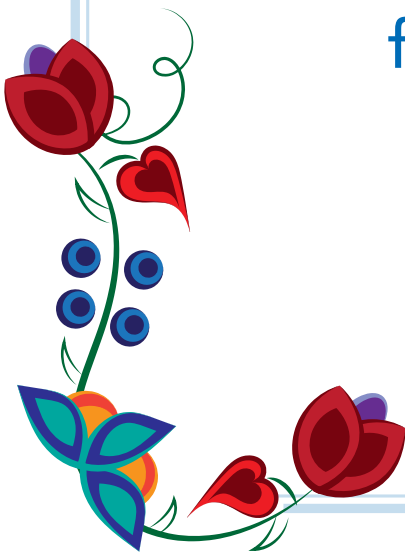


Expanding The Circle of Care

A Practical Guide
to Syringe Services
for Tribal and Rural
Communities



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CONTENTS

Acknowledgments . . . 1

Introduction . . . 3

I. Origins . . . 7

II. Our Harm Reduction Story . . . 15

III. Perspectives and Willingness
to Participate in Harm Reduction Services:
A Report of Findings . . . 25

IV. Applied Knowledge in Rural Harm
Reduction Practice . . . 39

Appendix to Part II . . . 53

- A. Gwayakobimaadziwin Bad River Needle Exchange:
Summary of Peer Reviewed Literature
on Needle Exchange
- B. Gwayakobimaadziwin Bad River Needle Exchange
Guidelines and Operating Procedures

Appendix to Part III . . . 69

- A. Consent to Participate in a Research Study
- B. Interview Guide
- C. References

Appendix to Part IV . . . 75

- A. Data Collection Sheet
- B. Instructions for Kits
- C. Volunteer Information Sheet





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*Dedicated to Nicole “Ziigwanikwe” O’Claire and Dan Bigg
who lived large and left us too soon
gifting us with a vision of our world oriented
towards justice and healing.*

ORIGINS, OUR HARM REDUCTION STORY AND APPLIED KNOWLEDGE IN RURAL HARM REDUCTION PRACTICE

*Authors: Philomena Kebec, Courtney Remacle
and Aurora Conley, Gwayakobimaadiziwin
Bad River Needle Exchange*

We wish to acknowledge the following groups and individuals for their assistance on this project: Patrick Mayotte, Eliza Wheeler, Steve Lang, and Maya Doe-Simkins for their help reviewing this document, and generally, their efforts to improve the world.

We would have nothing worthwhile to say about syringe services without the

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Finally, we extend gratitude to our families, especially our children, and acknowledge their contributions of time and space.

PERSPECTIVES AND WILLINGNESS TO PARTICIPATE IN HARM REDUCTION SERVICES: A REPORT OF FINDINGS

Authors: Sean Akerman, Ana Tochtermann; Center for Rural Communities, Northland College

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INTRODUCTION

In 2018, our community—the ***Bad River Band of Lake Superior Chippewa***—was awarded a two-year policy grant through the *AIDS United Syringe Access Fund* to assist in addressing gaps in the Tribe’s ability to care for those at risk of opioid overdose and exposure to HIV due to injection drug use. One outcome of this policy grant was to create a toolkit for tribal and rural community clinics in Wisconsin implementing **Syringe Services Programs (SSPs)**. Originally, we conceived this toolkit to resemble other currently available harm reduction and SSPs, such as:

- *Guide to Developing and Managing Syringe Access Programs* (Harm Reduction Coalition: 2010);
- *Guide to Developing and Managing Overdose Prevention and Take-Home Naloxone* (Harm Reduction Coalition: 2012); and
- *Recommended Best Practices for Effective Syringe Exchange Programs in the United States* (New York City Department of Health and Mental Hygiene: 2009).

These materials present helpful information written in an objective, theoretical manner.

As Native women who are deeply involved in the daily struggles of people in our community who use drugs, we approach the work of harm reduction with our whole beings (physical, intellectual, spiritual and social) and through a lens of time that encompasses past, present, and future generations.

NARRATIVES

We conceive of the world through personal and community narratives. Stories, for us, contain powerful, healing qualities on par with pharmaceutical medicines provided by state-licensed medical doctors. As Anishinaabeg living in the United States, our ability to recreate reality through the telling of stories is how we have persevered in the face of centuries of existential challenges. In order to be authentic and powerful, we took a subjective, narrative approach. **What follows is our harm reduction story.**

THIS PRACTICAL GUIDE IS ORGANIZED INTO FOUR SECTIONS

I.) Origins

II.) Our Harm Reduction Story

III.) Perspectives and Willingness to Participate in Harm Reduction Services: A Report of Findings

IV.) Applied Knowledge in Rural Harm Reduction Practice

Section I, **Origins** provides a historical background of our community. Problematic drug use is a community issue; we are convinced that it originated in our communal experience. Challenges we've endured continue to shape our current circumstances. By the same token, our endurance is something we can call on in our battle to address problematic substance use.

In Section II, **Our Harm Reduction Story**, we describe the process we used to develop *Gwayakobimaadiziwin Bad River Needle Exchange*, our SSP. We are not sharing our story to claim to be experts in the space of harm reduction. On the contrary, we hope to shed light on our humanity and the hard work of learning about and

implementing an evidenced-based way of responding to community drug use. We hope that our harm reduction story is helpful to other tribal and rural communities interested in creating SSPs.

Section III, **Perspectives and Willingness to Participate in Harm Reduction Services: A Report of Findings**, is a report prepared by the *Center for Rural Communities of Northland College* (CRC) to describe major and minor themes, and other findings, that came from the interviews conducted with people who inject drugs in our community.

We are excited to share these perspectives, as the voices of Native Americans who inject drugs have not been emphasized in other available publications.

In the final Section IV, **Applied Knowledge in Rural Harm Reduction Practice**, we offer on-the-ground, practical advice on the logistics of planning and implementing an SSP. Starting

an SSP can be a huge undertaking and emotionally overwhelming. Our experience is that addressing resource procurement, communications, and sustainability



Aurora Conley (l.) and Philomena Kebec (r.) visiting with Representative Debra Haaland during the AIDS Watch 2019 lobbying effort

is manageable when approached systematically, step-by-step. Again, we are not claiming expertise in this area. We are offering this information because we empathize with new programs that may be overwhelmed by what seems like an enormous project. This information may be used as a starting point to guide the organic process of creating an SSP.

SAFE SPACE

One of the most difficult aspects of running a successful SSP is providing safe space to people who use drugs. It is also the most essential.

In developing this practical guide, one of our main goals was to create safe space for people who use drugs to tell their stories. The discrimination against people who use drugs silences them. This silencing leads to victimization and isolation from the community.

Because their voices are too often ignored, we wanted the perspective of people who use drugs to center and ground this document. To collect their perspectives in a safe and respectful manner, we obtained assistance from the *Center for Rural Communities of Northland College* (CRC) to conduct ethical and professional research. With the CRC's help, we took steps to ensure that participants in our SSP understood that access to syringe services (e.g. sterile works, naloxone, sharps disposal, etc.) would not be affected by participation in the research project. More-

over, choosing not to participate in the project would not affect anyone's access to supplies. We took the time to explain our objectives, including the goal—by way of this practical guide—of laying the groundwork for real changes in our community by elevating the perspectives of people who use drugs. Participants responded enthusiastically and bravely by sharing their stories.

If we are successful in achieving our goals with this guide, it is due to the tremendous generosity of our participants.



I. ORIGINS

The ***Bad River Band of Lake Superior Chippewa*** is part of the Ojibwe Nation, one of the largest Indigenous nations in North America. We speak Ojibwemowin and enjoy a rich spiritual and cultural existence connected to our woodlands and waters.

We consider ourselves responsible for the long-term sustainability of the Bad River watershed: its land, waters and environment, and responsible to speak for and protect the non-human animal and plant communities living with us.

The Bad River Indian Reservation, our reserva-



The Kakagon and Bad River Sloughs, located at the mouth of the watershed on Lake Superior, are listed as wetlands of international importance and cover over 16,000 acres. They harbor the largest natural wild rice bed on the Great Lakes. The grey wolf, Canada lynx, and endangered piping plover are found here. The rice beds maintain genetic diversity in strains that grow around Lake Superior and are harvested using time-honored techniques. Above: The Bad River

tion homeland, is **125,000 acres of rugged wetland and woodlands, on the southern shore of Lake Superior.** The Bad River runs north through the heart of the reservation and empties into Lake Superior at a sublimely remote and undeveloped white sand beach. Within its swamps and woods, our reservation supports abundant beds of manomin (wild rice), herds of white-tailed deer, schools of walleye and trout, medicinal plants, maple sugar bushes, and a plethora of birds, predators, and prey species.

Approximately 2,000 people live within five



Wisconsin Historical Society, WHS-66598

Photo taken in Odanah in 1889 of Anishinaabedog and their home

established settlements, with most of our land remaining undeveloped and wild.

For the Bad River Band, overcoming impossible odds is nothing new. The Bad River watershed has been, and continues to be, a hotly contested landscape. The Bad River Band has become fiercely protective of the lands and waters entrusted to our care.

THE UPPER GREAT LAKES AS THE ANISHINAABE STRONGHOLD

The *Ojibwe*, *Odawa* and *Potawatomi* people, collectively known as the *Anishinaabeg*, have lived within the Great Lakes region for millennia. Ours is a history of creative and resilient survivance. Our ancestors relocated from the eastern seaboard to the west-



Chippewa Lake is an inland wild rice lake within the Ceded Territories of Bad River and related Ojibwe Tribes. Manomin is “the food that grows on the water.”

ern Great Lakes, upon receiving a prophesy which foretold of devastation if we remained in the east. Our ancestors traveled through the Great Lakes, with the Ojibwe ending the journey on the southern shore of Lake Superior, near what is now the Bad River Reservation. The story of the migration journey is a sacred story told within ceremonies and songs that can last for days.

Within a few decades, European traders came to our territories, seeking economic opportunities and bringing change. Europeans brought beads, iron kettles, and other consumer goods to trade.

They also brought smallpox, scarlet fever and alcohol.

Similar to other indigenous peoples of the Americas, we lost entire villages to

foreign infectious disease. Families and communities who survived the epidemics supported themselves by hunting, trapping, and growing their food. They trapped beaver and processed furs and other goods (e.g. maple sugar) to trade for European-made goods. The Anishinaabeg also engaged in centuries of warfare with other Indian nations and against England and the colonists, for control of territory. Our ancestors dominated in guerilla-style, hand-to-hand combat, and no one was fiercer on the water. By the 1800s, the Anishinaabeg had enjoyed centuries of territorial sovereignty in the Upper Great Lakes region; however, the newly-formed United States, flush with capital generated from labor of enslaved people, sought land and resources in the west.

Thus began the most difficult times for our people. In the 1820s, representatives of the United States came to Anishinaabe territory ostensibly seeking alliance. The Hereditary Chiefs, weighing their options, determined that forming an alliance was pref-



Top: Julia Bennett, Julia Clementine and Charlotte Manidoogizhig. Above: Julia Shabiash-Bennet.



Miinan (blueberries) and gi-bai'imin-aatig (sweet fern) are traditional medicines harvested during high summer.

erable to engaging in war against the United States. In a series of treaties with the United States, the Lake Superior Chippewa gave up control of millions of acres of land in exchange for certain promises: they would receive specific sums of money and supplies (annuity payments), healthcare and education, and would retain use of our traditional lands in perpetuity. In the **Treaty of 1854**, the United States promised the Lake Superior Chippewa Bands, including the Bad River Band, that they would never be removed from their reservation lands.

FORCED ASSIMILATION AND THEFT OF LANDS AND RESOURCES IN THE POST-TREATY PERIOD

Within less than a generation, the United States had seemingly forgotten about its treaty obligations. Land agents and county officials worked to swindle treaty-protected reservation lands from Ojibwe families without regard for the promise of a permanent homeland. **State game wardens jailed Ojibwe**

hunters and confiscated their weapons without regard for their rights to hunt and use their traditional territories as described in the treaties. *During this same period, federal agents entrusted to caretake reservation assets allowed logging companies to strip old growth forests off most of the Bad River Reservation, leaving the land barren of the flora and fauna that had supported the people and lessened the impact of annual spring flooding.*

Ostensibly, this policy was to create economic opportunity for the Indians on American-style farms; however, the soils found on the reservation specifically, and the northern climate generally, were not ideal for American-style monoculture. Deforestation of the reservation and federal agriculture project, while creating wealth for land speculators and logging companies, failed to create wealth or sustained economic opportunity

for band members. At the same time, **these efforts entirely destroyed many of the natural systems** within the reservation that the people depended on for food, shelter, healthcare, and spiritual connection.

The Bad River Reservation was seen by some as the center of the Ojibwe traditional life. This was the home of the chiefs, supporting a thriving culture of traditional medicines, songs and stories. Federal agents and American religious leaders saw our community as a threat to American culture and capitalism. Thus, *Christianity was weaponized and used as a tool of cultural assimilation.* Bad River families who refused to demonstrate their adherence to Christian beliefs and American lifestyle were publicly shamed and often lost their children. **Children as young as three years old were forcibly separated from their families for placement in boarding schools designed**





Top: unknown rickers, circa 1970

Above: Robin Powless and her granddaughter Brooklynn Whitebird at the 2019 Bad River Manomin Celebration.

to eliminate Ojibwe language and culture. Most of the schools brutalized the children, employing physical and emotional violence to engender fear within the “students.” Sexual abuse was common as well. To make matters worse, all Indian children were taught that their culture, religion, and science were inferior, and that they themselves were inferior. They were taught that partial redemption was only possible by emulating European-American traditions. Medicine

bundles, drums and other ceremonial items—considered alive according to our cultural traditions—became illegal to possess and were confiscated by church officials and federal agents. Most of these sacred items were then sold, destroyed or locked in museums. Traditional ceremonies, when conducted, occurred in secret. In a futile attempt to divorce Indian people from their homelands, the United States relocated families from reservations to urban areas beginning in the 1950s. Many Bad River families left for Milwaukee, Chicago, Minneapolis, and Detroit during this period of relocation.

TRAUMA AND GRIEF

The trauma and grief that our elders and ancestors experienced in that era is unimaginable. Although the United States eventually repudiated many of the policies that facilitated the theft of Indian lands and children, our elders’ experiences of being subjugated to myriad human rights violations has never been acknowledged, let alone apologized for, in any official manner. Nor were efforts made to address their trauma or the resulting functional disorders. Most of our grandparents heroically persevered. They raised families and did their best to rebuild Ojibwe cultural traditions. Unfortunately,

but not surprisingly, some became violent, subjecting the vulnerable members of their families and communities to the same physical, psychological, and sexual harm they themselves experienced. Disassociated or intoxicated parents left their children vulnerable to abuse by Native and non-Native perpetrators, with trauma passed on to younger generations. Many turned to alcohol, drugs, and other substances to numb the guilt and shame. To an extent, problematic substance use became its own ceremony and formed the basis of a certain modern identity as Indian people and survivors.



The Apostle Islands are a group of 22 islands in Lake Superior, off the Bayfield Peninsula in northern Wisconsin. The largest of these, Madeline Island, was long a spiritual center of the Lake Superior Ojibwe.



Traditional tobacco, called asemaa in the Ojibwe language, is a sacred plant grown and harvested to offer prayers.

RESTORING OUR CULTURAL IDENTITY AND ADDRESSING THE HARMS

Within the last few generations, our people have been participating in a world-wide indigenous peoples' movement to return to our cultural traditions, recover our indigenous languages, and protect our lands and

waters from further destructive development.

Within Ojibwe communities, this movement emphasizes abstinence from alcohol and drugs, harvesting, cultivating and consuming traditional Ojibwe foods and medicines, and relearning our songs, dances, and ceremonies. Resurgent Ojibwe art and literature is also a feature of this movement, as is political activism.

