

Title V Maternal Health Needs Assessment

A Research Study by the North Dakota Center for
Persons with Disabilities (NPCPD) Conducted On
Behalf Of The North Dakota Department of Health

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Conduct of Study

The North Dakota Center for Persons with Disabilities (NDCPD), a University Center of Excellence at Minot State University was contracted by the North Dakota Department of Health to conduct a statewide needs assessment study August 1, 2009 to November 30, 2009. The study assessed general behaviors of teenagers, ages 14-17, and young adults, ages 18-24, as well as needs relating to children with special health care issues and their families.

Purpose of study

The purpose of the study was to solicit information on the general behaviors of teenagers (14-17), and young adults (18-24) and also the needs of children with special health care issues and their families. A series of focus group sessions were conducted statewide by project staff, during October and November, 2009. The study was conducted to assess general behaviors of youth and young adults, identify patterns and themes and get suggestions from parents of children with special health care needs to improve existing services or create new ones. The three population groups identified were:

- youth ages 14-17;
- young adults ages 18-24; and
- parents of children with special health care needs.

The data gathered was compiled in a report to the North Dakota Department of Health and will be used for their Title V Maternal Health Needs Assessment Report.

Research Method

The research study used the focus group method to identify behaviors, needs and obtain suggestions from the target groups. This report describes the focus groups that were conducted in October and November, 2009, the process and the findings. Prior to conducting the focus groups, representatives of the North Dakota Department of Health, Family Voices and project staff met to provide input, make recommendations and reach decisions about the target populations, number of focus groups, locations and questionnaires to be conducted. The research project was reviewed and approved by the Minot State University Institutional Review Board, (see Appendix A) in order to comply with the procedures for the protection of human research subjects.

The focus groups were conducted in rural and urban areas of North Dakota. Project staff coordinated with various entities to organize the focus group location and times (see Appendix B). The focus groups were held in locations (see Appendix C) where meeting rooms were provided at no cost. Locations included public libraries, rooms at high schools, universities and community centers. Each participant received a stipend of \$30.00 for their participation. These stipends helped to reimburse individuals for their time and travel. The population groups included youth, ages 14-17, young adults, ages 18-24, and parents of children with special health needs. Parent consent forms (see Appendix D) were mailed and signed by the parents/guardians of the underage youth prior to conducting the focus group session.

Prior to the beginning of each focus group, the project staff introduced themselves to the participants of each focus group. They also provided a short description of the project, the reason for conducting the focus groups, explained how the results will be used and invited questions. Participants were also given the questions in written form (see Appendices E, F, G)

before the discussions started and were asked to write their response if they felt uncomfortable discussing it with the group. At each focus group, project staff informed the participants that participation was voluntary and that they could withdraw at any time. Project staff also explained the importance of confidentiality.

The focus group participants were recruited through a variety of means including: phone calls to family organizations; e-mails and letters to high school and university counselors; e-mails to consumer groups; letters and e-mails to Head Start Centers; public announcements via the NDCPD website; and announcements at project meetings throughout the state.

Data Collection and Analysis

A total of nine (9) focus groups were conducted (see Appendix C) across the state. The areas selected were grouped according to state regions to attract a more diverse population. Data collection instruments at each focus group included project staff notes and written participant's comments. All focus group comments were transcribed into text documents, omitting participant names. Data was analyzed to identify common themes, suggestions and trends evident throughout the state of North Dakota.

Focus Group Results

The following results were compiled using the information from the three questionnaires provided as well as comments from the Q&A sessions.

Parents of Children with Special Needs

Parents welcomed the opportunity to provide feedback on the services available in the state and the needs of their children and their family. They expressed hope that their comments will lead to provision of services that will eliminate some of the problems they are facing in taking care of the health needs of their children. Three locations were selected to conduct focus groups: Minot, Devil's Lake and Fort Totten. A total of six (6) parents participated in Minot, one parent in Devil's Lake and no participants in Fort Totten. Following are the compiled comments parents provided to the project staff.

1. Are you satisfied with the quality of primary care, obtaining referrals & appointments for needed services and coordination among both primary and specialty care?

Parents expressed the need for medical home, for the primary doctors to work together so when the child is referred to another doctor the parent will not have to go over the entire medical history of the child. Parents stated that there is no coordination of services and that they end up being the specialists and coordinators. Case workers need training in what to do to qualify children for the DD waiver. There is a great need for pediatric specialists in the state. Pediatricians need training in developmental disabilities and knowledge of services available in the state for children with special health care needs.

