations like the one we now find ourselves in throughout Southern Indiana and Evansville, the long-term cost we incur by laboring through that process significantly outweighs the benefits. The argument against SEPs cannot be one of their efficacy. On that subject there is little to no debate. We can't be anymore right on the fact that SEPs are effective at reducing HIV/HCV incidence while also increasing retention in abstinence based treatment by 5x on average.

According to 2010 estimates, the economic cost of lifetime treatment for HIV infection is around $380,000 per person. That means the lifetime cost to treat the 175 persons who contracted HIV in Scott County is 66 million dollars. Add to that the cost of a Hepatitis C treatment that averages roughly $89,000 for 12 weeks, and you have the recipe for an economic situation, that when put mildly, is crippling.

We have to get to a point where we realize we all want the same thing. We want our communities and families to be loved, healthy and safe. What we spend far too much time arguing about is how to get there.

An SEP isn't the silver bullet to the current HIV/HCV epidemic among persons who inject drugs. It cannot stand-alone. We still need abstinence based treatment facilities, NA/AA meetings, support groups, hospitals and community health organizations. We need law enforcement to carry naloxone and continue addressing the issue of narcotics coming into the city while we also work to keep them safe.

We need social workers and social service agencies to continue creating safe spaces where marginalized groups can come to receive comprehensive services without fear of judgement. We need to lead the advancement of HIV/HCV prevention with innovation and fearlessness by changing the structure within which we all live. We need to take the risk that we may be wrong, because there is no other way to know if we are right.

Above all, we need to remember that behind all the metrics and measurables, behind all the p-values and the 95% confidence intervals stand our brothers and sisters, our mothers and fathers and our significant others. That underneath all the multivariate analysis and the linear regressions is our family, our community, asking for just a little bit of the most inexhaustible resource on earth. Compassion.

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