To a certain extent, however, this movement is comprised of middle-class and college-educated Indians, a minority within our communities. While most younger people are attempting

to incorporate some aspects of traditional Ojibwe culture into their lives, the lack of economic resources to address basic needs is a significant barrier to learning about, and participating in, cultural activities.

Many of our people continue to regularly use drugs and alcohol and tend to avoid traditional gatherings for fear of being shamed.



Wisconsin Historical Society, WHS-73283

Anishinaabekwe with ceremonial items in Bad River, 1935. L-r: Julia Newago-Mayotte, Lizzie Stoddard-Connors, and Angeline Cedarroot. Holding the Bad River Women's Veteran Eagle Staff (circa 1870) is the mother of Julia Shibiash-Bennett, who traveled to Bad River from Lac du Flambeau.

HOUSING

Today, Anishinaabeg living on the reservation are mostly located in five settlements: Birch Hill, Aspen Acres/Franks Field, New Odanah, Old Odanah, and Beartrap/Kager-ville/Ackley. Most tribal members live off-reservation in Ashland, which shares a border with the reservation, and in Washburn, Bayfield, and further away.

There isn't enough housing stock to allow all of our members to live within the reservation. The majority of homes on Birch Hill, Aspen Acres, and Franks Field are public

housing units, with public housing units also located in New Odanah. The *Bad River Housing Authority* is funded by *Housing and Urban Development (HUD)*, which imposes the same severe standards on tribal organizations that apply nationwide. **One drug conviction permanently bars an individual from living in Bad River Housing, significantly impacting access to safe and affordable housing for many of our tribal members.** Homelessness and unstable housing is a perennial issue among community

members who use drugs and for those newly in recovery. The wide geographical spread of our community impacts provision of services, especially where many do not have access to a vehicle or personal phone.



Gichigami—Lake Superior—makes up the Bad River Reservation’s northern border.

meet everyone’s needs with respect to **bimaadiziwin: living a good and harmonious life.**

Our people were renowned as masters of tactical and strategic warfare, but also of the public rela-

tions and diplomacy needed to achieve big goals. To this day, we maintain a collective and distinct existence despite efforts of the United States of America to destroy us. **We draw on the super-human strength of our ancestors**—a strength that resides within us whether we are sober and engaging in ceremony or high on drugs.

It is critical to remember our collective history as it informs our current experience. **Do we understand our own strengths? Do others see our strengths, or only our weaknesses?** Our ancestors moved to new territories and rapidly acquired knowledge in order to maintain self-sufficiency and



Wisconsin Historical Society, WHS-3951

1900 photo of an Anishinaabekwe and child from Bad River. She is holding up her bead loom and showing off her finished loom beadwork and beadwork applique.



II. OUR HARM REDUCTION STORY

UNEXPECTED NEW RISKS

Injecting drugs is relatively new practice within the Bad River Indian Reservation. *As far as we can tell, injecting drugs became prevalent between 2010 to 2015 as methamphetamine and heroin became more readily available, and access to their prescription analogs (i.e. prescription opioids and Adderall) diminished.*

Until **Gwayakobimaadiziwin Bad River Needle Exchange** (our SSP) started in 2015, people in our community who injected drugs had very limited access to sterile syringes, syringe disposal, and overdose prevention services. Tribal members, whether they used opioids or not, did not know how to effectively respond to opioid overdoses and did not carry naloxone. Within the last decade, we have lost several beloved members of our community to opioid overdoses. Injecting drugs also put community members at increased risk for HIV, hepatitis, and life-threatening bacterial infections.

PREVENTION TRAINING AND NALOXONE

Since August, 2015, Gwayakobimaadiziwin Bad River Needle Exchange has offered services and supplies for people who use drugs in our community. Overdose prevention training and the provision of naloxone has become an integral part of the program. We endeavor to confront the discrimination endured by people who inject drugs and advocate for more humane law and policy. We also strive to deliver services in a culturally informed manner. **Our practice is rooted in the seven teachings of the Ojibwe: respect, humility, courage, honesty, wisdom, truth, and love.** We are sharing our harm reduction story in the hope that our experiences can help other people find solutions to the isolation and illness that can come with injecting drugs on Indian reservations and within rural communities.

Unfortunately, the direct service work did not begin as soon as the need for those

services was identified. We had to take time to educate ourselves to become useful to the community of people who were injecting drugs. We also had to gather resources in order to have anything to offer, and we wanted to foster a minimal level of community support prior to beginning operations.

COMMUNITY ASSESSMENT AND INFORMATION GATHERING

At the outset, we knew that the harm reduction movement offered models of intervention that had proven effective in many other communities. SSPs have been extensively studied. We looked to the peer-reviewed literature and ascertained that a consensus had been reached among public health researchers regarding the effectiveness of needle exchange, or syringe services, to improve the health of people who inject drugs and prevent the spread of infectious disease. *However, we found little guidance on how to run rural and reservation-based programs.*

Our goal became to develop an SSP consistent with the cultural traditions of the Bad River community and while meeting the practical needs of people who use drugs in a rural context. We were hopeful that harm reduction strategies around problematic

substance use will bring increased wellness and healing to our community.

WE BEGAN WITH CONVERSATIONS

In 2013 and 2014, we talked to public health workers, nurses, and doctors who worked for Ashland and Bayfield Counties, the *Bad River Health and Wellness Center*, and other agencies. These agencies encouraged us to seek solutions, including needle exchange, that protected the overall health of the community. These public health meetings also provided us with opportunities to talk to

law enforcement officials. For us, it wasn't absolutely necessary to get law enforcement on board because the possession of syringes is legal in Wisconsin (as long as they are not possessed within close proximity to controlled substances); however, we felt that conversations with law enforcement could be helpful for a number of reasons. Officers regularly interface with the public and could assist us in

dispelling misconceptions around syringe access. Rural communities struggle to find options for safe syringe disposal and people often look to the police to clean up improperly disposed syringes. Law enforce-



Aurora Conley and Philomena Kebec preparing for the Bad River Community Health Fair.

ment officers expressed concerns about needle sticks, for themselves, community members, and especially children. To the extent that SSPs can reduce the community's rates of infectious disease while encouraging the responsible disposal of syringes, they align with some law enforcement goals. In the community meetings we had with the county health department, we worked to ensure that key law enforcement officials were also present to learn about the benefits of syringe services and to observe the comfort that the established public health community had with this concept.

As it became clear that our activities would protect the public health, we began receiving tacit support from law enforcement; recently, a few law enforcement officers have publicly expressed appreciation for, and pride in, our community SSP.

The most important conversations we had (and continue to have) are those with people who use drugs. We knew that the people we wanted to reach would be wary about talking about their drug use, an illegal activity subject to criminal prosecution and significant community shaming. With this in mind we actively cultivated safe spaces and times to meet.

One of us (Aurora Conley) had many friends and relatives who had started injecting drugs. She started having conversations at her kitchen table when people stopped by.

Another of us (Philomena Kebec) worked as the Bad River tribal prosecutor in child welfare, often working on cases where the evidence of the parent's drug use was a major factor in the removal of the children, and in close, regular contact with the parents and their family members. Both of us made initial conversations safe by waiting for a private moment to have a one-on-one conversations.

ANONYMITY WAS CRUCIAL

These conversations were focused on the wellbeing of our community to communicate our desire to help, and also to communicate that we weren't looking for information to incriminate anyone. We asked about the person's "friends," or if

they were concerned about the things they were seeing in the community, like people sharing syringes or other risky behavior. We also made it clear that not only did we want to help, but we needed their assistance and leadership in order to make things better in our community. Sometimes, we would have an initial conversation about this topic by expressing concern that our community had no access to safe injection materials. Later, we might ask that

person some questions, such as whether people (in general) were injecting drugs and how were they doing it. We also asked if



Community sharps disposal bin on the Lac du Flambeau Reservation

anyone had access to sterile syringes, and if they thought an SSP was needed. Most of the people we approached opened up to share their concerns. They found it curious, but comforting, that someone was interested in their perspective, and cared about them. We found that it was widely known that sharing syringes spreads disease; they told us that this practice had become prevalent within our community. They were fearful that our community was at risk for HIV and hepatitis, and some felt guilt and shame about their involvement. **Access to sterile syringes simply did not exist. Some people had one syringe and used it over and over; others shared syringes with friends.** Some had heard of the SSP located in Superior, Wisconsin, but due to distance and lack of transportation, no one we spoke with had been there. Some people didn't know what a needle exchange was, but they supported access to sterile injection equipment if it was safe and confidential. They were also terrified of the judgment and discrimination if people knew they were injecting drugs. Anonymity was crucial to serving this community.

OUR PATH TO HARM REDUCTION: INTERNET RESOURCES, MENTORSHIP AND PRACTICE

The process of educating ourselves on syringe services and the global harm reduction movement was painfully slow. We scoured the internet for resources. The Harm Reduction Coalition and Chicago

Recovery Alliance websites were excellent resources. In particular, the *Harm Reduction Coalition's publication Getting Off Right Safety Manual* provides in-depth health and safety information on injecting drugs, and the *Chicago Recovery Alliance's Harm Reduction Outreach with Syringe Exchange – Guidelines and Operating Procedures* offers the gold standard on how to empower people who use drugs while honorably carrying out harm reduction in practice. We used these documents to form the policies and procedures of our program. We used these materials and peer-reviewed research on syringe programs to inform the community and tribal council. A summary of this research, which was compiled by Bad River Legal Program Student Intern Dyllan Linehan, is available in Appendix Part II on page 53.

As we learned more, however, we came to understand that there's a certain magic to harm reduction. ***The magic comes from heart acts***, which are difficult to explain, document, and reproduce through written words alone. Harm reduction has been passed down from person to person, through the demonstration of acts of free kindness, in service of the public good, clear of judgment and reproach.

Eventually, we connected with friends at the *AIDS Resource Center of Wisconsin, Sacred Spirits – Project CEDAR* (White Earth Nation), and the *Chicago Recovery Alliance*. Our friends within these Midwestern-based programs—Dan Bigg, Clinton Alexander, Maya Doe-Simkins, and Scott Stokes—

mentored us in harm reduction as a practice.

Dan Bigg (pictured at right) was a co-founder of the *Chicago Recovery Alliance* and was the **first to promote the practice of community distributed naloxone**. He spent his life saving others and passed away in August, 2018.

Jim Brunner, an outreach worker from the *AIDS Resource Center of Wisconsin (ARCW)/Lifepoint* came to our community from Green Bay (a four-hour drive) in the summer of 2015 with an outreach van and spent the day with us actually doing harm reduction. Only a few individuals came to the van that day, but everyone who did was treated with kindness and offered the supplies they needed. While this outreach worker only came to Bad River a few times, he made a huge impact. **Jim gave us the courage and wherewithal to begin our own outreach efforts.** For several months, a *Life-point* (ARCW) Superior staff member met with us regularly and handed off carloads of supplies. She also provided several overdose prevention trainings and distributed naloxone before our naloxone initiative began. Our collaborative relationship with ARCW was instrumental as a formative step in the creation of our program.



Dan Bigg and Philomena Kebec at the White Earth Harm Reduction Summit in May, 2018

DEVELOPING SAFE AND EFFECTIVE METHODS OF OUTREACH

At first we struggled to find ways to perform outreach the right way. Being too open about exactly where we would be distributing supplies invited harassment (on social media, mostly) and the people we sought to serve didn't have reliable transportation to get to a fixed location at a set time. The approach that we settled on was to find a free phone number app and

provide delivery/drop in syringe exchange as needed. The phone app enabled several of us to share one number, so we could all see when someone requested services. We kept supplies in different locations to enable us to set up meetings spontaneously based on the availability of volunteers and the needs of people seeking services. We put up flyers about the program in a few spots (gas station bathrooms, laundromats, community clinics), with tear-off tabs that displayed the number. Later, we printed business cards that were given out, and placed them in the kits of materials we handed out.

One benefit of the phone app is that it provided a secure "space" in which to converse. **Program participants were terrified of becoming identified, or outed, as people who inject drugs.** Derogatory labels

(e.g. junkie, addict, etc.) are weaponized to isolate people from supportive social networks, employment, and healthcare in rural communities. For the most part, the people who contact us keep their drug use secret, fearing discrimination and other negative repercussions. Even reaching out through a text message was frightening, but it enabled the one-on-one conversations necessary to convey communication about the program.

In those first few months, we would often receive text messages asking questions:

Who are you? How does the program work? Are you going to share my identity if I come get supplies?

Oftentimes, we spent hours texting with a person before meeting them. Sometimes these conversations lasted for days. With program participants, we described ourselves as community members, or simply peers, who are trying to promote public health and empowerment among people who use drugs. We described the steps we'd taken to ensure confidentiality. The only criteria for participation was desire; no data or unique identifiers needed to be shared. Meeting times and locations for exchange were negotiated to accommodate convenience for the participant and volunteer, but also to ensure safety and confidentiality. We



A basic safer snorting kit consists of short plastic straws (you can cut long straws) with a card in a small plastic bag. Having personal, clean equipment is important for staying healthy and not getting sick.

only kept track of generic data points, nothing that could be used to identify anyone we helped.

Interest in the program was initially very weak. We served a handful of people each month. This was our trial period. We understood that if we engendered trust and respect with people who use drugs, our program would grow and eventually address unmet needs for unique and essential services. Interest picked up as we developed positive relationships. Some brave souls invited us into their homes. People

we knew from the community stopped by our homes and told of their need for supplies. We continued to hold their identities in confidence and strove to maintain a commitment to nonjudgmental language and actions. In time, we became part of the community of people who inject drugs by being supportive allies.

WHO SHOULD DO THIS WORK?

One question we've been asked is who should do this work? In an ideal world, people who inject drugs should be in charge of syringe services. Unfortunately, in many communities the people who inject drugs are subject to tremendous discrimination, lacking access to resources

and authority. Although everyone involved in this program has a fairly extensive history with drugs, none of us ever injected drugs. Our history of working in the tribe's legal department was problematic, too, because of our involvement in child welfare cases (Philomena changed jobs a year before we began actively outreaching). On the other hand, our involvement in legal matters and with successful environmental justice work,



Aurora Conley with a canoe built by Marvin DeFoe of the Red Cliff Band on display at the National Museum of the American Indian in Washington, DC

provided us with political capital, in the form of voices that people in authority heard. This allowed us to build a very different kind of program. Our goal remains to support the leadership of people who inject drugs and those in recovery. We hope to cultivate leadership within this community, to turn over the keys of this program and to address the barriers to equality and freedom that they face.

CREATING AN INDEPENDENT TRIBALLY-BASED PROGRAM

By the fall of 2016, the program started catching on and we were outgrowing our relationship with the ARCW. It became inconvenient to arrange picking up supplies in bulk, while also arranging to meet with many individuals. There were times when we were getting calls, but had no supplies to offer. Bill Whalen, who was then employed

as the Bad River Tribal Planner, encouraged us to develop a budget for submission to the Bad River Tribal Council. A relative of his struggled with heroin and he understood the loneliness that people who use drugs can experience. We submitted a modest budget to the tribal council, including a one-page summary of our program. To our surprise, the tribal council funded our work. That fall, we submitted

another proposal to the *Comer Family Foundation*, which was also funded. With dedicated funding, we were able to provide our participants with the supplies they needed when they needed them. We also started incorporating overdose reversal training and naloxone kits within our regular menu of offerings.

Since then, our program has continued to provide services to people who use drugs. This work continues to be extremely challenging. Other tribal programs worked with us on developing our policies and procedures; however, the established programs have not been willing or able to share space or resources. To a certain extent, we had to take over space without asking for permission in order to secure a location to store supplies.