2. Does your child have a Care plan?

The majority of the parents replied their child did not have a care plan and identified the need to educate parents and medical doctors on what a care plan is and how to access it. They indicated that training in this area for all involved participants would be beneficial.

3. Do you understand the steps to the formal grievance or appeal when you are not satisfied with your child/family services?

Parents were unaware of the steps to a formal grievance or appeal. They need information on how to proceed when they are not satisfied with the provision of services. They feel that they have to do their own research if anything is to get done and then, services are not always forthcoming.

4. As a family member, have you been supported financially, emotionally for your involvement from providers or agencies in state and local activities?

Parents did not feel they have been supported adequately. They did indicate there were some supports but they were so limited that they were not worth mentioning.

5. If you are actively involved as a family member in policymaking at the state, local or national level in an advisory role, task forces, board of directors or committees do you feel you are an equal partner?

The majority of the participants responded they were involved but did not feel as equal partners. They did not feel their comments and concerns were always considered in an appropriate manner.

6. Does your child receive most of their health care services through a primary provider or specialist?

Care is received through primary physicians and nurse practitioners. There is a need in the state for pediatricians and other specialists. Parents mentioned they have to travel to Minnesota for specialists, which becomes an extra burden financially and emotionally.

7. Is the care your child receives satisfying for you, communicated in a way that is clear and understandable?

Participants mentioned that the health and mental care their child is receiving from primary physicians is satisfying, but there is a lack of specialists. The specialists also have waiting lists and services are not forthcoming when needed. They mentioned the need for specialists to teach children with autism spectrum disorders, social skills.

8. Are you presently satisfied with the covered costs of needed services for your child including: mental health, dental, well child checks, durable medical equipment, prescriptions, therapy services etc?

The overwhelming response was negative. Participants identified the need to increase and extend coverage for heart conditions and hearing loss. Currently hearing loss equipment is covered until the age of 18.

9. Does your insurance provide timely approval for needed care overall, clear information about coverage, resources and complaint procedures?

Currently, therapy is limited to a predetermined number of visits, after that, parents are financially responsible. There is a great need for more medical coverage for children with special health care needs. If the child does not have an MR diagnosis, Medicaid is not available.

10. Are you satisfied in the way your child's development is being monitored?

Participants responded they were not satisfied with the way their children's development was monitored. They mentioned the need for specialists in the state and they felt that the

current medical system does not support parents with children with special needs. Their wish was for a system that provides a seamless access to services.

11. Do you feel comfortable in your knowledge in health care financing i.e.: Medicaid, Health Tracks (EPSDT), SSI, Children's Special Health Services, private insurance?

Parents did not feel comfortable in their knowledge of health care financing. They wish there was a coordinator that would manage the system and help them with questions they have and lead them in the correct way to receive services.

12. Are you comfortable accessing comprehensive community based services/resources for your child and family and know who to call to locate information and services for your family?

Parents responded they felt comfortable accessing the services.

13. We feel it is important for families to have access and links to a variety of public and private resources and family support from the day a child is diagnosed. Tell us your thoughts in how families can receive this information and how Family Voices can assist new families in this process or share your experience.

Participants felt a good job is done in networking families with agencies in town linking other agencies. The chain is only as strong as the weakest link. One parent mentioned that a child with a disability can divide a family. Often one of the parents also has a similar disability but many times that disability goes undiagnosed. To alleviate the blame, jealousy among siblings for the extra time that the disabled child receives, and other conflicts from added stress, families should have time with a trained professional who can recognize these conflicts and help reduce some of the stresses associated with a family who has a member with a disability.

14. Tell us what would have been helpful for you and your family?

“We have had a great DD case manager who always helps us get in touch with who we need assistance from.”

“It would have been helpful to have access to professional family counseling to address the extra stress associated with a child who needs the extra time and attention. It also would have been helpful to realistically encourage the family and the disabled individuals to set high, but realistic goals and not lower expectations if they are within the capabilities of the person with the disability.”

Parents expressed the need for respite care and individuals that qualified to provide the needed services.

15. Also share with us what ongoing informational needs that you may have.

Need for service coordinators who are aware of what is available.

16. Tell us what have been the biggest barriers, challenges and gaps in services you have faced with your child with special health care needs.

