



PEOPLE LIVING WITH HIV IN NORTH DAKOTA

KEY INFORMANT INTERVIEW REPORT

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Introduction to the Needs Assessment

The North Dakota Department of Health (NDDoH) Health Equity Office (HEO) works to understand and reduce health disparities among all North Dakotans. The primary goal is to reduce rates of disease by providing opportunities for interventions and improving access to health care. This will ensure all North Dakotans receive the highest quality of health (NDDoH, 2020).

The Health Resources and Services Administration's (HRSA) Ryan White HIV/AIDS Program provides a comprehensive system of HIV primary medical care, essential support services, and medications for low-income people with HIV. The program funds grants to states, cities, counties, and local community-based organizations to provide care and treatment services to people with HIV to improve health outcomes and reduce HIV transmission among hard-to-reach populations (HRSA, 2021).

Purpose of the Needs Assessment

The purpose of this study is to understand core and support services accessed among People Living with HIV in North Dakota, barriers to existing services, and areas of improvement. It is also intended to get an understanding of beliefs, stigma, and knowledge around HIV. And finally, to learn how to improve the experience for people living with HIV as well as improve services for people in the future who may find themselves in similar circumstances.

STATEMENT OF THE PROBLEM

People living with HIV in North Dakota face unique challenges living in rural communities. There are barriers to HIV prevention and diagnosis, access to HIV care and support. Additionally, HIV stigma and education are key areas to focus on with a large rural population. Overcoming these challenges can significantly improve the outcome for people living with HIV as well as make it easier for others in the future.

Research Questions

1. Could you think back to the time when you were first diagnosed, could you describe what was happening in your life and how you came to be diagnosed?
2. When you were diagnosed, how did you feel when it came time to inform any people that may have been exposed? How was your experience telling your family or peers about your diagnosis? What if anything, do you feel could have been helpful in making that experience better?
3. How did you come into HIV care, did you experience any barriers to entering care, and/or how long after your diagnosis did you start treatment? What would you say were the circumstances around what led to your decision about how to move forward with your care?
4. Thinking about the care you receive now; do you think that you and your doctor are a good fit? What would you say could be improved in the relationship between you and your doctor? Are there things you think they need to learn about how to better care for you? How about your case manager if you are in Ryan White? Can you describe that experience? If not enrolled in RW, why not?
5. Thinking back to the past, what advice would you give to someone who may be at risk for infection? Is there something that you wish you would have known about HIV, HIV prevention, and HIV testing? Is there a service that you think may have helped you in your journey before you were infected that could have helped you to stay negative?
6. Do you have any suggestions on things community-based organizations and local health departments can implement to reduce HIV-related stigma to enhance the utilization of prevention and care services? What kind of information would you or your family/community find helpful to provide HIV information and address stigma?
7. Anything else you want to discuss or talk about?

Participants were also asked about their experience in specific categories such as HIV Care & Support, HIV Prevention & Diagnosis, and HIV Stigma & Education. There was an

opportunity to share barriers they may have experienced and how to improve those for others. Participants were also asked for suggestions and solutions they might have based on their experience.

Table 1: Specific Categories that survey participants were asked their suggestions on

Participants were asked for suggestions and solutions they might have based on their experience
1. Relationship with your HIV Provider
2. HIV medications (taking on time, side-effects, paying for meds)
3. Relationship with your RW case manager
4. Health coverage
5. Dental care
6. Vision care
7. Mental health
8. Substance abuse services
9. Housing
10. Transportation
11. HIV support groups (do you attend? your ideal support group?)
12. Do you experience any food insecurity?
13. HIV Prevention and Diagnosis
14. HIV prevention education
15. Relationship with your HIV Provider
16. HIV medications (taking on time, side-effects, paying for meds)
17. Relationship with your RW case manager
18. Health coverage
19. Dental care
20. Vision care

21. Mental health
22. Substance abuse services
23. Housing
24. Transportation
25. HIV support groups (do you attend? your ideal support group?)
26. Do you experience any food insecurity?
27. HIV Prevention and Diagnosis
28. HIV prevention education

Delimitations

1. Only persons who are HIV-positive living in North Dakota were included in the study.
2. Data was collected with questionnaires, and key informant interviews.
3. Data was limited to what participants self-reported in the questionnaires, and key informant interviews in a 7-week time frame.
4. The participants in the study were limited to people who indicated in earlier surveys an interest to participate in further studies.
5. The information was provided anonymously.