The work of creating safe spaces for people who use drugs is also challenging

on a theoretical level. Harm reduction can be a battle of words. Detractors rely on established stereotypes about “drug addicts” and the use of fear-based and non-scientific messaging, often leveling hurtful and personal insults on social media platforms. **As harm reductionists, we try to emphasize the humanity of people who use drugs and show that hateful words directed towards them amounts to bullying.**

We also talk about public health benefits associated with supporting positive choices: for example, offering sterile injection equipment is an extremely effective way to reduce community transmission of blood-borne disease and providing naloxone to people who use drugs has significantly reduced the number of overdose deaths in our area. Although using the harm reduction framework is a different way of thinking about drug use, it’s based on common sense and is understandable if it’s discussed in regular language. We’ve also used humor, carefully, in these conversations, and extend offers to help community members address syringe litter. As an example, during the spring thaw, people find a syringe on the ground and post a photo of it on the Bad River Facebook group. In response, we sometimes say very little and simply post

photos of the giant sharps containers we use to throw out thousands of used syringes. Our participants, through the research study they assisted with, have encouraged us to do more in this area. As a result, in the next year, we’re planning several community sessions to engage on topics such as syringe services and drug decriminalization.

WE STRIVE TO SERVE EVERYONE

Today, we offer sterile injection and wound care supplies, syringe disposal, overdose reversal training, as well as naloxone, fentanyl test strips, food made by members of the community, peer support/social engagement, and referrals. Despite the fact



Before disposing, containers are securely closed for safe transportation and handling by sanitation workers.

that we are now a tribal program, we have not modified our need-based, territorial criteria. Access to our services is not limited to tribal members or any criteria other than need; we strive to serve everyone we can reasonably reach. Given the fact that people who use drugs are typically generous with each other and have formed community around providing access to injection supplies without regard to race, gender or political

status, it makes sense for us to mirror this approach. Furthermore, we believe that living within an environment of public wellness and solidarity strengthens tribal

communities and supports tribal sovereignty.

At one point we considered turning our operation into an independent nonprofit organization. Ultimately, we settled into a tribal government/volunteer-based model. Tribal governments enjoy a similar tax status as nonprofits, when the funding is allocated to the provision of governmental services to benefit the people. It's beneficial to collaborate with the tribal government on fundraising. The indirect cost line items on grants is retained by tribal administration, which supports the tribe's accounting department, legal program and other essential governmental functions. Many nonprofits are seeking opportunities to fund tribal programs.

On a practical level, relying solely on volunteers is not ideal. People who do harm reduction should be compensated for their time. Because of the rural landscape we work within, we put a lot of miles on our vehicles and spend a lot of time away from our families. The intangible benefits associated with the work have helped to keep things in perspective: being in community with people who have benefited from the program, opportunities to travel to harm



Top: Each load of sharps is weighed at the transfer station. We keep track of this data to help gauge the rate of returns.

Above: Ideally, used syringes are stored in sharps containers, out of reach of children and pets.

reduction gatherings and commune with like-minded people, and being recognized in our community for doing good work. This last part feels particularly good because the idea of harm reduction was not well-received at the outset. Our hope is that the change in attitude towards us as harm reductionists also translates into changing attitudes around people who use and inject drugs.

One of the challenges that we struggled with is the need for data to justify funding and other forms of support. We developed an unobtrusive method to collect demographic data related to the materials being distributed, more fully described in part IV. The

data we collected told us that annually more than 60% of program supplies are distributed to Native American women, who, historically, have acquired HIV through injecting drugs at rates significantly higher than other similar groups (populations categorized by race/gender). Our working hypothesis is that HIV prevention and drug decriminalization movements have not prioritized Native American women nor encouraged their leadership. While we celebrated the fact that



Safer smoking supplies are a new element that we've recently added. Pipe covers fit onto glass pipes and help protect tender lip skin from becoming blistered and burned. Single-use foil is clean, of uncoated material, and it can be used to fashion a pipe on the fly.

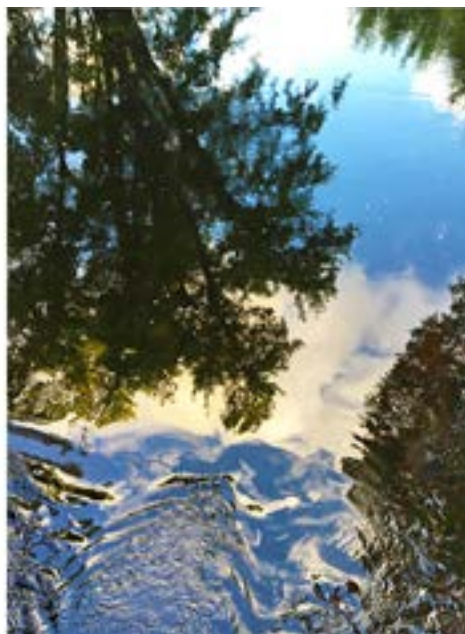
we were reaching a historically under-served group, **we wanted to find a way to elevate their voices and share their stories.** Our quantitative data was inadequate, but none of us wanted to compromise the anonymous, free syringe services by requesting more information than absolutely necessary. Our fear was that a participant would think that a quid pro quo would be necessary: they would be required to share personal information in order to obtain life-sustaining sterile injection equipment or naloxone. **Still, we wanted to better understand the people we were serving and find a way to help them share their stories. Section III describes the results of collaborative research.**



III. PERSPECTIVES ON AND WILLINGNESS TO PARTICIPATE IN HARM REDUCTION SERVICES

INTRODUCTION

The research team at *Northland College Center for Rural Communities* was enlisted to participate in this project in 2018. In collaboration with those who provide harm reduction services as well as those who support individuals seeking harm reduction services, the intent was to develop an interview instrument based on a search of relevant peer-reviewed literature, conduct interviews with participants, transcribe the interviews in their entirety, develop a narrative to explain trends, and identify meaningful content. A report of findings are described here.



Bad River flows through Tribal land.

BACKGROUND AND REVIEW OF RELEVANT LITERATURE

This study aimed to understand participants' experiences with formal and informal supports, willingness to use services in clinic settings, barriers to services, and service needs. The interview guide was developed in consultation with staff at the *Gwayakobimaadiziwin Needle Exchange Program*, the *Bad River Health and Wellness Center Pharmacy*, and *NorthLakes Community Clinic*. The study was intended to inform programming to address identified needs and preferences, designed to increase access

to respectful and appropriate healthcare for people who inject drugs in rural northern Wisconsin.

Research shows that people who inject drugs (PWIDs) experience excess mortality compared to the general population. PWIDs are at higher risk of illness, including Hep C and HIV/AIDS, psychiatric illness, and overdose (Hari, 2015). Research also points at PWIDs low rates of both health and mental health service use (Syme et al., 2011). Further, studies suggest that harm reduction services improve the overall health outcomes for PWIDs (Wilson et al., 2015). This study aimed to understand local perspectives on services to inform programming that is responsive and appropriate for PWIDs in our service area—Ashland and Bayfield counties, Wisconsin.

In a review of existing literature, several trends are worth noting because of their relevance to the present study. Interviews in Canada with PWIDs revealed a willingness to use a safe injecting facility. However, that willingness declined substantially when individuals were asked about using a facility operated under local health restrictions and in the event that police were stationed near the entrance. In essence, while the idea of a safe injecting facility was appealing, its institutionalization and possible accompanying police presence were cause for concern among PWIDs (Fast et al., 2008). Another study of PWIDs in San Francisco reported enthusiasm for a safe injecting facility, only on the condition that there would be

no video surveillance, and no identification required to use the facility (Kral et al., 2010). Scholarly literature points to a fine line wherein PWIDs benefit tremendously from a variety of harm reduction services, but those services must be delivered with an ethos of care, with a high value placed on confidentiality, and with an awareness of fears for police involvement that many individuals hold (Switzer et al., 2015).

Other areas of relevant literature have focused less on substance use and more on the conditions of people's lives. For instance, a survey-based study of PWIDs in Australia found that the majority of respondents were unemployed, homeless and had a history of incarceration, and 82% reported they had been diagnosed with a mental health problem, but only 24% reported they were receiving treatment. Respondents had poor social networks, had experienced multiple traumatic events, and a high number of respondents had scores indicative of post-traumatic stress disorder. Most notably, those who were receiving treatment were initiated into care via mental health services, suggesting that it was often a therapeutic environment that contributed to their engagement in services (Goodhew et al., 2016). Still, social determinants feature prominently into the struggles of many PWIDs. A longitudinal study of adolescents injecting drugs in Canada found that loss of a secure place to live was the factor most associated with increased and unsafe injections. Research transpiring in urban areas of

the United States has reaffirmed this triggering tendency of homelessness (Cheng et al., 2014).

Participatory action research in Canada and the U.S. points to the ways in which PWIDs incorporate many personal harm reduction practices into their daily lives, in addition the use of sterile syringes. These practices and moments of resilience often clash with the stigma many PWIDs experience in various healthcare settings (Hari, 2015). While scholars of harm reduction have long argued for more personalized, de-medicalized conceptualizations, the socio-structural barriers and stigma for PWIDs engaging in healthcare services remains substantial (Alexander, 2012). Another tactic—taken by a number of authors (e.g. Zampini, 2018)—argues for the incorporation of harm reduction programs in hospitals where there is a high prevalence of drug use. The argument underscores a pragmatic, patient-centered, nonjudgmental approach, in an effort to bring harm reduction policies more into the mainstream. Still, few authors have adequately identified how such a transition would be made.

Global studies of PWIDs have pointed to an increase in risk-taking behaviors such as needle sharing among young people (e.g. Young and Havens, 2012). These studies highlight not only early initiation into substance use—as early as late childhood for some—but a lack of knowledge about safe practices of injection. Thus, **many authors argue that additional funding and**

efforts should be geared toward adolescent populations who may lack the necessary knowledge to use substances with a measure of safety (Paquette et al., 2018). Most generally, research on harm reduction services highlights the value of such services in providing safe sites or sterile syringes for PWIDs, as well as reducing infectious diseases and the overall burden—both financial and emotional—of healthcare costs (Wilson et al. 2015). Still, as harm reduction interventions are met with mixed reactions among the general public, it can be vital to show the effectiveness of such services as a public health intervention in order to increase public support and further refine the scope of practice in order to meet the needs of individuals who depend upon those services (Zampini, 2018).

MORE THAN ONE DIMENSION

Peer-reviewed literature and statistics provide but one dimension to an understanding of this topic. A glaring omission from much literature about the use of harm reduction services is the extensive inclusion of perspectives by those individuals who use harm reduction services. One important exception comes from a study (Ruefli and Rogers, 2004) of 120 PWIDs in New York City, in an effort to explore how this population envisions a better life. Ten significant outcomes were identified, including ways of:

- 1) making money;
- 2) getting something good to eat;
- 3) being housed/homeless;

- 4) relating to families;
- 5) getting needed programs/benefits/services;
- 6) handling health problems;
- 7) handling negative emotions;
- 8) handling legal problems;
- 9) improving oneself; and
- 10) handling drug-use problems.

Findings also provided insights into individuals' lives and values, as well as a window into understanding how this population envisions a better quality of life. These results challenged traditional ways of measuring PWIDs based solely on quantity used and frequency of use. **The results point to the importance of viewing PWIDs as complete people with an array of dreams, hopes, and fears.** In so doing, harm reduction as a concept can stretch beyond narrow concerns with harms related to drugs and use practices in order to address the historical, sociocultural, and political forces that come to shape many people's lives.

The work of the present study continues in this vein. However, while much research on harm reduction services has transpired in urban areas, the rural geography of our region adds an important dimension to this topic that is surely relevant to other rural areas. Thus, we ask: beyond established health outcomes, what exactly is effective about these services? What could be improved? And what are the challenges faced by individuals who utilize these

services? Thus, central to the work of this endeavor was an effort to hear the words of individuals who have used harm reduction services in a rural area. Their voices figure prominently in these findings, as conclusions are drawn "from the ground up" in order to capture the nuances of lived experience, and especially their challenges.

RECRUITMENT OF PARTICIPANTS

In the present study, the rural poverty and geography of Ashland and Bayfield counties adds an important dimension—and challenge—to the participants described herein. Much of the population lives in unincorporated rural townships or within the Bad River or Red Cliff Indian Reservations, with low population density spanning a large geographic area, where **travel time, weather, and road quality limit access to services and contribute to isolation.** Distances to clinics are long, and travel is often difficult especially during the winter months. Racism against Native Americans is pervasive within many of the settler-dominated local towns, limiting access to educational opportunities, housing, and employment. In this research, this context of rural poverty and geography played a significant role in framing the possibilities and limitations for all participants.

Recruitment of participants was guided by those working in clinical and support capacities, who described the research project through word-of-mouth and flyers. Ensuring confidentiality and anonymity

was paramount. Researchers held the interviews at discrete locations in the community. Scheduling the interviews was achieved through setting aside a weekly block of hours that could accommodate participants' schedules. Once recruited, participants were directed to the location of interviews. Creating a context that was respectful of participants' experiences and challenges was a central part of these efforts.

Participants were told that the purpose of the study was to understand their experiences with formal and informal supports, their willingness to use services in clinic settings, barriers to services, and service needs. **Informed consent is discussed in Appendix to Part III on page 70.** The interviews ranged from one to two hours in length, and when completed, participants were given a \$75 Visa gift card. Interviews were conducted by two researchers with an extensive background in qualitative and community-based research. Confidentiality was further safeguarded as participants were never asked to provide identifying information, and transcription and analysis of the interviews was completed only by those who were certified in human subjects research. Furthermore, the interviews were kept on a secure server.

Constructing an appropriate, well-informed interview guide was achieved through researchers' efforts to capture emerging trends around best qualitative practices about harm reduction research, as well as the collaboration of team members

who reviewed multiple drafts. **A copy of the interview guide begins on Appendix B on page 70.** The interview guide was divided into seven parts, including:

- use of harm reduction services;
- personal history questions about substance use;
- the utilization of other healthcare services;
- barriers to accessing more services;
- supports in terms of housing,
- ways to make money, and social networks;
- hypothetical questions about ways to improve needle exchange services; and finally,
- demographic information.

From a research perspective, the central lesson learned about recruitment and conducting interviews was around allowing enough time to schedule and conduct interviews. The emotional intensity of the interviews, evident in the participants' stories, made it challenging for researchers to conduct more than two interviews in one day, in order to be fully present and attentive. At times, it was necessary for researchers to divert somewhat from the interview guide when questions proved unclear to participants (such as listing all healthcare engagements in the last year, for example).

Participants were exceptionally generous in speaking openly with researchers about their strengths and barriers. The number of participants exceeded what researchers originally forecasted, pointing to the general enthusiasm of many to

share their experience and improve existing services in order to meet the needs of many individuals. A breakdown of relevant demographic characteristics for the 19 participants are found below.

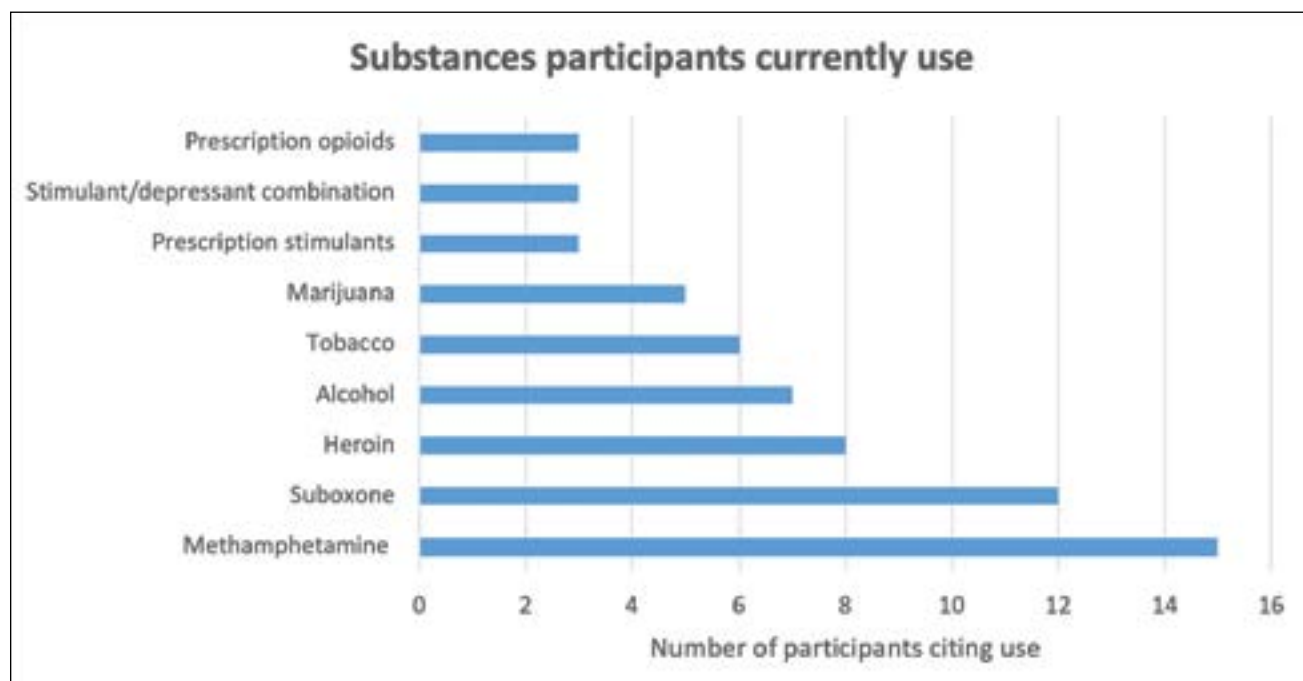
Finally, and in order to provide further context, an overview of substances that participants used can be found below.

cant number of participants who used both methamphetamine and suboxone daily.