“There is a lack of communication between vendor and specialty health care clinics when ordering equipment. I constantly have to call to make sure things are progressing when an order for equipment is placed. We were ordering a new wheelchair through Great Plains Rehab in Bismarck. They said they faxed the info to Gillette Children’s in St. Paul. Gillette said they had faxed it to Great Plains. I questioned why nothing had been done for two months. Somewhere, someone dropped the ball and nothing had been done.”

No appropriate services are available. There is limited intensive, effective social skills training and coordination between schools and health care. There is a need for a medical home to help families navigate the system.

17. Are you having financial stress due to your child's health care needs?

All participants replied they are facing financial stress due to their child's special health care needs. Parents also mentioned they face issues with employers not understanding what it takes to take care of a child with special health care needs.

18. Tell us what would assist you as a family to better meet the needs of your child's healthcare? Examples: eligibility criteria changes, a Medicaid Buy-in program, waiver etc.

There is a great need for accessible services; parents felt case workers need to be trained so they can better assist families caring for a child with special health care needs. There is also a need to assist families financially when they have to travel outside North Dakota to access needed services. Parents felt Protection and Advocacy should advocate more on behalf of the children with special health care needs.

19. What challenges do you encounter in your child's education? What has been helpful?

Parents mentioned some of the challenges they face included:

- Making sure he is getting his therapies as scheduled at school.
- Having to go to Gillette Children's Hospital in St. Paul.
- Having to go to Bismarck for a baclofen pump refill.

- No services available for high-functioning autism. They need instruction in social skills and behavioral plans from a trained professional.
- Parents need to push to get services.
- School administrator told the parent “we don’t have the resources.” Even though the IEP requires services to be provided, children do not receive them and the parents have to pay out of pocket.
- Teacher misconceptions assuming the child is not capable of understanding the concepts or learning the information presented and treating the child according to their misconceptions.

20. How have your child's learning/educational needs changed as they've grown?

There is a need for special education services such as preschool special education that are not always available in small rural towns. There is a need for appropriate communication devices if the child is to succeed academically. And, there is also a need to address social and behavioral issues, not just academic issues.

21. What supports or services would help your child and family?

Parents mentioned the need to help pay for out of state travel; the lack of funding which prevents children for receiving appropriate services; the need for teaching sign language in the public schools; the need to provide intensive social skills training; and the need to provide families with budgeting and financial information so they can better manage these two issues.

22. What challenges do you anticipate for their future? ...coming in the next year?

Parents mentioned the following challenges:

- What happens when my son turns 21? Will he ever want to live away from home? I'm unsure about his transition after high school.
- Lack of funding creates a financial albatross that affects my child's self-esteem as well.
- Housing issues when they become adults.
- Behavioral and social issues that preclude them from learning, developing friendships and overall quality of life.

23. Are there agencies or people in your community you have found helpful? Could you tell us how we can work with them?

- Easter Seals
- Minot Public Schools
- Minot State Communications
- NDCPD
- Pathfinders
- Dreamcatchers
- Nancy Gassman
- Dan Olson
- Trinity Hospital-Hippotherapy
- Medicaid
- Disabilities Clinic
- Dr. Messrly
- MedCenter One-Bismarck
- Great American Bike Race

- Vocational Rehab has been somewhat helpful.
- Parents do not have a lot of support. Need groups that will support them with similar disabilities.
- There is a need for respite care and people that are qualified.
- GPAST does not feel accessible.
- Family Voices

Participants mentioned the need to find qualified, reliable people.

Teenagers, Ages 14-17 Years

Focus groups were conducted in the following areas: Bismarck, Minot, Devils Lake, Grand Forks and Fargo. Following are the compiled comments:

1. In your opinion what is a healthy and successful teenager? What are some of the characteristics?

The most common response was that healthy and successful teenagers eat right and are involved in activities, do not do drugs, drink alcohol or smoke. Also teenagers that were involved in activities in schools and the community were seen as well rounded and successful.

2. What kinds of programs or activities does your community have for teenagers? Do you participate in those activities? If not why?

Activities available to teenagers included YMCA, DECA, school activities, hockey camps, bowling leagues, Playmakers, swim clubs and softball leagues. The majority of the teenagers indicated that they are involved in one or more extracurricular activity.