Limitations

1. Information collected is limited to what participants were willing to share in key informant interviews.
2. All data collected was voluntary.
3. Information was limited to the number of people who responded from an available pool of participants who indicated an interest in helping with further studies after completing an earlier survey.
4. Participation was limited based on people's willingness to disclose personal experiences.

Methodology

A list of questions for the key informant interviews was formulated with the help of the Ryan White Program Coordinator, Health Equity Office, similar previous questionnaires, and suggestions from an earlier survey. A list of potential participants was compiled based on people who indicated in the needs assessment survey that they were willing to provide additional feedback. They were contacted via email or telephone. Participants received a \$25 Wal-Mart gift card for their time. They could choose between receiving an electronic gift card or a regular card that was mailed to them.

Prior to beginning the interview, the interviewer read the informed consent statement. The consent described the risks and benefits of the interview as well as information to find further assistance after the interview. Confidentiality, note-taking, anonymity of the interview, and that the interview was not recorded were also discussed at this time. Once this was agreed upon the interview began.

Interviews lasted anywhere from 32 minutes to 1 hour and 17 minutes. On average, interviews lasted 55 minutes. A follow-up email or text was sent thanking participants, giving them information for further questions and care, as well as how their gift card would be sent to them. When all interviews were completed, they were reviewed to find common themes and impactful statements. The process was completed over a 7-week period and limited to those who were willing to respond and the information they were willing to provide.