METHODS

Thematic analysis guided the process of understanding the interviews. As a form of qualitative research, thematic analysis has long-held significant currency in its ability to

Average age	Gender	Sexual orientation	Enrollment?	Health insurance?
29 (range: 19-42)	9 identify female 10 identified male	All 19 identify: heterosexual	15 enrolled in local tribe / 4 were not	16 had insurance 3 did not



Overwhelmingly, participants used several substances each day, several times a day. The low end of this range includes using substances to regulate sleep/wake cycles, to using more frequently to manage stress, to using up to ten times per day. Of the particular combination of substances, no general trend can be identified, other than a signifi-

identify trends across common experiences, specifically those related to healthcare, substance use, and stigma. In essence, a thematic approach gives voice to lived experience, respecting the individuality of stories while also looking for linkages across stories in order to zero in on shared senses of struggle and success.

The analysis took place over three steps. The two researchers who conducted the interviews guided the process of collaborative analysis with team members involved in supporting those who use harm reduction services, as well as several student research assistants. Once the interviews were transcribed verbatim, team members read through the transcripts to identify salient moments, tensions, and issues that seemed to recur. From there, team members generated codes to summarize notable points in the transcript. Once all transcripts were coded, researchers identified areas of similarity and overlap between the codes, across participants, which were the themes. Themes ultimately reveal a deeper layer of the transcript and point to its most meaningful content.

The analysis was guided by several broad questions, including:

- **What are the experiences of people who use harm reduction services?**
- **Based on their experiences, how could those services be improved?**
- **What are the types of challenges faced by people who use substances?**

The themes identified here provide answers to these questions. Major themes are identified first, with a summary as well as supporting quotations embedded, and additional themes are described after that. Major themes capture trends evident across most, if not all participants, and minor themes address notable commonalities across some participants.

MAJOR THEMES

1) Participants have experienced significant stigma via interactions with health-care providers.

Across many interviews, it was clear that participants felt stigmatized when healthcare providers asked people who injected drugs unnecessary questions. These questions were often posed with a sense of judgment and curiosity, and often contributed to participants not returning to certain health-care facilities. **The effect of this stigma on their own well-being has been substantial.** Some participants spoke of physical health problems that they left untreated; others described issues with anxiety and depression that also went untreated. Some who sought treatment for pain were viewed as simply seeking drugs by their providers.

It is important to add that this issue of stigma is multi-layered. It was often not clear exactly what questions participants felt were unnecessary, and how the due diligence of some providers may have been understood by participants as intrusive and stigmatizing. Overwhelmingly, beyond any specific description of poor interactions with providers, there was a sense of judgment participants felt, and a lack of understanding about their substance use. The effect on their ability to trust healthcare providers in general was notable. For many, it was this stigma in a context of vulnerability that had lasting, pernicious effects on their perceptions of themselves and the community at large.

“When the nurse started to question me about the marks on my arms, I hate that ... cause then it seems like they look at you differently.”

“They’re supposed to have professional attitudes, some people don’t. If you say anything about drugs people who don’t understand it frown upon it.”

“Just to see the new people who look at me and have this look that they’re like ... like you’re a drug dealer or looks like he’s on something or stuff like that will go through my mind.”

“I won’t even go to an appointment if I have a lot of shot marks or something like that.”

2) Needle exchange services play a vital role in participants’ lives so long as they are confidential.

The benefits of needle exchange services were clear, whether in terms of access to sterile equipment, moral support, or sense of connection. The positive interactions with those involved in these services had an enormous sense of importance in participants’ lives. The level of understanding and nonjudgmental attitude of those involved in the services were cited by many participants as crucial to building trust and care. A small number of participants who benefited from the needle exchange service expressed uncertainty about whether the service was truly confidential. Most often, this skepticism was directed at the low population size of the area and the close-knit quality of the

community. The need to keep this service as confidential as possible was highlighted repeatedly, with one suggestion that the card advertising the service could include a promise of confidentiality.

During the interviews, participants were presented with several hypotheticals about what would be the most effective way to engage in needle exchange services: at a clinic, at a mobile van, through a peer specialist with lived experience. To this question there was no uniform set of responses, and there is no one conclusion that can be offered. Some appreciated the mobility of a van to meet them where they needed as going to a clinic sometimes ran the risk of being identified in a way they did not want. Others felt more at home using a clinic for such services. The value of peer specialists was highlighted, though many said it would depend a lot on who exactly the specialist was. In essence, while there is no one method of delivering these services that was cheered by all participants, the value of confidentiality again came to the foreground.

“They understand, they just want people to be doing it the healthy way.”

“Yeah, and they’re real, like, knowledgeable about a lot of stuff, not just the needles, but, like, I’ve had infections before, and they knew what to do...”

“Maybe on [the card] they could have something like that it’s confidentiality ... Cause I was really scared to do it at first.”

“Some random person shouldn’t just have a bunch of needles,” [in reference to the possibility of a needle exchange service located at someone’s house].

3) Limitations of resources make participants feel doubly marginalized.

The lack of reliable and adequate transportation was cited by participants as a hindrance to their participation in programs they would have benefited from. Those who were in treatment programs for substance use described inflexible requirements that often barred them attending and getting the support they needed, and how they were often removed from such programs after missing a certain number of appointments. Sometimes this was also tied to the fact that participants did not have phones to call and cancel. Even as it relates to these interviews, participants often struggled to find a ride, or access local services. For those who lived in more rural locations and did not own a car, the possibility of finding work was almost out of the question. Across several interviews, **participants expressed distress that those who were initially trying to help them did not understand the scope of their logistical limitations.**

Several participants were aware of programmatic requirements around absences that often led to their dismissal from certain services. Still, it was evident that what they sought was a degree of understanding about their logistical limitations, as well as the flexibility to continue engaging in treatment in some way. Thus, treatment

provided at local clinics and hospitals was often viewed in a positive light; it was more the requirements around attendance that proved problematic for participants.

“Everything went downhill” [when kicked off a suboxone program].

“They kind of got mad for not calling when I miss my appointments and stuff.”

“I mean, they were nice at first, but when I tried to explain that I couldn’t get there [to the appointment], they just told me to take the bus and hung up. It’s like they were too busy to help me.”

“People at the programs would talk to me about getting a job and how that’s important and stuff, but I’m like how am I going to do that when I have a bicycle and winter is really long?”

“I was put in the same situation [after detoxing]. Nothing changed, but I changed, so I kind of fell back into using.”

“Is there like some other program I can go to that understands if I miss a few appointments?”

4) Unstable housing situations and fragile social networks often exacerbate substance use.

Prior experiences with homelessness and being cut off from family members were often cited as causes of increasing substance use. Several male participants in particular spoke of how it was difficult for men to find assistance with housing. Homelessness often meant staying with friends and relatives, at times in unsafe situations that made

current substance use worse and unsafe. Others slept in cars or under awnings for long periods of time and found themselves interacting with law enforcement as a result. Additionally, the role of family varied significantly. Some tried to achieve distance from what they saw as toxic family dynamics, while others spoke of parents, siblings, and children as their only sources of support. Overwhelmingly, there was a sense of fragility to these networks. Many were without the means to enlarge their social networks, even if they wanted to.

Given that participants often had few people to trust, the value they placed upon those involved in the needle exchange service was central. Again, themes of confidentiality emerge as being very important.

“Sometimes you end up in places you don’t want to be, because it’s like, negative 20 out and you have to be warm. And then it’s easier to use.”

“My kids love me no matter what and know that I love them. It’s nice to have that support.”

“Some people you just have to stay away from, but it’s not like this is some big city or something, so you run into the same people; kind of hard to get away from them.”

“Yeah, I’ve slept in cars for a while. When that happens, it becomes easier to use because it’s a really hard situation.”

“It sometimes seems like the only people who understand this are the ones at the needle exchange.”

5) Fear of law enforcement and Child Protective Services/Indian Child Welfare kept many participants hesitant about seeking certain services.

Concerns about being caught with a syringe and concerns about using the emergency room (and then being flagged if a warrant is out for that person’s arrest) were cited as reasons they did not seek certain services. Many participants had a negative experience with seeking help and then ended up in legal trouble, or they knew of someone who had. Even in instances of an overdose, some participants would not seek medical help for this reason. The danger that many participants felt around this issue was palpable.

Akin to the aforementioned theme of experiencing stigma at various healthcare provider locations, participants’ fear about being identified was more often intuited than it was described in actual interactions. In other words, while some had experienced actual negative interactions with legal matters when they sought health care, it was more often a feeling of dread not unrelated to the stigma from various providers.

“They were worried about getting in trouble, and I was like ‘are you serious? Like you just almost died.’”

“At the hospital, it’s like they know me as a drug dealer, so it’s a red flag any time I walk in.”

“I don’t get care how sick I get. I’m not going in there [the hospital] because I know what will happen.”

“It is true that the front desk everywhere kind of keeps track of who is walking in.”

“My children have been pointed out and ridiculed.”

6) Forms of healing need to focus on more than just “substance use.”

A number of participants described the distance they felt from their own traditions and opportunities for healing. Some had benefited from participating in sweat lodges previously but felt that they were only accessible when a person was not using substances. Others described how they would like to have the opportunity to talk more with elders in their community but believed that their substance use kept them from doing so.

Some participants, including those who had gone through recovery programs, believed that raising awareness in the community about harm reduction—through community dinners or public events, for instance—would be beneficial to decrease widely held stigmas and make it more possible for people to seek the type of support they need. Others described the necessity of increasing healthy recreational activities in the area, for adults who can do more than “be treated” and for children, to prevent them from being initiated into substance use.

“I’m kind of separate from ceremonies and stuff like that because of my drug use. I was taught that you’re supposed to be clean from everything.”

“More things that kids will be able to go at or feel they want to go to, like a new bowling alley.”

“Elders are there, I know, to help, but it’s kind of like I don’t want to talk with them about my use. It’s embarrassing.”

“Sometimes I wish people would see me as more than a person who uses. But when you do that stuff, it has a way of making people forget the other things about you.”

“Maybe there can be a potluck or something like that. Something that tells everyone that we’re not bad people and if we use, there are reasons for that, and maybe there can be some understanding.”

MINOR THEMES

1) Due to negative experiences with some healthcare providers, participants would like to have the possibility of being tested for infectious diseases through the needle exchange service.

Chronic illness was a reality for many participants, though because of the aforementioned stigma in healthcare settings, many were proceeding without a diagnosis or treatment to help them manage. Some participants wondered if it would be possible to be tested for infectious diseases through the needle exchange service in the future. Others so appreciated the ethos of care and confidentiality within the needle exchange services that they wondered what other services could be included.

2) Many have engaged in treatment and recovery programs in the past, and remain open to engaging again “when ready.”

As to the possibility of engaging in some form of treatment in the months or years to come, many participants recognized that they had thought about it, and would pursue that possibility “when ready.” The refrain “I have to fix myself” was repeated across several interviews. In the meantime, there was--for many participants--a hope of not using substances one day, though most remained vague on what would have to change in order to actualize that.

3) Many began using substances in early adolescence due to a variety of reasons related to family and friends. Present day use tends to be regular and includes multiple substances.

Substance use characterized the early adolescent lives of many participants, who were first introduced to substances through family, friends, or through medical or dental procedures that often went awry and required significant medication. Many used at first to feel good, and then later to manage mood shifts. Others used to regulate sleep and waking cycles. Generally speaking, most participants used several substances several times a day most days.

4) Most participants had seen someone overdose, and most were versed in how to use naloxone.

Almost all participants said that they had seen someone overdose, and a few had

overdosed themselves. Descriptions of what happened during an overdose varied significantly. As it relates to potency of substances in the area, some expressed concern since several very potent batches had moved through the area in recent years. In terms of being prepared for an overdose, almost all participants knew how to use naloxone and did not seem interested in further training. Many were appreciative in the “how-to” around naloxone that had been provided formally and informally in recent years.

5) A number of participants have employed safer practices in their use of substances, and some of this can be attributed to participating in the needle exchange program.

Whether using prescription opioids for maintenance purposes, or regularly exchanging used needles, or seeking out information about overdose prevention methods, it is clear that a number of participants have employed safer practices over the course of time they have used substances. Some of those shifts were attributed to conversations with individuals involved in the needle exchange program. Some of the shifts were attributed to hearing about safer practices through friends, and word-of-mouth. This is not unrelated to the finding about participants being versed in how to use naloxone. However, this minor theme extends more generally to the mere presence of a needle exchange service as a means of raising consciousness around practices, in addition to the benefit of making substance use safer.

CONCLUSIONS

In summary, this report highlights the value of harm reduction services and points to the varieties of stigma faced by individuals who use other services in the community. **As many of those who inject drugs have a long history of strained social support and limited logistical resources, services that place confidentiality and a nonjudgmental attitude in the foreground are all the more important.**

It is worth noting that all participants endorsed the continued work of existent harm reduction services, though there was not widespread agreement about the best way to expand those services in the future. Again, the importance of confidentiality was cited as the most crucial component. Whether based at a clinic, delivered through a mobile van, or hosted by a peer specialist, participants retained an openness and flexibility about the continuation of such services, so long as they could trust those offering the services.

The interviews described herein highlight the many challenges faced by those who inject drugs, and the sense of exclusion they feel from various sectors of the community. In the words of one participant, “there is often nowhere to turn,” which leads to further isolation. Without a phone, without a secure place to live, without adequate transportation, participants are often unable to engage in programs and with appointments that are meant to improve the qual-

ity of their lives. The scale of struggle both immediate and long-term for many participants should be emphasized. Homelessness has often persisted for several years, substance use can often be dated back to early adolescence, numerous relationships have been fractured. The degree to which trust has been corroded with many people in their lives creates a certain skepticism toward many services.

SOME UNDERSTANDING

It is clear that participants have benefitted from various treatment programs, but it is also clear that requirements around poor attendance and lack of engagement in those programs have led to dismissal and negative rapport with several providers. To that end, it is worth exploring what sort of community education could be developed to make more widespread among providers the obstacles faced by participants in hopes of achieving a measure of flexibility for program participation, while being mindful that those programs also have to abide by certain requirements.

Along the lines of community-based education, it was striking when one participant noted, “Maybe there can be a potluck or something like that. Something that tells everyone that we’re not bad people. And that if we use, there are reasons for that, and maybe there can be some understanding.” Thus, as confidentiality about the use of harm reduction services was highlighted over and over, there was also an expressed

desire to decrease stigma in the community through an awareness-raising effort that would not only normalize harm reduction services but would also point to the fullness of who they are, as not simply people in need of treatment.