3. What activities do you want to see your community providing for people your age?

Answers included indoor amusement parks and dance clubs for teens. Participants in all areas of the focus groups expressed their wish for an indoor facility offering activities for teenagers year-round but especially during the long winter. Participants mentioned, “Clubs are needed for minors with activities to keep us out of trouble.” They also mentioned that excessive security would deter them from participation.

4. What are your goals for the future?

All teenagers responded they would either attend college or vocational school after high school graduation. One teenager indicated he would join the army for four years then go to college and become an Air Force Officer. A number of teenagers already decided what they would like their major to be and where they want to attend college.

5. What are your greatest supports and biggest barriers to achieving your goals?

The majority of teens responded that their greatest supports included their parents, family members and best friends. Financial limitations were the most common barrier in achieving their goals.

6. Who are your role models?

Participants responded that parents, grandparents, siblings, uncles and cousins were their role models. Other responses included Albert Einstein and celebrities, Carrie Underwood and Lady Gaga.

7. Where do you see yourself in 2-4 years?

The most common response was going to college and either working part-time while in college or finding work right after graduating.

8. What are your biggest fears/concerns about leaving your parent's home? What kind of supports would make the transition easier?

The most common concern was not having the financial means available to support themselves. The second most common response was the fear of no longer having the emotional support of parents and not feeling safe. As one teenager replied, "I am afraid of having to live on my own and not having the safety of my parents. Staying close to my parents and being able to go home to visit would make the transition easier." Others mentioned having the support of friends would make the transition easier.

9. Do you use seatbelts when you are driving or when you are a passenger in a car?

Most indicated they always wear their seatbelts, with the exception of a couple who said they never wear their seat belts.

10. Why do think it is important to wear seatbelts? Do you know of any accidents that are the result of driving without wearing a seatbelt?

Safety is the main reason for wearing seatbelts. Teenagers indicated they had known someone who has died from not wearing their seatbelt, or had heard of fatal accidents because drivers or passengers were not wearing their seatbelts.

11. If you don't wear seat belts what are some of the reasons?

The most common reason for not wearing a seatbelt is because they are traveling a short distance or they simply forget.

12. What risks do you think teenagers associate with driving without wearing seatbelts?

Death, serious injury and getting ejected from the vehicle were the most common responses.

13. Do you know teenagers that talk on their cell phone while driving?

Every single teenager replied yes to this question.

14. What do you think are the dangers?

The most common response was that being on the cell phone is a distraction that can lead to an accident, even death.

15. Has there been a cell phone related accident? (crash, death, injury)

The majority responded they personally knew of accidents or they had heard it on the news.

16. What are your suggestions for solving this problem?

Making it illegal was the most common response. As one student stated, "Make it a law that you can't talk/text while driving. Make cops give a fine."

17. Do you know teenagers that text while driving?

All responded they did.

18. Do you know of any accidents that are the result of texting while driving?

The majority answered that they have either heard or knew of people that had gotten hurt in accidents involving drivers who were texting.

19. What should be done to inform teenagers of the dangers of texting while driving?

The main response was to show photos depicting the dangers of texting while driving.

Some responses included, “Keep educating them about it. Show examples to prove what could happen” and “Show images, videos and skits showing what could happen.” Use billboards and TV commercials to warn them about the dangers.

20. What are the biggest problems that affect teenagers in your community? What can be done to solve those problems?

Drug and alcohol abuse were identified as the biggest problems. One teen mentioned that it was harder to find drugs in the slums in Phoenix, Arizona than in Minot, North Dakota. Solutions included mandatory drug and alcohol testing in schools and arrests. Some teenagers thought that nothing can be done because “teenagers can always have them if they want them.” The second problem identified was teen pregnancy. Ideas for solving the problems facing teens included providing more activities in the community and holding workshops or assemblies as an open forum for teens to discuss their issues. The group also indicated the pregnancies occurred with their younger siblings, ages 12-14.

21. If you or your friend has a problem with drinking or using drugs do you know where to go for help?

Responses included counselors, parents, hotlines, websites and the internet to find state agencies.

22. What agencies are there to help?

Agencies mentioned included Heartview, Prairie, North Central Human Resources Center and Trinity Hospital.

23. How can the community help to let you know what is available?

The most common response was through advertising such as billboards, posters and commercials. Other suggestions included having speakers come into schools to educate them on resources available and role playing.

24. If you have a disability where do you go to receive information that could help you transition into adulthood? What types of information would be most helpful to you?