Figure 1: Participants by Ryan White Program Enrollment

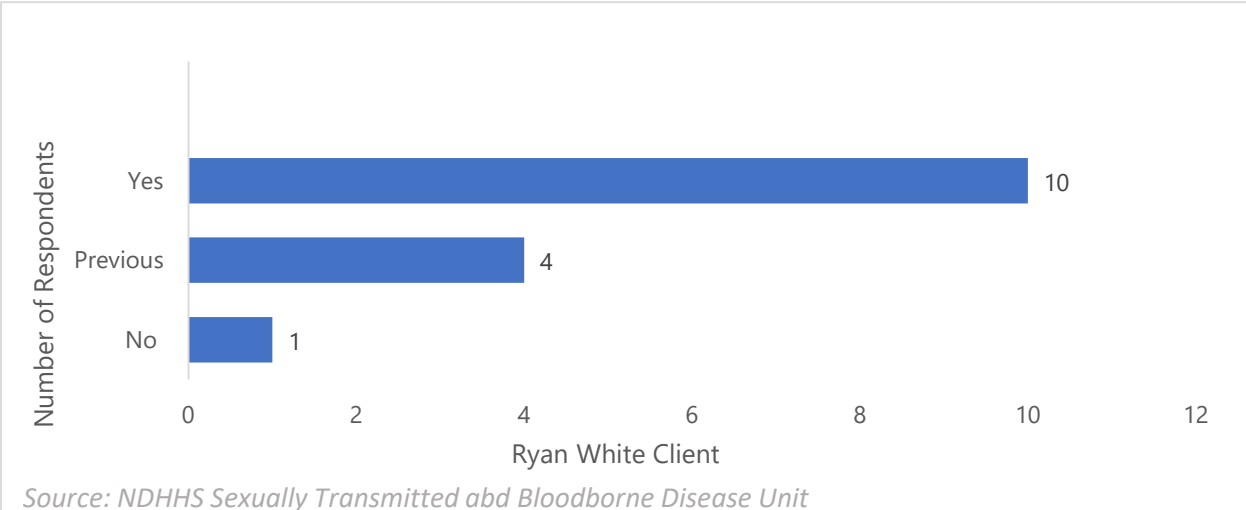


Figure 2: Participants by Age

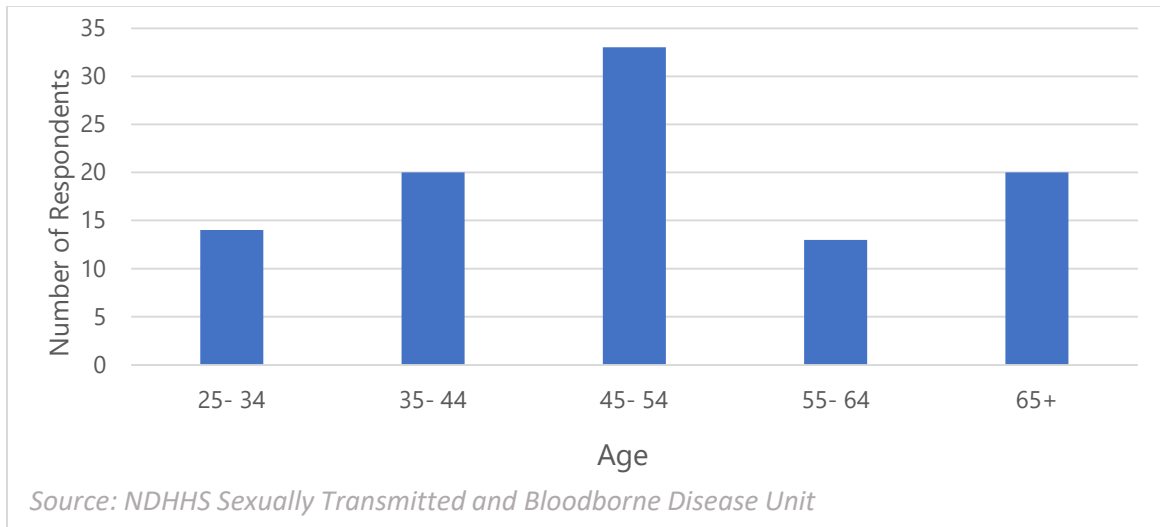


Figure 3: Participants by Gender

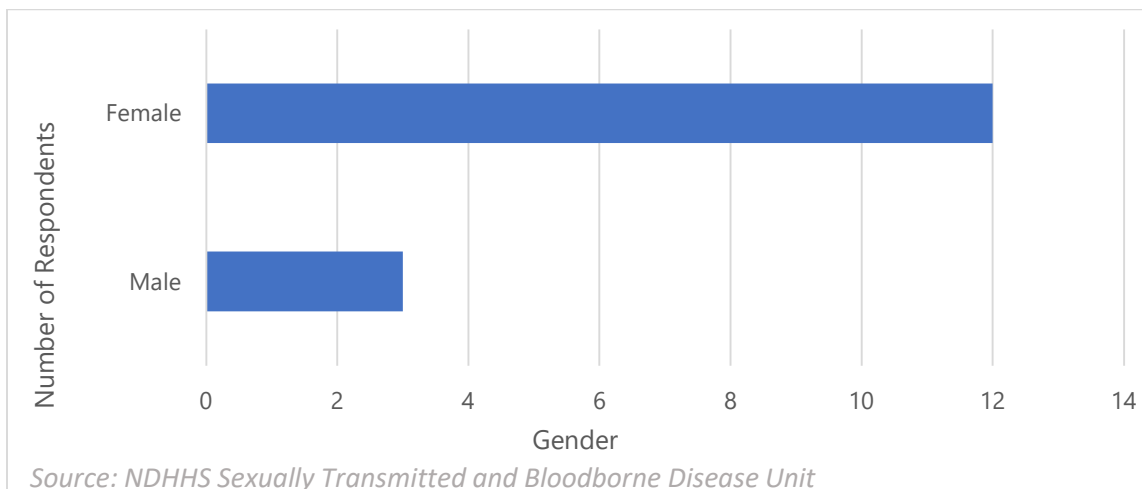
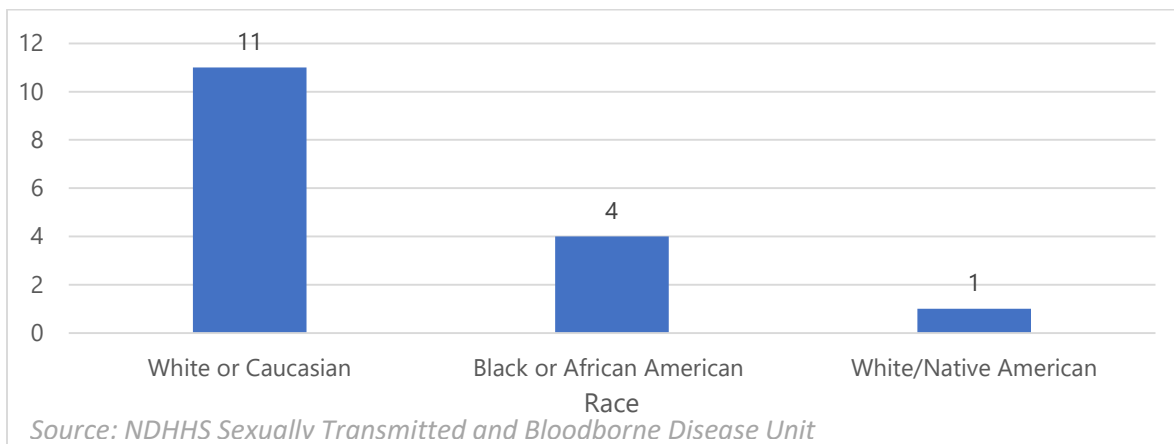