IV. APPLIED KNOWLEDGE IN RURAL HARM REDUCTION PRACTICE

We compiled the following information to provide new and developing SSPs with a discussion of the major areas of consideration for program development. After doing this work, and through conversations and collaborations with others, we have come to understand that what works in one place won't necessarily work somewhere else.

Successful programs are adaptable and tailored to the particular needs and context of a community. Therefore, we won't offer much by way of prescriptive advice, but offer our experience administering a reservation-based, rural SSP.

PURCHASING INJECTION SUPPLIES

Most SSPs purchase their supplies from:

- *NASEN, the North American Syringe Exchange Network* (www.nasen.org) or
- *Points of Distribution (POD, www.facebook.com/pointsofdistribution)* buying clubs.

NASEN and POD offer a syringe exchange

buyer's club to leverage bulk ordering to get the lowest cost on supplies. Clinics might find that it's cheaper or easier to purchase supplies from a current medical supplier.

What you order depends upon the needs and demographics of your community, but for beginning programs we recommend:

- Several hundred syringes in a variety of gauges and lengths; these are typically 27, 28, 29, and 31 gauge and 1/2" and 5/8";



Syringes are generally packaged in bags of ten or blister packaging (individually wrapped). Based on participant feedback, we try to order bagged syringes.

- Large and small cotton balls (packaged in 2" x 2" Ziploc baggies) and/or prepackaged cellulose filters;
- Sterile water;



Sterile water in safer injection kits helps to prevent the introduction of bacteria, viruses or other impurities which may be found in other sources of water.



Antiseptic wipes are provided to clean and sterilize the injection site, prior to injecting in order to minimize bacterial infections.

- Alcohol and/or benzalkonium (BZK) wipes;
- Tourniquets;
- Cookers;
- Condoms & lubricant;
- Sharps containers in a variety of sizes;

(most of our participants prefer the quart size) or empty and cleaned detergent bottles with tightly-fitting caps;

- Ziploc and paper bags in multiple sizes for packing supplies;
- Disposable gloves (i.e. nitrile gloves) and
- Supplies for making naloxone kits.



A basic naloxone kit contains 2-3 doses of naloxone, the same number of intramuscular syringes and instructions packaged together.

NALOXONE PROCUREMENT

We highly recommend incorporating naloxone into your harm reduction program.

*Naloxone is a very safe medication and is not known to have side effects. **Naloxone operates by blocking the opioid receptors in the brain, restoring respiratory function to people who are overdosing on opioids.***

Community distribution models generally work by training groups or individuals in the signs of overdose, administering naloxone and aftercare, and prioritizing people who

use drugs as they are in the best position to respond to an overdose. The *State of Wisconsin Department of Health* has a naloxone trainer program and offers certification and good training videos are also available online. Many harm reduction programs have developed informal training programs to facilitate naloxone distribution. In Bad River, we have trained hundreds of lay people on how to respond to an overdose. Community training has led to improved outcomes for people who have overdosed, and has led to decreased rates of mortality associated with opioid overdose on the Bad River Reservation.

We believe that it's also a good way to address discrimination against people who use drugs. Community overdose prevention training engenders empathy for victims of overdose and it also transforms passive bystanders to the opioid epidemic into people who are activated and aware.



We are extremely grateful to be able to purchase naloxone in bulk. Pictured here are 500 doses of naloxone prepped for making individual kits.



A vial of naloxone, pictured above constitutes one dose for intramuscular injection.

free naloxone to people who use drugs. OSNN facilitates a community listserv for discussions on naloxone and other topics related to overdose and recovery. In order to purchase naloxone through the OSNN Buyer's Club, your program must meet

Naloxone can also be purchased through NASEN; however, a more cost-effective way to purchase naloxone is through the *Opioid Safety and Naloxone Network* (OSNN). The OSNN Naloxone Buyer's Club is an option for community programs distributing

certain requirements. To request more information, contact Maya Doe-Simkins (**mdoesimkins@gmail.com**) or **Eliza Wheeler** (**ejwharmreduction@gmail.com**) who coordinate the OSNN Naloxone Buyer's Club.

Health departments, clinics, or other health-care centers may purchase naloxone through their existing medical suppliers or receive free injectable naloxone through Direct Relief, a

humanitarian organization that provides free medical supplies to qualifying organizations. Direct Relief only serves certain healthcare organizations. More information, along with the program application, can be found at www.directrelief.org.

Several states have recently established funds for the purchasing and distribution of naloxone. Many new programs have been able to leverage this funding to receive free naloxone for distribution, and in some states specific funding streams have been created for Tribal and Rural health initiatives around opioid use and overdose. Contact your state's administrator of SAMHSA State Opioid Response (SOR) funds to learn more about these opportunities.

Finally, *NEXT Distro* (www.nextdistro.org) is an online, mail-based harm reduction program that will mail naloxone to groups that are underserved or underfunded and unable to access naloxone on their own.

Both the OSNN Buyer's Club and Direct Relief require a prescriber's license to set up an account to set up or receive naloxone. This can be a barrier to new programs,

programs in rural areas, or programs in politically conservative areas. If your program encounters difficulties in procuring naloxone, we would recommend working with a SSP that has an established naloxone program to troubleshoot the barriers. You can also receive support and technical assistance from OSNN or other the Harm Reduction Coalition around finding a prescriber

and setting up your own naloxone procurement and distribution project.

BUILDING KITS

The types of supplies that SSPs distribute can vary, depending upon geographic location, program budgets, participant needs, and regional drug use trends. As much as possible, without being intrusive, we suggest gathering feedback from your participants about which supplies they do or don't use, which brands they like best, and what things they would like to use, or use more of,

if it were available to them. Currently, we provide the following materials for safer injection kits.

- Syringes in the gauges and quantities they request or per policy. Manufacturers package



Our program received a donation of two metal supply closets last year. We appreciate the functionality of these closets to help us keep things safe and tidy.

syringes individually (blister packs) and in packs of ten. It's a good practice to distribute syringes in the original packaging as a measure to prevent the spread of hepatitis. Our participants prefer 10-packs to blister packaging.

- Personal sharps container with top securely attached, sufficient in number and volume to hold syringes contained in the kit
- A bag of small cotton balls, or cellulose filters used to filter large particles which can be dangerous if introduced within the bloodstream
- 5-10 cookers (a clean and safe container to prepare the solution to be injected) which come either with small handles attached or non-handled
- A handful of sterile water ampules (to create a solution free of harmful organisms which may be present in tap water)



- A small pack of alcohol or benzalkonium wipes (above) to clean an injection site before injecting



Cooker and filters

- Tourniquets (to aid in the injection process and decrease the risk of infection from a missed shot)
- A few packages of cellulose swabs (soft, absorbent squares of material used to apply pressure to a site following injection to aid in healing and stop bleeding)
- Vitamin C/ascorbic acid (can be used as an alternative to lemon juice to break up solids within the injection solution to prevent the introduction of harmful organisms into the bloodstream)
- 2-3 packs of triple antibiotic ointment (for infection prevention)
- Condoms & lubricant
- Several fentanyl test strips with instructional sheet/sticker (recently employed as an overdose prevention strategy at the request of our participants)



CPR face shields are distributed with naloxone kits (when available) to provide a sanitary barrier for rescue breathing.

- Overdose reversal kit (2 or 3 doses of IM naloxone, 23 gauge syringes, CPR face shield, instructional brochure)

Most people know what supplies they like to use and what works best for them, so we fill their specific requests from participants about which of these available supplies they do or don't want, and in what quantities.

In addition to traditional harm reduction supplies, we also offer our participants food and personal hygiene supplies whenever possible. Through a partnership with another community program, we have access to a regular supply of frozen, homemade soup, and we also collect donations of travel-sized toiletries to be able to hand to people who need them. We believe that being able to offer these additional forms of care and mutual aid to our participants is an important component of a harm reduction ethos, valuing our participants as whole people, and taking a holistic view of health. Offering a variety of differently-sized items for patients in a clinical setting may also be a strategy to create anonymity for SSP participants; they wouldn't be the only ones leaving the clinic with larger packages.

Based on participant feedback, we've found it best to distribute supplies in as nondescript packaging as possible. We often reuse grocery bags, both paper and plastic, and order paper bags in various sizes to pack kits in. Earlier on in our operations, we packed kits in reusable bags specifically ordered for the program but were told that the bags were too conspicuous, and people were reluctant to be seen carrying them. It can be a challenge to make the packaging appear nondescript when you're distributing

a large quantity of supplies, but we try to make it difficult to identify what's in our kits just by looking at them.

Our standard practice is to give one box (100 syringes) of the gauge of syringes they specify, per participant contact, unless they specify otherwise. Though this is greater amount than many other programs we know of, we've found this to be effective for several reasons: first, our participants engage in a high rate of secondary exchange, so we anticipate that the supplies we provide to one person will be shared with others. (This is a great way to get at more people in rural communities and we appreciate that participants are so willing to take care of friends by sharing new supplies.) Within rural, high-poverty areas, many people who use drugs may not have access to transportation, a cell phone, or cell phone service to set up an exchange themselves, and they may have hesitations related to confidentiality and/or legal concerns about accessing syringe services. Providing ready access to a sufficient quantity of syringes (i.e. to achieve a community goal of one syringe per injection) is a good public health practice and helps us reach those who might not directly access services.

Secondly, because of the practical barriers listed above (lack of transportation, limited phone service, etc.), combined with the fact that we are an all-volunteer program, we try to make sure our participants will have enough supplies to last for as long as they need until they are able to reach us again.

Given that we are the only low-barrier SSP within our local area, we get requests from people that are well over an hour's drive away. The participants we've made contact with in some of these further-away places do an incredible amount of secondary exchange, often acting as the contact person for their area. We feel lucky to have cultivated these contacts and do our best to provide them with as many syringes and supplies as needed. We feel lucky that our program that has the resources available to us to do this, and we recognize that some places need to limit the supplies they give out and/or their service area for program sustainability reasons.

COLLECTING USED MATERIALS

All participants are encouraged to return their used syringes at every meet up. **In our experience, participants who are stably housed return used materials at extremely high rates.** People



A lesson learned early on was to firmly secure lids on sharps containers before they are distributed. Tops are easy to lose and containers without tops are much less safe to handle.



On a field trip to Prevention Point Philadelphia in 2019, we were able to see how a large, urban syringe services program works in the Kensington neighborhood.

who are un-housed and those experiencing instability due to incarceration, domestic abuse and other complicated life situations experience difficulty in returning used materials. Within our program, we track rates of return and have conversations with participants who aren't bringing materials back. However, we cannot condone enforcing a one-for-one exchange model, limiting participants' access to supplies for punitive reasons, or coercing someone to change their use habits. These practices are contrary to the recommendations of all available public health research, as well as the principles of harm reduction and trauma-informed, decolonized models of care. Also, because we encourage and appreciate secondary exchange sometimes

it's hard to get all the syringes back through those same channels. This is okay! We ask participants to communicate the safest way to dispose of used syringes.

To promote the safety of participants and volunteers, however, any syringes returned are required to be contained in sealed sharps containers or detergent bottles. Volunteers never count out individual syringes because of the time that would take, and due to the increased risk of an accidental needle stick; the number of syringes returned is estimated based on weight and the volume of the sealed container.

A NOTE ON LANGUAGE

Use of affirming and respectful language is critical to reaching harm reduction goals of developing respectful and positive relationships and addressing discrimination against people who use drugs. **We avoid referring to the syringes we distribute as “cleans” and syringes that have been used as “dirties.”** Instead we prefer to use language that is less loaded; for example: “new” or “sterile,” and “used” or “old” are descriptive adjectives that don’t carry the negative connotations as “clean” and “dirty.” We refer to the injection supplies offered as “materials,” which is another neutral word. We would encourage clinics and other organizations that engage in drug analysis testing to consider changing the practice of identifying results of testing as “clean” and “dirty” as this language is demeaning and clinically inaccurate.

We also refer to people who participate in our program as “people who use drugs” and “people who inject drugs” instead of “drug users” and “injection drug users.” This

is meant to emphasize their humanity first, and to avoid defining participants solely by their association with drug-related activities. The friends and neighbors who participate in our program are people who have diverse interests and passions unrelated to drug use. They sew and cook; love their pets; work hard; are parents and children; and are educated and knowledgeable. They are passionate and committed, and love living.

DISPOSING USED MATERIALS

The disposal of used syringes continues to be a challenging aspect of harm reduction work. The disposal of biohazard waste is a highly-regulated activity—only certain waste handlers are licensed to handle this type of material, making the service expensive. When we started our program, we worked with the tribal recycling program to identify all of the state-licensed biohazardous waste vendors that serviced the area and request bids for the Tribe’s business. This process enabled the Tribe to save money on biohazard disposal and provided our program with an opportunity to dispose of the sharps containers that we collected from our participants.

While biohazard waste disposal is expensive and complex for newer programs to manage, it is a particularly “fundable” aspect of SSP work. SSPs are uniquely positioned to effectively handle and dispose of used syringes, greatly reducing the amount of materials disposed of irresponsibly in community spaces. **Our program has also**

conducted community trainings on safely collecting used syringes found in outdoor spaces and has distributed a three-minute video on the topic for social media. In the springtime, especially, improperly disposed syringes are often discovered in communities. We have found the best approach is to partner on community clean-up activities to demonstrate our concern about this problem and collaborate on addressing it.

COMMUNICATIONS AND OUTREACH

Figuring out what model of distribution will work best for your program and your community is crucial to doing successful, sustainable, and person-centered harm reduction work. We've found that anonymous, on-demand, mobile services work best for our community. However, this program model wouldn't be possible without the incredible dedication of a small number of dedicated volunteers. While we believe this model to be particularly effective for rural and tribal communities, we also understand that not every program will have the capacity to operate this way. We encourage new programs to be realistic about what they can offer while ensuring that the services they offer ensure confidentiality and the dignity of participants.

Our program utilizes a free, anonymous phone number that participants can call or text to request supplies. The number is supported through a free app and can be accessed on multiple phones simultaneously, which has been especially helpful as our

program is completely volunteer supported. Other programs have utilized Google voice, WhatsApp, or other phone apps; or actual on-duty phones that are shared among volunteers and staff.

Mobile outreach vans are often thought of as standard practice for harm reduction services in rural areas. We initially partnered with a statewide harm reduction program to bring mobile van services to our area but found this wasn't an effective service delivery model for us because of the stigma associated with utilizing the service and concerns about participant confidentiality. Utilizing volunteers in personal vehicles has helped mitigate some of these concerns.

Providing harm reduction services in a healthcare or clinic setting could offer a huge benefit to community members who inject drugs, who often face significant barriers in accessing regular healthcare services. However, as the previous section of this report describes, people who use drugs can be extremely reluctant to open up about their healthcare needs related to using drugs in a clinic setting. Programs that intend to offer syringe access services in a clinic setting need to acknowledge this reality and actively work with potential program participants and clinic staff to ensure that the clinic can deliver syringe services in a trauma-informed, low-barrier, and empathetic way.

Regardless of what distribution model is utilized, access to services will likely be slow as programs get started. It is unrealistic to expect your program to move faster than

the speed of trust. Though we started very slowly, our program has experienced exponential growth through the years because we built relationships and developed a reputation in the community that makes people feel safe accessing services.

DATA COLLECTION

Collecting data in tribal communities, and with people who inject drugs, must be undertaken mindfully. As Ojibwe women, we are acutely aware of the damage that can be done through improper data collection.

Data mining and the theft of indigenous peoples' data by nongovernmental agencies and funders is a form of resource colonization. As discussed in Part II, requiring syringe services participants to divulge

personal data in order to access services can be a substantial barrier to providing effective services, especially in rural areas. As a matter of policy, we feel that if people who use drugs are asked to engage in extensive data collection endeavors, they should be compensated for their time. Ideally, they should be also be engaged on how that data is collected and ultimately used.