Responses included flyers, posters, pamphlets, where to find tutors, personal help and different classes.

25. In your opinion would it be helpful to have a youth advisory group in ND that understand you and can help you with what you may be going through?

The majority of students replied yes, having a youth advisory group in ND would be helpful. One student replied, "I believe we do need a place for teenagers. We hold so much emotion inside that could tear us apart and cause emotional issues in our future."

Young Adults, Ages 18-24 Years

Focus groups were conducted in the following areas: Minot, Devils Lake and Grand Forks.

1. How would you describe a healthy and successful young adult? What are some of the characteristics? Who are your role models?

The most common answer in this age group was exercising regularly and eating right. Most young adults associated healthy with a physical state of being, such as not being overweight and going to the gym regularly. The second most common response was associated with a state of happiness, either at educational success or job success. Also

knowing oneself and having goals were also included. Role models included parents, family members and peers.

2. What are your goals? What are your greatest supports and biggest barriers to achieving your goals?

Short term goals included graduating from college and finding a job. Long term goals included having a successful career and eventually getting married and having a family. Some of the biggest barriers mentioned were financial issues, time management and procrastination. Supports included family, friends, teachers, co-workers and teammates.

3. Where do you see yourself in 2-4 years?

The most common responses were working or still in college, either finishing up undergraduate work or enrolled in a graduate program. A number of them expressed the desire to leave the state and move to a more popular one with better job prospects.

4. Is health care a serious problem in your community? If yes why? What are your suggestions for solving this problem? If not, in your opinion what systems are in places that have eliminated this problem?

Half of the participants agreed that health care was a serious issue and the other half didn't feel that health care was an issue because they were covered under their parent's health plans. Participants who felt that there was a problem with health care in their community believed it was a problem because of affordability.

5. How important is health insurance to you? Why? Do you have health insurance? If you do, is it through your employer or did you purchase it yourself?

All of the participants, but one, agreed that health insurance was very important to them in the event they became ill or had an accident. The majority had care through their

parents' health insurance and one mentioned he had purchased health insurance on his own.

6. What are some of the reasons that you and others you may know might not buy health insurance or sign up for coverage? Probe: healthy? Too expensive? Can get care anyway?

The overwhelming response was that health coverage was too expensive. One mentioned due to a pre-existing condition, he could not get health insurance.

7. Why do you think young adults engage in risk behaviors such as drinking and driving, not wearing seatbelts, texting while driving etc? What are your suggestions to help change those behaviors?

The most common response among the participants was that young adults believe they are invincible and that nothing will happen to them. Other reasons for engaging in risk behaviors were peer pressure, rush of adrenaline, the thrill of going against the rules, ignorance of the consequences and trying to fit in. Suggestions to help change these behaviors included educating them on the consequences of their actions and by enforcing stricter laws and rewarding good behavior. As one participant replied, "My suggestion is just to drill it in people's heads that it is wrong and use shocking statistics to get them to think about who they are harming."

8. What are your biggest fears /concerns about leaving your parent's home or when you left your parents home? What kind of supports will make or made the transition easier for you?

The biggest concern in this group was finances, not being able to afford living away from home. Other concerns included the fear of something happening to their parents, being homesick, a sense of loss of security and not making new friends. Supports that would

make the transition easier included continued support from parents, friends, faith and being able to visit family frequently.

9. How do you access services that you may need (housing, health care coverage, mental health, food stamps)? What would make it easier for you to access those services?

Most participants still receive financial assistance and health care coverage from their parents. In addition, most mentioned research and the internet as a way to find other services in the event they needed them.

10. What activities are available in your community to support young adult health? Do you participate in these activities? If not what are some of the barriers that prevent you from participating? What kind of activities would you like to see your community providing to people your age?

Participants mentioned they are involved in sports (intramural, golf, running), go to the gym regularly, the YMCA and utilize the biking and walking paths. College students at the University of North Dakota named their campus' Wellness Center as a means for supporting their health. Participants from Minot and Lake Region were aware that their college had activities such as intramural sports but most were unaware of any community activities for young adults. Barriers included time constraints and study requirements. Suggestions for activities mentioned were outdoor activities during the winter and classes on healthy cooking.

11. What are the biggest problems that affect young adults in your community? How can these problems be solved?

The biggest problem was drugs and alcohol, followed by stress and financial problems. Suggestions for solutions included tougher law enforcement, non-alcoholic activities, personal finance workshops and job placement programs.