Figure 4: Participants by Race



Out of a total of 39 possible participants, 15 interviews were conducted for a response rate of 38 percent. Participants included 12 males (80%) and three females (20%) ranging in age from 28 to 67 from various areas in North Dakota. Ten were current Ryan White clients along with four previous clients and 1 person that never received Ryan White services. Eleven (73%) of participants were White, four (27%) were Black or African American, and one (7%) was Native American.

Themes

The key informant interviews were broken down into three categories with several themes emerging in each category. These categories were HIV Prevention and Diagnosis, HIV Care and Support, and HIV Stigma and Education. Themes were identified from analysis of all interviews. Each of them includes quotes from key informant interviews.

Category 1: HIV Prevention and Diagnosis

THEME 1: HIV PREVENTION & EDUCATION

This area provided insight about what people have experienced as well as suggestions for improvement. The main theme was that people felt that HIV could not happen to them. There were multiple participants who noted knowing others who had previously died from HIV/AIDS but thought it was a big city problem. Many felt that it could not happen in North Dakota and other rural areas. They also noted that there was a lot of misinformation at the time and still is today. Many suggested starting HIV education in high school and earlier. Many felt that condoms are a solution in addition to more education. They also felt that more outreach needs to be done in rural communities and among people who are at risk. One respondent noted that celibacy was the only option.

"People don't know what undetectable means."

"No one is immune to HIV."

"People should never assume that HIV cannot affect them or their family, a conception that most people have."

THEME 2: HIV TESTING & COUNSELING

Most people noted positive experiences in their initial HIV testing and counseling. One participant noted waiting close to a month to see the infectious disease provider after their diagnosis. Some felt that testing and outreach needed to start earlier and to reach high schools. Some were immediately directed into care. One felt that doctors needed to suggest HIV testing rather than a patient requesting it.

THEME 3: HIV PREP/PEP

Many people reported not knowing what either of these things are or confusion as to what they do. This could be due to them having HIV for many years and not knowing about current HIV prevention means. Most felt that there needed to be more education about PrEP/PEP. Those that knew about PrEP/PEP recommended it to others and felt it needed to be available in rural areas as well. There was also concern about the cost. One person noted that they take BIKTARVY when discussing PrEP/PEP, so there is confusion as to what it even is.

"More rural access."