Data collection, however, is critical to evaluating whether the services are reaching people in need, and addressing equity concerns. Data collection is also necessary for substantiating a program's work for funders and the community at large.

Our program does collect a variety of data. Aggregate forms of data collection include the pounds of used injection equipment disposed of, the number of syringes purchased and the number of events held, on an annual and semi-annual basis. We also collect data on program participants, for select periods of time. We assign a unique alphanumeric sequence to each individual served (e.g. ABC123) along with their race (Native/non-Native), gender and approximate age to keep track of the number of syringes going to that person, and an approximate number of syringes that are returned. Our data sheet is included in Appendix III on page 76. We've also used this system to keep track of naloxone kits distributed, pursuant to a request by a funder. We keep track of this fine level of detail for three to six months in order to gauge demographics served, and determine

DATE	WEIGHT	NAME AND SIGNATURE
10/4/18	17 lbs	[Signature]
10/31/18	17 lbs	[Signature]
10-31-18	16 lbs	[Signature]
11-5-18	17 lbs	[Signature]
11-17-18	31 lbs	[Signature]
1-18-19	25 lbs	[Signature]
2-23-19	45 lbs	[Signature]
3-16-19	19 lbs	[Signature]

Every batch of medical waste is weighed by the Bad River Recycling Program. We keep this data and use it to analyze rates of return for syringes distributed.

trends on syringes out and back into the program. Our data is kept secure by the nature of its collection. Only program volunteers understand how the alphanumeric system works, and it does not relate back to easily identifiable characteristics. It's also the policy of our program to refuse to share our raw data. Instead, we use the raw data to demonstrate the number of contacts our volunteers make, demographic trends and other useful information when requested by funders or others.

Due to safety concerns, individual syringes are never counted by volunteers. We require syringes to be securely packaged in Sharps containers, or other equivalent packaging. Therefore, the number of returned syringes is made by educated guess based on the size of the container and its weight.

FUNDING

Since the 1980s, Congress had banned the use of federal funds to support needle exchange; however, in 2016, the ban was partially lifted to address the public health implications of the “opioid epidemic.” In jurisdictions determined by the Centers for Disease Control and Prevention (CDC) as experiencing, or at risk for, increased rates of drug-related cases of HIV or hepatitis, federal funds may be allocated to support syringe services. Within these areas, federal dollars still cannot be used to purchase syringes and supplies used to facilitate drug using (i.e. cookers and filters) but they can be used to purchase other program supplies

(i.e. wound care, naloxone, etc.) and to compensate staff who work for syringe services programs. The CDC has published on its website the jurisdictions where the partial federal funding ban has been lifted, which, at the time of printing, included forty states (including Wisconsin), Washington D.C., Cherokee Tribal Nation and Puerto Rico. This information is available at the CDC website (cdc.gov) within Syringe Services Programs (SSPs) and Determination of Need. Since the partial lifting of the federal funding ban, federal agencies have provided some grant funding to support syringe services programming. Additionally, state funding may be available.

Most harm reduction programs are supported through grant funding. The two primary sources of private grant funding are AIDS United and the Comer Foundation. Private grant funding can help fill in funding gaps, or, depending on the size of your program, can fund your program completely. There are, of course, thousands of other grants available through organizations and private foundations which may provide funding to your program, even if they are not harm reduction specific, and we encourage programs to look at all available funding sources and be creative when applying. In addition to grant funding, many programs, especially newer and smaller programs, have been able to receive donations from, or work in partnership with, larger harm reduction programs, especially those located in urban centers. Some programs also do

their own fundraising, which can be very effective but also time-consuming for staff and volunteers.

Our program started with no funding whatsoever. There was no sustainability plan because there was nothing to sustain. We had little community support and no prospects for funding. To begin providing services, we relied on the generosity of ARCW to share supplies and provide mentorship. Thankfully, it also took several years to generate robust participation. One year into the work, we received a mini-grant and a modest amount of funding from the tribal general fund to purchase our own supplies.

We would encourage other tribal programs to seek funding from their tribal council. We are also fortunate to have been awarded private grant funding, and to receive individual donations to our program. Had we been more deliberative in the beginning, the program may never have existed. Our organizational theory came from the sweat lodge: we believed that if we prayed hard enough and asked for help in a pitiful and humble way that our thoughts and actions would be influenced by the manidoog (spirits) and money is no barrier to the manidoog!

SAFETY

A frequent question that we get, especially from people who are new to or haven't done harm reduction work, is how we feel "safe" meeting our participants on our own.



CPR masks

Most of our meetings take place in public spaces, though we do go to people's homes and people come to our homes, as well. The assumptions underneath this question of safety usually seem to be that people who use drugs are inherently untrustworthy/unstable/"unsafe" people. **We fundamentally reject the idea that our participants are any more or less "safe" than any other member of the general public.**

Our meetings and exchanges likely pose a greater risk to our participants than they do to us, as our participants are much more likely to encounter problems with law enforcement, employers, family and friends, and housing providers if they are known to use drugs or access our services. While we encourage our volunteers to be practical and trust their intuition when entering into new situations and spaces, we believe

that building relationships and valuing our participants is an essential component of this work. That can be difficult to do if you are convinced that your safety is in jeopardy every time you interact with a person who uses drugs.

Maintaining appropriate boundaries is healthy and necessary. Our program includes guidelines for all participants and volunteers. Violence and threats of violence are not tolerated. When delivering to new people or at new locations, volunteers sometimes stay within their vehicles. The use of the phone app as a collective organizational tool also allows us to keep track of each other's activities.

DOING WORK FOR THE LONG HAUL

We, like most other harm reductionists we know, balance this work with our other paid and unpaid work, family and community responsibilities, and, if we are lucky, time for rest and self-care. Our volunteer capacity has ebbed and flowed over the years as people move away or change jobs, families expand or shrink, vehicles break down, and the grind of daily life catches up with people. In an ideal world, our program would probably have more volunteers and a more manageable schedule but we, like everyone else, are doing the best we can with what we have.

Beyond harm reduction itself, we see this work as an essential component of fighting for our collective liberation. Interest in harm reduction programming has seen a definite

uptick in the last several years as more and more people are responding to the overdose epidemic, but there seems to be not enough analysis about the ways in which harm reduction is, or needs to be, an anti-colonialist and de-colonizing project. We are tied to doing this work because we see it as an essential component in our relationship to ourselves, our community, and the land. We do this because none of us can imagine doing otherwise. While we hope that our capacity continues to increase, we'd also like to see more of this work done by others. We know there are so many other potential programs, collaborators, and friends out there who simply need to get started.



APPENDIX TO PART II

Exchange Guidelines and Operating Procedures Summary of Peer-Reviewed Literature

Gwayakobimaadziwin Bad River Needle Exchange – Summary of Peer-Reviewed Literature on Needle Exchange

(July 2014)

This document was created by a 2014 by summer intern, Dyllan Linehan, to provide an introduction to the issues of tribal leadership. Using peer-reviewed and government-published literature, it describes the public health risks associated with injecting drugs and describes how needle exchange programs (**SSPs**, or **syringe services programs**) can address those risks and effectively reach out to people who inject drugs.

Introduction: Why a Needle Exchange Program is Essential

A **needle exchange program (NEP)** is an essential aspect of health care in Ashland County because of the significant risk that

used syringes pose to the community, to both IV (intravenous) drug users and non-users. Without a NEP members of the community face an increased likelihood of contracting a blood-borne disease because IV drug users will share needles amongst themselves if they are unable to access sterile supplies. Further, without access to safe and secure disposal sites, syringes will be improperly disposed of, which increases the risk of the transmission of blood-borne diseases to non-users, including law enforcement officers, children and sanitation workers. Decreasing the transmission rate, and overall rate, of HIV, hepatitis and other infectious disease benefits the entire community.

Quick Facts

- More than 1.1 million people in the United States are living with HIV infection, and almost 1 in 6 (15.8%) are unaware of their infection.¹

- AIDS is now one of the 10 leading causes of death among 25- to 50-year-olds in the United States.²
- Youth aged 13 to 24 accounted for an estimated 26% of all new HIV infections in the United States in 2010.³
- Studies have shown that by providing such drug users with clean needles, programs are reducing HIV spread through intravenous drug use.⁴ Currently, the lifetime treatment cost of an HIV infection is estimated at \$379,668 (in 2010 dollars), therefore a prevention intervention is deemed cost saving if its CE ratio is less than \$379,668 per infection averted.⁵
- The cost to treat hepatitis C for one individual is between \$66,000-\$84,000.⁶
- Studies have consistently shown that NEPs are not associated with increases in drug use.⁷

How Blood-Borne Diseases (HIV and Hepatitis C) Are Transferred through Sharing Needles and Accidental Needle Sticks

Transmission of HIV and Hepatitis C through Intravenous Drug Use

Transmission of blood-borne diseases through needles occurs through the following process.⁸ Drug users inject themselves with drugs into a vein under the skin or into a muscle.⁹ If the drug user is HIV positive¹⁰ the needle they use may contain small amounts of HIV infected blood.¹¹ The drug user will then, in order to insure they have

fully injected the drug, draw their blood into the needle and then reinject it into their vein.¹² The needle is later shared with another drug-dependent person who follows the same procedure.¹³ This results in the mixture of the former user's blood with that of the latter.¹⁴ The entire process, which results in the mixture of blood among IDUs, is a highly efficient manner of transmitting the HIV virus.¹⁵

HIV and Hepatitis C Statistics in the U.S. and Wisconsin

General Statistics¹⁶

- Over 8,000 people in the United States are newly infected with HIV every year due to syringe sharing.
- Over 16,000 people in the United States are newly infected with hepatitis C every year due to syringe and equipment sharing.

Statistics for Wisconsin

- Trend: In 2013, 255 cases of HIV infection were diagnosed in Wisconsin. Between 2004 and 2013, the number of diagnoses ranged from a low of 225 in 2012 to a high of 284 in 2009, with an average of 253 diagnoses per year.¹⁷
- In 2013, in Wisconsin, 71 people were newly infected with HIV due to syringe sharing. (41 IDU, 30 MSM/IDU)¹⁸
- Since 2011 hepatitis C rates have been on the rise in Wisconsin.¹⁹
- Hepatitis C rates in Ashland county tripled in 2011-2014.

Harm Reduction Strategies to Prevent Outbreaks of Blood-Borne Diseases ²⁰

- Aims to reduce the harms associated with the use of drugs in people unable or unwilling to stop
- Recognizes that many people continue to use drugs despite even the strongest efforts to prevent the initiation or continued use of drugs
- Understands drug use as a complex, multi-faceted issue that encompasses behaviors from severe abuse to total abstinence
- Meets people where they are in the course of their drug use

Harm Reduction Strategies to Prevent Blood-Borne Diseases from Affecting Non-IV Drug Users

Sex Education

Sex education is important for non IV-drug users as well because they need to know that they may contract the blood-borne diseases that their partners contracted through their IV-drug use by sharing or reusing needles.

Accidental Needle Sticks

Accidental needle sticks (accidental punctures of the skin by a needle) are a serious concern for individuals who may come into contact with used needles on IV drug users or that have been improperly disposed of.

i. Police Officers

Police officers face an increased risk of contracting blood-borne diseases when there

are a large number of used and shared needles in the community²¹ due to the lack of NEPs.

ii. Sanitation Workers

Sanitation workers are also face an increased risk²² of contracting blood-borne diseases if no NEP is available in a community because many used needles will be disposed of improperly. Without a NEP, many IV-drug users will discard their needles in the garbage, which can lead to accidental needle sticks when sanitation workers are engaging in their everyday work routine.

iii. Community Members

Community members, especially younger children who do not know the danger of used needles, face increasing risks, much like police officers and sanitation workers, because used needles are often discarded in public places such as beaches and parks.



Gwayakobimaadziwin Bad River Needle Exchange Guidelines and Operating Procedures

The policy and procedures document was created when we were developing our program. As it rolled out, we made modifications to operating procedures in consideration of available resource, staffing and time. However, we hope that our way of doing

things continues to be consistent with the philosophy and principles articulated in this organizing document.

I. Philosophy

- a.** We are all connected. When drug users are at risk for contracting HIV and hepatitis because they are sharing needles, we are all at risk for contracting those same diseases. Children, sanitation workers, and emergency and law enforcement personnel are at the highest risk for accidental transmission.
- b.** Harm reduction is a humane, cost-effective and sensible way to deal with the problems associated with drug abuse.
- c.** Most injection drug users are not in treatment, are not accessing AODA services, and are not receiving medical services. Reaching these individuals is critical to reducing their risk of infection and the community's overall risk.
- d.** Operating a harm reduction program with syringe exchange attracts injection drug users and provides them with resources to help them reduce risky behavior, increases referrals to treatment and other services, and results in less HIV and hepatitis transmission.
- e.** Syringe exchange has never been shown to increase drug use or other harm.
- f.** Syringe exchange and related public information campaigns will reduce the amount of discarded syringes in the community and will reduce the risk of disease transmission by accident.

II. Guiding Principles

- a.** The Anishinaabe values of respect, humility, courage, wisdom, truth, honesty, and love shall guide all of our work.
- b.** Harm reduction is any positive change based upon the individual's needs and goals. Working toward recovery for an individual is making any positive change—as they define it themselves.
- c.** Harm reduction advocacy is best done on a one-to-one basis.
- d.** People injecting drugs are the experts in reducing their own risk.
- e.** The outreach services will be as safe as possible to the men and women working the outreach and to the communities served. Outreach services will be delivered in a culturally-sensitive and culturally-centered manner, with the understanding that not all clients identify with the same cultural values.
- f.** Getting as much contaminated drug injection equipment out of the community as possible and replacing it with clean drug injection equipment is part of all effective syringe exchange programs.
- g.** Women and men injecting drugs need access to comprehensive healthcare (medical, dental, AODA, mental health services), as well as housing, legal services, shelters, food, warm clothing, child care, and spiritual guidance.
- h.** Outreach with men and women who don't inject drugs and institutions about

harm reduction is important to making space for men and women who do inject drugs to make positive changes in their lives.

III. What We Do

- a.** Provide materials for, and discussion about, reducing sexual and injection risks of HIV and hepatitis C;
- b.** Exchange used barrels and/or detachable needles for sterile syringes;
- c.** Conduct research regarding the effectiveness of our services to determine harm reduction effectiveness, demographics and harm histories, and analyzing trends over time;
- d.** Keep client information absolutely confidential, as explained in the Confidentiality Policy;
- e.** Build relationships among drug users and outreach workers, through kindness, respect and an additional avenue for change; and
- f.** Respectful operation of the outreach includes being non-condemning and non-confrontational while stressing personal responsibility in harm reduction.
- i.** Harm reduction in reducing HIV and hepatitis prevention messages will always be constructive and geared towards the needs and interests of the client (e.g. “Doing it like this can reduce harm in this way ...” instead of “Don’t do this ...”).
- j.** Women and men who use syringe exchange services won’t be pressured into taking a certain approach to stop using

drugs, but instead, voluntary and anonymous referrals will be made based on the individual’s goals for treatment of alcohol and other drug problems, medical care, and other risk reduction services of a person’s choosing.

- k.** Outreach services shall be performed by teams, with outreach workers providing each other with support. We will seek to recruit outreach workers who have experience as syringe users.