12. If you have a disability where do you go to receive information that could help you transition into adulthood? What types of information would be most helpful to you?

Most participants indicated they did not have a disability, but they did know where to get help. Sources to receive information included doctors, the internet to get information on federal and state programs or non-profit organizations and disability experts.

13. In your opinion would it be helpful to have a youth advisory group in ND that can assist you and understand what you may be going through?

The overwhelming response was yes. Participants indicated that an advisory group would be helpful as a means for them to be able to talk with others and share feelings. One participant replied, "I think it would be very helpful especially for people who are homesick and feeling lonely. Also, voicing and sharing your fears and stresses often leads to common grounds with a group and the feeling that you are not alone and that your problem may not be as big as you think."

Appendix A



Institutional Review Board

MINOT STATE UNIVERSITY

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Notice of IRB Approval

Name of Principal Investigator: Christy Carroll

University Address: NDCPD, Memorial Hall 205A

Title of Project: Focus Group Study Targeting Youth and Adults ages 14-24 for Title V Maternal Child Health Needs Assessment

August 13, 2009

The above project has been reviewed and approved by the IRB under the provisions of Federal Regulations 45 CFR 46.

This approval is based on the following conditions:

1. The materials you submitted to the IRB provide a complete and accurate account of how human subjects are involved in your project.
2. You will carry on your research strictly according to the procedures as described in materials presented to the IRB.
3. You will report to the chair of the Institutional Review Board any changes in procedures that may have a bearing on this approval and require another IRB review.
4. If any changes are made, you will submit the modified project for IRB review.
5. You will immediately report to the IRB Chair any problems that you encounter while using human subjects in your research.



Dr. Brent A. Askvig
Chair, Minot State University's IRB

Appendix B

Focus Group Regional Schedule

Devils Lake (Ages 18-24)

Date: 10/21/2009

Time: 12:00-1:30 p.m.

Place: Lake Region State College (Heritage Hall)

Status: 18 registered, 18 participated

Minot (Ages 18-24)

Date: 10/22/2009

Time: 5:00-6:30 p.m.

Place: Memorial Hall

Status: 6 registered, 6 participated

Bismarck (Ages 14-17)

Date: 10/26/2009

Time: 2:30-4:00 p.m.

Place: Bismarck High School (Conference Room A)

Status: 10 registered, 10 participated

Minot (Ages 14-17)

Date: 10/27/2009

Time: 3:30-5:00 p.m.

Place: Magic City High School (Room C)

Status: 11 registered, 11 participated

Minot, Devil's Lake (Parents)

Date: 10/27/2009

Time: 7:00-9:00 p.m.

Place: Memorial Hall (Nelson Room)

Status: 8 registered, 8 participated

Fargo (Ages 14-17)

Date: 10/29/2009

Time: 4:00-5:30 p.m.

Place: Fargo North High School (Room 102)

Status: 12 registered, 12 participated

Fort Totten (Parents)

Date: 10/30/2009

Time: 12:00-1:30 p.m.

Place: BIA Conference Room

Status: 10 registered, 0 participated

Grand Forks (Ages 14-17)

Date: 11/5/2009

Time: 4:00-5:30 p.m.

Place: Grand Forks Central (Counseling Room)

Status: 10 registered, 10 participated

Devils Lake (Ages 14-17)