THEME 4: HIV DIAGNOSIS

Participants discussed knowing others who had HIV prior to getting diagnosed but they did not think it could happen to them. There were two participants who stated they felt they do not have HIV. Many stated they felt devastated to find out they had HIV and like their world was falling apart at the time of diagnosis. Most felt that more counseling needed to be available at the time of diagnosis as this is a time of shock. Most noted this was a scary time for them. Some noted that protecting yourself is essential.

"In other states, case management was available immediately on how he needs to access services at that initial appointment."

"Was devastating. Wasn't expecting a positive diagnosis. Couldn't keep it together and went home."

THEME 5: PARTNER SERVICES & FAMILY/PEER DISCUSSIONS

Most people reported not telling family members or waiting for a significant amount of time to inform family members. Some noted telling partners but not family. This appeared

to be an area where improvements could be made. Others noted that they told partners and friends and were in peer groups where friends were also HIV positive. Most noted this is a scary discussion to have. Some suggested resources on how to talk to others about your status.

"I didn't tell anyone for 2 years."

THEME 6: FIRST ENTRY INTO HIV CARE & TREATMENT

People also noted that finding care in larger cities was easier for them. Some refused to seek care while others went into care immediately. Those who were diagnosed more recently knew that HIV is no longer terminal but a chronic manageable disease. Some noted that they could not accept having to take medications for the rest of their life. Those who were diagnosed in the early days of HIV and AIDS noted the numerous drugs they have tried and the side effects and even having to smuggle better drugs in from Mexico.

"Refuse to start medication, not until after two (2) months! Just couldn't accept that I would be on medication for the rest of my life."

"First experience going into a clinic, it was with the State. Was such a shock and the nurse that was working with me, asked my count and it was 230, I had no idea what that meant. Asked the nurse, and she replied, "that's not good" This lived with me for so long. Blew me away that she would say that. I felt terrified and helpless."

Category 2: HIV Care & Support

THEME 1: RELATIONSHIP WITH HIV PROVIDER

Most participants had positive things to say about their HIV care provider. Most noted that they were a good fit. Some felt that their relationship could be improved by providing more than numbers and getting to know them as people as well as patients. Those who had experience in larger cities outside North Dakota noted that it was easier to find care and more specialized care in larger cities. Some felt places were understaffed and could be better funded. Few participants noted that they would like their primary provider to manage their HIV care. Few noted a really positive relationship with their Ryan White case manager and liked the help and services they receive. They felt in-person meetings were important.

"I have directed my care through the years."

"The more you hide, the less you get help with."

THEME 2: HIV MEDICATIONS

Most people reported having no issues with their current medications and that they take them as directed. Many thought it would be helpful to have an injection or fewer pills to take. Many noted the cost of medications was too high and sometimes not available at their pharmacy in a timely manner. A few noted side effects as being an issue. Others noted that a 60 or 90-day supply of medications should be made available to reduce stigma in rural communities. One noted that it would be helpful if their primary care physician was able to treat and care for HIV patients in a rural area where an infectious disease provider was not available. Some noted that they would like the pharmacy to call them to remind them when their refill is due.

"Insurance won't sign off on a 3-month supply of HIV drugs. This would help with stigma in small communities."

THEME 3: HEALTH COVERAGE, DENTAL, VISION, AND MENTAL HEALTH SERVICES

The biggest issue in health coverage was that participants were confused as to what is available and what is not available through the Ryan White Program. There was a lot of varying information given as to what people thought could be covered.

Dental care seemed to be the biggest obstacle for most people as well as one of the most important for people living with HIV. Vision care ranked second in need followed by mental health services. Most people had health coverage either through the Ryan White Program or through an employer.

The cost was a big factor for people as well as knowing what procedures were covered. Some suggestions were a National Health Care System, following other states who covered vision and dental care, as well as more funding for these dental and vision services. People also noted better care in larger cities. Some noted mental health services targeted for persons living with HIV to address trauma from diagnosis and living with HIV.

"Giving people a roof over their heads doesn't solve the problem. Do more follow-ups and make sure clients are improving in their mental health."

"Would be nice if someone advertised a specialty in HIV-related therapy."