IV. The Goals Of Our Efforts

a. Cultivating Community Education and Support

We believe that our efforts will be more effective if they are supported by the larger community. Outreach needs to extend to networks of active drug users and to the broader community. Our goals in this area include:

- i.** Developing strong connections to communities served prior to and during our harm reduction efforts;
- ii.** Meeting with and listening to people who inject drugs, former drug users, health care workers, human service agencies, other community members, law enforcement and community organizations;
- iii.** Incorporating feedback from communities served by the program;
- iv.** Discretely providing information on the program and its services; evidence gathered on the program’s work and evidence regarding harm reduction efforts worldwide,

our plans or activities for harm reduction outreach with syringe exchange, other information on harm reduction, addiction, recovery and HIV/hepatitis; and

v. Developing cooperative relationships with law enforcement to assist outreach workers in case of emergency, but to avoid interfering with the outreach work by hovering near the outreach unit, harassing outreach clients, or targeting outreach workers or clients in possession of used syringes, sharps, or other paraphernalia bound for disposal.

b. Strengthening Community Health

We have chosen to create a harm reduction outreach with syringe exchange because there are no other service providers in this area offering these services. We are aware of an increasing popularity of injection drug use, with evidence from other communities showing that harm reduction with syringe exchange can be highly effective in preventing the spread of communicable diseases and providing drug users with needed medical care and/or treatment. Our basic goal is to prevent untimely death among community members who use drugs. Our specific public health goals are:

- i.** Increased proportions of safer injections and safer sexual encounters;
- ii.** Increased knowledge about the risks of HIV and hepatitis infection to injectors, their sexual partners and their children;
- iii.** Reduced discarded drug injection equipment in communities served;

iv. Increased availability of materials for reduced risk injections and sexual behavior;

v. Increased discussion about, referral to, and enrollment in drug treatment, health-care, etc.;

vi. Reduced levels of harm from all drug use to the person using drugs, their sexual partners, their children and those in the community; and

vii. Increased knowledge of this program's effectiveness as a harm reduction opportunity.

V. Communications

a. The project will start off as a peer-to-peer delivery model, with outreach workers making deliveries to individual drug users.

b. Upon securing the means to conduct exchange events, outreach workers will be available at selected locations, times and days determined through as much community input as possible. Once locations, times and days are chosen, we will attempt to keep a set monthly schedule and communicate this schedule through the means of communication most likely to reach the exchange's clients.

c. We will also work on public information campaigns to the general public about syringe disposal and safety, and about HIV and hepatitis C. These campaigns will be directed to adult and youth communities.

VI. Volunteer/Staff Recruitment, Training and Support

Gwakobimaadiziwin will work to recruit volunteers and staff that reflect the diversity in our community, including individuals who have used needles to inject drugs. Participants working on the project need to challenge themselves to consider the personal impact of this work. Everyone's primary responsibility is to **take care of themselves—physically, spiritually and mentally—before helping others**. Everyone working on the project should honestly challenge themselves to determine if this work is part of recovery for them. All recruits shall meet or adhere to the following:

- a.** Participate in all required training sessions. Be familiar with how HIV and hepatitis C is transmitted and what practices can decrease transmission, including practices related to sex and IV drug use. Be comfortable discussing these things with others.
- b.** Demonstrate competence in understanding and applying the material within the "Guidelines and Operating Procedures" as evaluated by the Site Coordinators.
- c.** Be able to communicate well with co-workers and adequately perform all functions while working on the project.
- d.** Have no outstanding warrants or signs or smells of intoxication (be sober) while working/volunteering at an outreach site.
- e.** Be respectful of all community members using the exchange at all times "we are in their house."
- f.** Meet with Site Coordinator(s) prior to exchanges/exchange events to obtain materials and touch base; also report back to Site Coordinator(s) on how things went and data reporting.
- g.** Support other workers of the exchange while working with them.
- h.** While conducting exchange events, remain at the exchange for the scheduled period, except for serious emergencies.
- i.** Upon agreeing to deliver materials, follow through on delivery unless circumstances make it impossible/impracticable.
- j.** Refrain from touching used syringes or needles. Always ask the person who brought used needles, sharps and syringes to place them in the disposal receptacles and to pick them up if they fall down.
- k.** Prior to working the exchange, bandage all open cuts. Consider wearing sterile gloves, always wash hands after working the exchange and be aware of the emergency post-exposure protocol.
- l.** Get tested for HIV and HCV prior to begin working on the project; consider getting a hepatitis B vaccination.
- m.** Take responsibility to work out any interpersonal conflicts in order to keep principles above personalities.
- n.** Be responsible to take care of yourself to make sure that you are not having a negative influence on the operation of the project or that your work on the project is not negatively influencing you.

VII. Allocation of Duties Among Volunteers/Staff for Exchange Events

a. Van Staff

There are always at least two Van Staff members, both sharing these duties:

- Greets each person coming to the exchange and asks about their interest in coming (e.g. “What can we help you with?” or “Do you know what we do here?”); and
- Determines if the person is familiar with the options of assistance offered by the exchange. If not, provide a brief description of the information and resources offered at the exchange.
- Each client may be asked to complete a voluntary survey, using the client identifier and no name. Clients should be asked whether they would like to provide their phone number or email address for reminder messages about future events.
- If the person is interested in safer sex information and materials, Van Staff assists the person by providing them with snag bags and offering material and discussion on safer sex.
- If the person is interested in safer injection, Van Staff should provide the person with safer injection materials and discussion on safer injection.
- If the person is interested in exchanging needles or syringes, the client should drop his or her needles or syringes to the sharps container for disposal. If a person brings in a large quantity of sharps already within a proper disposal container, Van Staff should

seal the container with duct tape for disposal or place it inside the sharps disposal unit. Together, Van Staff and clients can estimate the number of needles a client has brought.

- If the person is interested in overdose prevention, Van Staff can conduct a training (watch the DVD and answer questions), and provide the client with an overdose prevention kit(s).
- At no point should Van Staff touch any of the used needles or syringes. Clients are responsible to place them in the sharps disposal container. If used equipment is ever dropped and the person refuses to pick them up, no credit should be given for these needles, and the Van Staff should use a broom or tongs to get the needles/syringes into the sharps disposal.
- For people exchanging for the first time, the client should be provided with a sufficient number of needles to ensure one needle per injection. After that, syringes are exchanged on a roughly one-for-one basis. Clients who are filling a sharps container at home might not bring back used needles every time they use the exchange.
- Van Staff offers clean water, cotton, cookers, alcohol pads, tourniquets, and other supplies as available.
- Other items may be available for clients to take for free: hygienic supplies, traditional medicines, hats, gloves, scarves, candy, etc.
- Van Staff should keep data sheets for every event. Client identifiers are used for identification purposes, no names. Data sheets will record what items are collected

for disposal, and the approximate amounts, and the number of syringes, snag kits or other materials given out.

- If the person has questions that the Van Staff is unable to answer or indicates interest in health or AODA services, the Van Staff should provide referrals and ask for contact information in order to follow up.

b. Site Coordinators

- Site Coordinators are responsible for getting the van stocked with sufficient supplies for outreach work, including gas and snacks for the Van Staff. The van should be ready to go 15 minutes before start.
- Site Coordinators call/email/text clients who have requested a reminder prior to each event and post a reminder to the project's Facebook site.
- Site Coordinators ensure that each Van Staff member is capable of working the exchange and remain available during each shift to assist van workers with questions, assist in case of emergencies, and processes with Van Staff before and after each shift.
- Site Coordinators assist in training of workers/volunteers.
- Site Coordinators collect completed surveys and data sheets and stores securely.

VIII. Operational Guidelines

a. Delivery Protocols

- Clients call the hotline number requesting a delivery.
- Site Coordinator(s) answer the calls/texts,

finds out what the client needs and when/ where the client is available to meet.

- Site Coordinator(s) contact volunteers available to meet the client and/or meet the client herself.
- Site Coordinator(s) ready the supplies and/or surveys for the delivery and meets up with the volunteer and/or client.
- During the delivery, do your best to provide clients with information about the program and services available. Make sure clients are aware of the brochure. Also be aware of surroundings and personal safety.
- Volunteer provides Site Coordinator with information about the exchange, delivers any used sharps collected to Recycling and/or the Site Coordinator(s), delivers surveys to Site Coordinator(s).

b. Pre-Operation Meetings Before Beginning Exchange Event

- The pre-operation meetings starts 15-30 minutes before the time the exchange event is set to begin.
- Van Staff and Site Organizer(s) will meet and assess the team.
- Talk about anything that should be shared away from clients.
- Clarify who will do what.
- Ensure that the van is fully-stocked and secured for transport.

c. Post-Operation Feedback Session Required at the End of the Exchange

- Before leaving the site of the exchange, Van Staff will work together to pack up the

materials, secure them within the van and check the van and site to ensure that all sharps are accounted for. Any found needles/syringes should be picked up with tongs and disposed of.

- Van Staff and Site Organizers will ensure that data sheets have been properly filled out;
- will provide the Site Coordinator with completed data sheets and surveys and process feedback received from clients;
- will share personal and professional feedback among team members;
- deliver used syringes to the disposal site; and return leftover supplies to a secure location. Only non-federally funded staff or volunteers should carry containers with new syringes.

d. Syringe Collection

- Returning clients cannot get more needles until they return some. Work on getting all the needles back.
- DO NOT count needles within sharps container/detergent bottles. Just take the client's word for it.
- At no point during the operation of the exchange shall any staff or volunteer touch a used syringe, needle or barrel.
- When the sharps container is full, it shall be carefully closed and secured in an out-of-the-way place. The container is not to be reopened or reused after this point and it proceeds directly to disposal (as outlined here). All containers with used needles shall be sealed with duct tape and secured prior to moving the van.

e. Accidental Needle Stick

In the event of a blood or bodily fluid exposure, Van Staff shall immediately contact the Site Coordinator, quickly close the operation and follow the Bad River Health and Wellness Center Blood Borne Pathogen Exposure Policy on page 65.

f. Closing Down the Operation

- The safety of exchange staff, volunteers and community members is the top priority of this project. Any threats to the safety of the operation or the community will result in shutting down a shift. The decision to shut down should be made by the team on site, but if the team is divided, the Site Coordinator will make the call.
- Such threats may include, but are not limited to the following:
 - * Threats or acts of violence perpetrated against workers, exchangers or community members at the exchange or in the vicinity of the exchange;
 - * Severe weather;
 - * A location fails to be conducive to exchanger confidentiality or safety.
- In any life-threatening situation, law enforcement and/or emergency personnel should be called. If law enforcement is called, any clients at the site should be immediately informed or warned in advance, if possible.
- Explaining these limits up front to clients is essential if difficulties are expected. The purpose for closing the exchange early and

involving law enforcement is to establish boundaries to conduct the exchange safely and effectively. We believe that the community of clients served will see value in the program and will work to keep the exchange safe for exchange volunteers, staff and community members.

- In the event of an early shut down, volunteers and staff shall quickly and efficiently secure all contaminated materials and sharps, to the extent possible, before moving the van.

g. Restrictions

- All persons using the services will remain anonymous except as they freely agree to giving identifying information for the purpose of providing that client with referrals.
- No exchange staff member or volunteer will lend money or accept gifts during their shift at the exchange.
- No exchange staff member or volunteer will threaten or harm any community member.
- Each exchange staff member or volunteer must be at least 18 years old.
- Pregnant women should refrain from working or volunteering for needle exchange in positions with direct contact with clients.

h. Mandatory Reporting

- Mandatory reporters are required to report any observations of child abuse or neglect to Bad River Abinoojyag Resource Center, law enforcement, and Ashland County within 24 hours.

- Bringing a child to a needle exchange event does not automatically constitute child abuse or neglect.
- Participating in the needle exchange when pregnant does not automatically constitute child abuse or neglect, however, observing an individual caring for a child or pregnant who is obviously high or intoxicated, or observing them ingesting, smoking or injecting drugs or alcohol in the presence of the child or while pregnant, does constitute child abuse and/or neglect and requires reporting by mandated reporters, as does any other observation of abuse or neglect of a child by a care provider.

i. Emergency Situations

- In the event that a client appears to be a danger to self or others or reports harming another, Van Staff should assess the situation and make referrals to mental health professionals or contact emergency services, including law enforcement.
- In the event that a client is experiencing medical distress (i.e. overdosing, bleeding in or around the van), the staff member trained in emergency protocols should assist the client, with the other staff member or volunteer contacting emergency services and/or the Site Coordinator.
- Blood spill kits should be used to contain any spills of bodily fluids within or around the van. The staff member trained in emergency protocols should take the lead in handling any spills, with all Van Staff members exercising caution and wearing gloves.

- Following each emergency situation, Van Staff should contact the Site Coordinator as soon as possible and fill out an incident report at the end of the shift.

j. Vehicle Policy

The vehicle policy of the Bad River Band applies to the operation of the needle exchange when Bad River vehicles are used.

IX. Research

- a. Research is important to analyze the impact and efficacy as an ongoing and essential part of performing services. We want to take every opportunity to better the project by determining the value of the services provided and what we can do to improve the work.
- b. At the minimum, we strive to monitor the following:
 - * Analysis of data gathered at exchange events for longitudinal evaluation of harm reduction behavior changes; and
 - * Analysis of demographic information regarding program use and users.
 - * With increased funding and/or support from other agencies, we shall perform the following:
 - * Testing syringes exchanged for HIV antibody and other indications of pathogens; and
 - * Data on hospital admissions, county-wide and state-wide rates of HIV and HCV infections, other public health data related to the project;

X. Confidentiality Policy

- a. Workers and volunteers shall agree to abide by confidentiality policies that protect clients' identities, health information, and general questions. Any data that is collected shall be free of information that identifies individuals and shall be kept secure at all times. Data collected on the Bad River Reservation is the intellectual property of the Bad River Band and may only be disclosed by resolution of the Bad River Tribal Council.
- b. Client data shall be maintained absolutely confidential. It shall not be shared outside of the program, except in emergency situations when disclosure is necessary to save a life or protect an individual from serious bodily harm (i.e. if you suspect that a client is overdosing and sharing this information with the 911 dispatch or EMTs is necessary to obtain emergency services). Staff should not discuss information related to one client, in front of others.
- c. Information about the program (budget, statistics, etc.) shall also be kept confidential. Site Coordinators shall be responsible for sharing information about the program to other agencies, coordinating media relations, etc.
- d. At no point shall any information about needle exchange clients be shared with law enforcement, except in limited emergency situations (see section b, above). Site Coordinators and/or volunteers may provide information to the Ashland County Sheriff

about the location, time and date of needle exchange events.

Bad River Health and Wellness Center Blood Borne Pathogen Exposure Policy

a. Purpose

The purpose is to maximize employee safety in the setting of providing medical and dental care to patients where exposure to body fluids is possible; and

Provide a consistent approach for evaluating and managing Bad River Health and Wellness Center employees who sustain a work related exposure to another individual's blood or body fluids.

b. Definitions

Blood Borne Pathogen is an infection which may be contracted through exposure to blood or other body secretions.

HBV: Hepatitis B Virus: This virus can survive up to 6 months outside the body, i.e. on a used needle. If stuck with a needle contaminated with hepatitis B, there could be up to a 30 % chance of transmission to non-immunized persons.

HCV: Hepatitis C Virus: There is up to a 4 % chance of getting hepatitis C from a needle stick if it is on the needle.

HIV: Human Immunodeficiency Virus: There is less than a 1 % chance of getting HIV infection from exposure to an infected individual's blood.

PEP: Post-exposure Prophylaxis: The antiviral medications that may be used to reduce the risk of contracting HIV infection from an exposure to blood or bodily fluids. Recommendations vary with risk, and there are side effects.

CDC: Center for Disease Control: Authoritative resource for recommendations regarding PEP and immunizations.

c. Scope of Policy

Scope of the policy Applies to all *Bad River Health and Wellness Center* employees, plus students, volunteers, or "good Samaritans" who may provide care for our patients.

d. Policy

Upon notification of a work-related blood or body fluid exposure, the supervisor of the employee is responsible for the immediate instruction of the employee to wash appropriately and to go directly to the ER for assessment.

- The ER provider is responsible for the initial lab draw, counseling, and initial hepatitis B and HIV prophylaxis if indicated. Post-exposure prophylaxis (PEP) needs to be within hours to be most effective.
- Follow up is supplied at the *Bad River Clinic*. The employee may choose to go to their personal provider.
- Within 15 days of the incident, the provider will supply test results and recommendations to *Bad River Health and Wellness Center*. The medical director will review the results and assure that follow up is appropriate.