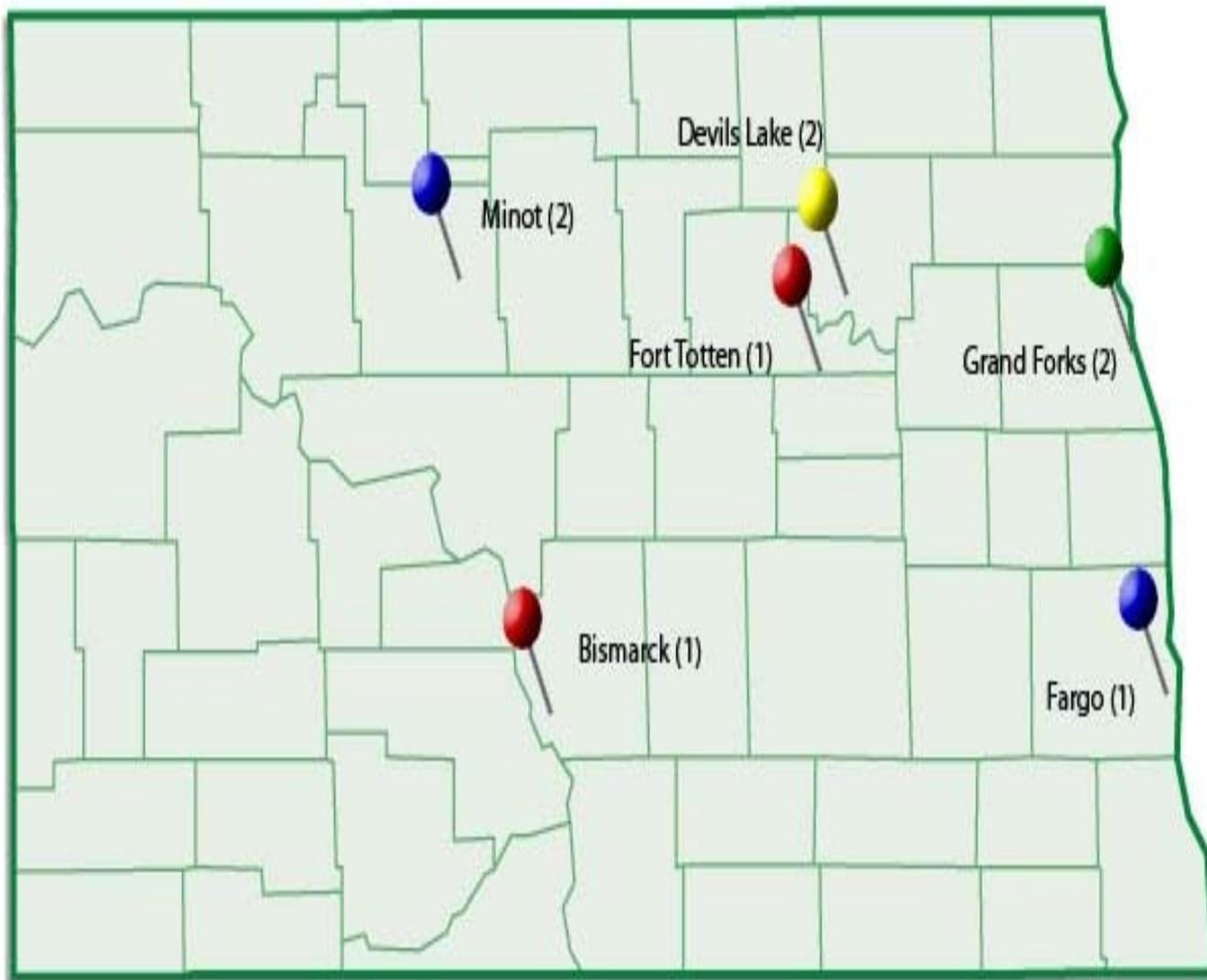
Date: 11/6/2009

Time: 4:30-6:00 p.m.

Place: Devils Lake High School (Library)

Status: 11 registered, 11 participated

Appendix C



Appendix D

PARENT CONSENT FORM

Assessing the Needs of Focus Group Study Targeting Youth and Adults ages 14-24 for Title V Maternal Child Health Needs Assessment

We are conducting a study about general behaviors of youth on behalf of the North Dakota Department of Health. We invite your child to participate in this research. Please read this form and ask any questions you may have before allowing your child to be in the study.

Background Information:

The purpose of this study is to identify general behaviors and health care needs of North Dakota youth through face-to-face interviews with a group of youth in your area. Your child will also be asked to complete a survey of 43 questions at the beginning of the meeting asking about different behaviors. For example we will ask you what likes to eat, if he/she exercises regularly, whether he/she knows of people your age that use alcohol or drugs. Your child is not obligated to answer any of the questions he/she does not feel comfortable answering. Your child will not be asked to write his/her name on the survey.

Procedures:

If you allow your child to be in this study, we will convene a meeting of approximately twelve youth participants in your area and will ask them questions about their eating habits, exercise regiments and alcohol or drug use. The meeting will take place once and will last one to one and a half hours.

Risks and Benefits of Being in the Study:

The only risk involved may include discomfort with answering questions. Your child is not obligated to answer any questions he/she may feel uncomfortable with. Your child will also be free to end his/her participation at anytime. Your child will receive a light lunch and payment of \$30 as compensation for his/her participation in the study.