THEME 4: TRANSPORTATION

There was also a lot of confusion as to what is available for transportation services and how to access them. Some utilized transportation services while others did not know they were available. Some noted that they were able to use it to get to appointments and that it was very helpful. Others noted that what works for some may not work for others such as issuing gas cards if a person doesn't have a vehicle.

"Ryan White gas vouchers would be helpful. Was using gas vouchers from the catholic church and Lutheran Social Service."

"Instead of a gas card, provide Amtrak [train] tickets to see an infectious disease specialist in Minot."

THEME 5: HIV SUPPORT GROUPS

Most respondents said that they did not utilize support groups. Many noted that they relied on their friends and peers for support. People felt that support groups are necessary but what has been done in the past is no longer working. Many people noted that once per month meeting is not enough. Other issues included the low number of attendees, time of the day support groups were held (most were held during the day) that did not work with their schedule and stigma around attending a support group. Some noted that they needed support groups but were not sure where to find them. Many noted that they had gone in the past but no longer attend. One person noted that they would like close family members to be able allowed to attend support groups.

"Maybe something online, maybe people will feel more open than seeing in person."

"I was told those aren't the kind of people you want to be involved with."

"I don't feel like I need support now but feel I could help others."

Category 3: HIV Stigma & Education

THEME 1: STIGMA IN THE COMMUNITY

This area was one of the most widely commented on. Most people felt stigma living with HIV in North Dakota. Most noted that they do not disclose their status due to stigma. Some people felt that those closest to them were supportive, but they would not disclose at work for fear of losing their jobs. One noted having to find a place to work where other people from their African community did not know them so that they

would not discuss their status. One person even noted having to go back in the closet due to stigma. There is a stigma in the rural communities and even in the gay community. People felt that there needs to be more education to reduce stigma and more people need to speak out about HIV at a larger level nationally. One person noted that they had experienced stigma and harassment on the same day that we spoke.

"I think North Dakota is still not a safe place to live with HIV."

"Worried about my kids if people know parents are living with HIV."

THEME 2: FAMILY AND PEER SUPPORT

Many people again noted here that their families do not know their status. Some had no issues, and some noted that their peers were aware but not their families. Also, some noted ease in telling peers over family. Peers tend to be more understanding and empathetic. Some noted that it took years to tell their families and that it was difficult. Suggestions were made to have more resources available on how to tell people about status, and that sometimes people get lost in the process. There was a suggestion for more groups, online support groups, and safe places to meet. One person recommended childcare to be available during these meetings.

"Family support is few and far between."

"I don't know any peers since we don't meet anymore."

THEME 3: HIV KNOWLEDGE NEEDS

This was another area that received a high response rate. Most people felt that there needed to be more HIV education and awareness. Multiple people noted that public health and public awareness were keys to spreading information. There were also suggestions for updated materials. Some felt that they have been self-guided through the process and had to find their own information. The need for education for youth was noted here. Some noted seeing TV advertisements about HIV treatment but none on HIV prevention or general sexual health information. There were also multiple suggestions for having information available on dating sites for people to access. Information in the form of sexual health, PrEP, and testing videos on the dating apps was listed as needed. Some felt that more testing sites would help with knowledge and testing. Most noted that this needs to be done in all areas of the country and not just in larger cities. Few noted that information about U=U needs to be more widely shared.

"Tell people before they need the information."

Conclusion

Key informant interviews have provided useful information from people living with HIV in North Dakota. The themes and categories that have emerged from these interviews will help the Ryan White Program and the North Dakota Department of Health better work with people living with HIV in North Dakota. Suggestions from participants will also help those who may come into care in the future as well as help educate and inform public and private health care and community needs.

References

Health Resources & Services Administration (2021) About the Ryan White AIDS Program. Retrieved from <https://hab.hrsa.gov/about-ryan-white-hivaids-program/about-ryan-white-hivaids-program>

North Dakota Department of Health (2020) Mission Statement. Retrieved from <https://www.health.nd.gov/health-equity-committees>