- Positive tests for hepatitis B or C and HIV will be reported to the Health Department in accordance with state laws.
- The employee's medical information relating directly to the exposure will be kept in the medical records area in a secure file separate from personal medical records.

Procedure

1) Employees exposed to a blood-borne pathogen should immediately wash the affected area with soap and water.

If it is a mucous membrane exposure (eye, inside of mouth or nose) they should rinse repeatedly with water.

2) The exposed employee is to notify their supervisor immediately after washing. If the supervisor is unavailable, they may contact the medical director or clinic director.

3) The supervisor will provide them with instructions and forms, get the name of the source patient if known, and direct them to the Urgent /Emergency Room at Memorial Medical Center (hospital) in Ashland for immediate assessment.

4) The forms given to the employee include: "For Employees," "For Medical Providers," "Needle Stick/Body Fluid Exposure Incident Report Form," and "Bad River Band of Lake Superior Human Resource Department Employee Incident and Accident Report Form"

5) If the source patient is known, the supervisor will give the "For Interview of Source Patient by the Department Provid-

er" form to a provider in the department, or a provider in the medical department if unable to conduct the interview with the patient. The form should be completed, and labs drawn by the Bad River lab personnel as soon as possible. A rapid HIV test should be performed as soon as possible to help determine the advisability of PEP. When the test results are back, the provider who interviewed the patient and ordered the labs will call the patient and inform them of the results. A copy of the results will be put into the source patient's record and the employee health record, which is kept separately.

6) The emergency room provider will order the HBV (HBsAg & HBsAg antibody), HCV (HCV antibody), and HIV (HIV antibody) tests; counsel the employee regarding their risks; and administer HBIG, hepatitis B Vaccine and/or the first dose of PEP (HIV chemoprophylaxis) where indicated. Consultation with the PEpline is strongly encouraged in decision making.

7) Follow-up care will be at Bad River Clinic or the employee's provider of choice. Follow-up may include hepatitis B vaccination completion if needed, completion of PEP if needed, and/or decision to terminate PEP, repeat HIV screening at six weeks, three months, and six months, and hepatitis C re-screening at three and six months.

8) An employee medical file separate from any personal medical file and separate from their personnel file will be established and kept in medical records in a secure designated area.

e. **Associated Procedures:** none given

f. References

CDC Center for Disease Control:

www.cdc.gov

National **HIV/AIDS** Clinicians Consultation Center: www.nccc.ucsf.edu

Most SSPs purchase supplies from:

NASEN, North American Syringe Exchange Network: www.nasen.org or

POD, Points of Distribution buying clubs: www.facebook.com/pointsofdistribution

For information on **OSNN Buyer's Club**

contact Maya Doe- Simkins (mdoesimkins@gmail.com) or Eliza Wheeler (ejwharmreduction@gmail.com)

Health departments/clinics/health-care centers may receive free injectable naloxone through **Direct Relief**: www.directrelief.org.

NEXT Distro will mail naloxone to underserved or underfunded groups: www.nextdistro.org

PEPline, Postexposure Prevention: Warmline 888-448-4911

1. CDC, *Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 U.S. dependent areas*. HIV Surveillance Supplemental Report 18(No. 5). (October 2013). http://www.cdc.gov/hiv/pdf/2011_monitoring_hiv_indicators_hssr_final.pdf.

2. CDC, *10 Leading Causes of Death by Age Group*, National Vital Statistics System, National Center for Health Statistics, (2010), http://www.cdc.gov/injury/wisqars/pdf/10lcid_all_deaths_by_age_group_2010-a.Pdf.

3. CDC. *HIV Incidence*, Statistics Center, (May 22, 2013), <http://www.cdc.gov/hiv/statistics/surveillance/incidence/>.

4. Diane Logan, G. Alan Marlatt, Harm reduction therapy: a practice-friendly review of research, *Clinical Psychology*, 66(2): 201-14. (Feb. 2010).

5. PG. Farnham, et al., [Medical costs averted by HIV prevention efforts in the United States, 1991-2006](#). *J Acquir Immune Defic Syndr*. 54(5):565-7. (August 2010).

6. Kathleen Doheny, The High Cost of Hepatitis C Drugs, *WEB MD*, (April 14, 2014), <http://www.webmd.com/hepatitis/news/20131126/new-hepatitis-c-drugs?page=2>.

7. David Vlahov et al., [Needle Exchange Programs for the Prevention of Human Immunodeficiency Virus Infection](#). *Epidemiology and Policy*. 154 *Am. J. Epidemiology* S70, S71 (2001).

8 Larry Gostin, [The Interconnected Epidemics of Drug Dependency and AIDs](#), 26 *Harv. C.R.-C.L. L. Rev.* 113, 115-116 (1991).

9 *Id.* This process is referred to as “skin popping.”

10 HIV positive is the medical term connoting the presence of human immunodeficiency in the body. Stine, *supra* note 1, at 441.

11 *Id.* at 441.

12 *Id.* at 441. This process is referred to as “booting.”

13 *Id.* at 441.

14 Gerald J. Stine, [Acquired Immune Deficiency Syndrome: Biological, Medical, Social, and Legal Issues](#) xxiv, 1 (1993). This process is referred to as sharing the “works.” *Id.* at 182. The “works” is the syringe and needle used to inject the drugs.

15 Gostin, *supra* note 2, at 116.

16 AIDs Resource Center for WI. *Harm Reduction and Needle Exchange*, (2014).

17 *Id.*

18 *Id.*

19 CDC, *Viral Hepatitis Statistics & Surveillance*, Division of Viral Hepatitis and National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, (August 19, 2013), www.cdc.gov/hepatitis/statistics/2011surveillance/table4.1.htm

20 AIDs Resource Center for WI. *Harm Reduction and Needle Exchange*, (2014).

J. Pagane, et al., [New York City Police Officers Incidence of Transcutaneous Exposures](#), *Occupational Medicine* 46(4):285, 285 (October, 1996).

21 Steven, Lawitts. [Needle Sightings and On-the-Job Needle-Stick Injuries Among New York City Department of Sanitation Workers](#). Vol. 42, No. 6, Suppl. 2, *J Am Pharm Assoc.* S92, S92 (November/December 2002).

22 Dorothy, Moore. [Needle Stick Injuries in the Community](#). *Paediatr Child Health*. 13(3): 205–210. (Mar 2008).



APPENDIX TO PART III

Consent to Participate in a Research Study Interview Guide and References

Consent to Participate in a Research Study

You are being asked to be in a research study of harm reduction services. You were selected as a possible participant because you have experience with injecting drugs. We ask that you read this form and ask any questions that you may have before agreeing to participate.

Purpose of Study

The purpose of the study is to understand participants' experiences with formal and informal supports, willingness to use services in clinic settings, barriers to services, and service needs. The study will inform programming to address identified needs and preferences and was designed to increase access to respectful and appropriate healthcare for people who inject drugs. Ultimately, results will be presented to local stakeholders and may also be published.

Description of the Study Procedures

If you agree to be in this study, you will be asked to do the following things: participate in a 90-minute interview.

Risks/Discomforts of Being in this Study

The study has the following risks. First, we will be discussing your experiences with injecting drugs which carries a legal risk. However, a confidentiality breach is not likely given that your name or any other identifying information is not being recorded, and the research team is also trained in handling confidential information.

Benefits of Being in the Study

There may not be a direct benefit to the participant, but the study aims to inform programming so that local services can be adequate and tailored to local needs. You

will receive information about safe use and local services if you are interested.

Confidentiality

The records of this study will be kept strictly confidential. Research records will be kept in a locked file, and all electronic information will be coded and secured using a password protected file. Audio recordings will only be accessible to the research team and are only for the purposes of helping in understanding the information collected. We will not include any information in any report we may publish that would make it possible to identify you.

Payments

You will receive the following payment/reimbursement: A \$75 Visa gift card given to you at the end of your interview.

Right to Refuse or Withdraw

The decision to participate in this study is entirely up to you. You may refuse to take part in the study at any time without affecting your relationship with the investigators of this study or Northland College, or the services you receive. Your decision will not result in any loss or benefits to which you are otherwise entitled.

You have the right not to answer any single question, as well as to withdraw completely from the interview at any point during the process; additionally, you have the right to request that the interviewer not use any of your interview material.

Right to Ask Questions and Report Concerns

You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have any further questions about the study, at any time feel free to contact me, **Ana Tocherman at atocherman@northland.edu** or by telephone at **715-682-1282**.

If you have any other concerns about your rights as a research participant that have not been answered by the investigators, you may contact the **Northland College Institutional Review Board** at **irb@northland.edu** or **(715) 682-1536**.

If you have any problems or concerns that occur as a result of your participation, you can report them to the **Institutional Review Board** at the number above.

Consent

Your verbal consent will indicate that you have decided to participate in this study, and that you have read and understood the information provided above. You will be given a copy of this form to keep.

Interview Guide

Part I: Use of Harm Reduction Services

Do you currently use services through the needle exchange program?

Perspective on Needle Exchange Program

- What made you seek out the needle exchange program?
- What parts of the program do you like?
 - * Access to drop in services
 - * Sterile equipment access
 - * Moral support
 - * Positive interaction with staff
 - * Information
 - * Sense of connection
 - * Counseling
- What parts could be improved?

Part II: Personal History

We have some questions about your personal history which will help us better understand what services could be provided:

- When did you start using substances?
(Why did you start?)
- When did you start injecting drugs?
(Why did you start?)
- What substances do you currently use?
- How often did you use _____ in the last three months?
- How often did you use _____ in the last year?
- Where did you learn how to inject?
Where did you get information about that?
- How often do you inject?
- What time of day do you use?
- Can you walk me through how you prepare a shot?
- Do you ever need help injecting?
If so, why?

- Do you re-use your needles? (Ask how often and what is the most you have re-used.)
- Have you ever injected using equipment (syringe/water/needle/cookers/more) that has been used by someone else? Did you clean it, and how? Why did you clean it?
- Have you ever shared a needle?
- How do you dispose of your needles? Sharps container? Garbage? Save them in your house?
- Do you ever substitute one drug for another?
- Have you ever overdosed?
When and who helped?
- Have you ever witnessed an overdose?
How often and what happened?
- Have you heard about naloxone?
 - * Do you carry it?
 - * Have you ever used it?
 - * Are you interested in carrying naloxone?
- Do you have any concerns about drug potency?
- Would you like some information about safer injections?

Part III: Use of Services

Please consider all services you received in the last year, including medical, pharmacy, dental services, substance use/recovery treatment programs, counseling, group therapy, recovery coaches, etc. in programs like Bad River Health and Wellness Center, Northlakes, MMC, Crossroads, etc.

• What providers have you visited in the last year (program names)?

- * Type(s) of service received?
- * What do you like about it?
- * What don't you like about it?
- * Are staff supportive?
- * Do you feel like you have a say in the treatment you are receiving?
- * Are you given information about treatment choices?
- * Did your providers follow up with you?
- Have you ever sought traditional or culturally significant practices to support you in recovery? What do you like about it? What don't you like about it?
- Have you gone to sweat lodges or participated in any ceremonies that have been helpful?
- Have you discussed your substance use with elders or other community members? What was that like?
- Can you describe your experiences with recovery programs? (How often have you completed programs and relapsed? Did you go back? What made you seek the services in the first place?)
- Have you ever used the ER or have you been hospitalized? (How often? What helped? What was hard?)
- Are you receiving treatment for any specific health conditions? (Ask: HIV, Hep C, diabetes, abscesses? Have you been tested? Want to be tested? Received treatment?).
- Some clinics in town now have recovery coaches. Have you had any interactions with them?

Part IV: Barriers to Services

People don't use healthcare programs for a number of reasons. Can you tell us what keeps you from using some healthcare programs?

- Information about what's available
- Wait lists
- Clinic environment
- Attitudes of staff / providers
- Distance
- Health insurance / cost
- Fear of law enforcement (Ask: can you tell me more about that? Previous experiences?)
- Treatment hasn't worked in the past
- I can manage my use
- Family / friends wouldn't be supportive
- Fear that my admission could be used to take my kids away

Have you ever delayed treatment because of using substances?

Have you ever been refused treatment?

Are there types of services you would like that are not available?

Part V: Supports

We would like to learn more about what supports you may have.

Networks—See sample table on next page.

Housing

- How long have you been in your current home?
- Can you describe your current arrangement? (Who is on the lease? Who makes

Who is an important person in your life?	How long have you known this person?	How would you describe the relationship you have with this person?	Could you count on this person to help you? Can you talk to them about your use?

payments? Do you anticipate any problems making your housing payment?)

- Do you feel safe there?
- Did you ever stay overnight in a place not designed for sleeping? (When? Where?)
- Have you ever doubled up / stayed in someone else’s home or apartment (When? Where?)

Transportation

- Do you have access to transportation? How do you get around? (type, reliability)

Employment / Economic Stability

- What do you do to earn money?
- Does your substance use create any challenges in the work that you do?
- Do you feel like you’re able to make enough money to get by?

Part VI: Hypotheticals

We want to ask you a few questions about services that could be useful. We’re not promising that these options will be available in the immediate future, but your responses will be helpful in determining what types of services people could benefit from.

- Would you be willing to go to a clinic to do a safe needle exchange?
- Would you be willing to visit a mobile van to do the safe needle exchange?
- Would you be willing to do this with friends?
- Would you be willing to do a safe needle exchange with peers (by peers we mean peer specialists; they are people with lived experience who you may or may not know)?
- If given the choice to do a needle exchange at a clinic, at a mobile site, with friends, or peers, what would you prefer?
- What would be your preferred locations? (Ask: mobile site, building, at home?)

- Is there someone in your community who could facilitate this?
- Do you think your friends, or other people you know, would use a facility like this?
- Would you ever be willing to participate in a peer-based training, such as overdose-prevention training?

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Part VII: Demographics

- What is your age?
- What gender do you identify with?
- What is your sexual orientation?
- Are you a member of a local tribe?
- Do you have health insurance?
- Please specify

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APPENDIX TO PART IV

Data Collection Sheet Instructions for Kits

Monthly Data Sheet on Materials Delivered to Program Participants

This is our basic data collection sheet, filled out on a monthly basis by volunteers to document the number of supplies provided to community members. This data helps us gauge how effective our program is reaching various demographic groups and to evaluate general trends related to syringe services.

Instructions for Putting Together Materials for Deliveries

1. Ask what gauge needle they prefer.

We carry 27, 28 and 29 gauge (longs) and 31 gauge (shorts). Lower number gauge needles have a wider circumference, which is preferable for sticky or chunky materials. The 31 gauge needles are better for smaller veins (hands and feet, or sometimes women prefer them). If you aren't able to ask or the



client is unsure, you could bring a variety and let them choose when you see them, or just take 29s.

2. We generally provide clients with the following amounts of materials.

You can ask whether they need more or less of certain supplies, but if not, give them (as supplies are available):

- 1 box of 100 syringes (see note to the left about the size)
- Box of alcohol/BZK swipes
- 3 ointments
- Handful of sterile water ampules
- 3-5 tourniquets

Data Collection Sheet

Site/Office: Gwayakobimaadziwin																																
Staff	Day	PWID#	Gndr	Ethn	Age	Zip	Dir. Exch.			# Syringes				# Distributed / Given			Referral?															
							New	Repl	Exc	M	F	InjPk	Broch	Biz	Cndms	M20		N														
1							N	R																								
2							N	R																								
3							N	R																								
4							N	R																								
5							N	R																								
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Sheet totals:																																

*InjPk means tourniquet, tins, alcohol, cottons

- 10 cookers
- 1 bags of small cottons or cellulose filters
- 10 condoms and lube
- At least one pamphlet/contact card
- Sharps container, with top securely fastened, or detergent bottle, with securely closing top
- 1 naloxone kit, including instructions
- 4-5 fentanyl test strips

3. If clients have detailed questions about safety

Direct them to the link for the *Harm Reduction Coalition Safer Injection Manual*, or other website links on the topic they're interested in (e.g. websites on overamping or overdosing on stimulants, graphics on wound care, etc.).