Confidentiality:

The records of this study will be kept private. In any sort of report we publish, we will not include information that will make it possible to identify your child in any way. Research records will be kept in a locked file at Minot State University and will be turned to the Department of Health at the end of the study where they will be kept locked for three years at the end of which they will be shredded and discarded.

Voluntary Nature of the Study:

Your child’s participation in this study is entirely voluntary. Your decision whether or not to allow him or her to participate is up to you. If you decide to allow participation, you are free to withdraw your child from the study at any time without penalty.

Contacts and Questions

My name is Dr. Christy Carroll. If you have any questions you may contact me at 701-858-3121. You may also contact the Minot State University Institutional Review Board at _____ with any questions or concerns.

You will be given a copy of this form to keep for your records.

Statement of Consent:

By signing below I have read the consent information above and agree to allow my child to participate in this study. I understand that I may terminate his/her participation in this study at anytime without penalty.

Signature of Parent or Guardian

Date

Appendix E

Family Focus Groups Survey Questions

1. Are you satisfied with the quality of primary care, obtaining referrals & appointments for needed services and coordination among both primary and specialty care?

Yes_____ No_____ If you replied NO please explain:

2. Does your child have a Care plan? Yes_____ No_____

3. Do you understand the steps to the formal grievance or appeal when you are not satisfied with your child/family services?

Yes_____ No_____

4. As a family member, have you been supported financially, emotionally for your involvement from providers or agencies in state and local activities? Give examples: committee meetings, board meetings etc.

Yes_____ No_____

Examples:

5. If you are actively involved as a family member in policymaking at the state, local or national level in an advisory role, task forces, board of directors or committees do you feel you are an equal partner?

Yes_____ No_____

6. Does your child receive most of their health care services through a primary provider or specialist?

Yes_____ No_____

7. Is the care your child receives satisfying for you, communicating in a way that is clear and understandable?

Yes_____ No_____

8. Are you presently satisfied with the covered costs of needed services for your child including: mental health, dental, well child checks, durable medical equipment, prescriptions, therapy services etc?

Yes_____ No_____

9. Does your insurance provide timely approval for needed care overall, clear information about coverage, resources and complaint procedures?

Yes_____ No_____

10. Are you satisfied in the way your child's development is being monitored?

Yes_____ No_____

11. Do you feel comfortable in your knowledge in health care financing ie: Medicaid, Health Tracks (EPSDT), SSI, Children's Special Health Services, private insurance?

Yes_____ No_____

12. Are you comfortable accessing comprehensive community based services/resources for your child and family and know who to call to locate information and services for your family?

Yes_____ No_____

13. We feel it is important for families to have access and links to a variety of public and private resources and family support from the day a child is diagnosed. Tell us your thoughts in how families can receive this information and how Family Voices can assist new families in this process or share your experience.

14. Tell us what would have been helpful for you and your family?
15. Also share with us what ongoing informational needs that you may have.
16. Tell us what have been the biggest barriers, challenges and gaps in services you have faced with your child with special health care needs.
17. Are you having financial stress due to your child's health care needs?
- Yes _____ No _____
18. Tell us what would assist you as a family to better meet the needs of your child's healthcare? Examples: eligibility criteria changes, a Medicaid Buy-in program, waiver etc.
19. What challenges do you encounter in your child's education? What has been helpful?
20. How have your child's learning/educational needs changed as they've grown?
21. What supports or services would help your child and family?
22. What challenges do you anticipate for their future? ...coming in the next year?
23. Are there agencies or people in your community you have found helpful? Could you tell us how we can work with them?

Appendix F
Needs Assessment Questionnaire
Teenagers, Ages 14-17 Years

1. In your opinion what is a healthy and successful teenager? What are some of the characteristics?
2. What kinds of programs or activities does your community have for teenagers? Do you participate in those activities? If not why?
3. What activities do you want to see your community providing for people your age?
4. What are your goals for the future?
5. What are your greatest supports and biggest barriers to achieving your goals?
6. Who are your role models?
7. Where do you see yourself in 2-4 years? (work, college etc.)
8. What are your biggest fears/concerns about leaving your parent's home? What kind of supports would make the transition easier?
9. Do you use seatbelts when you are driving or when you are a passenger in a car?
10. Why do think it is important to wear seatbelts? Do you know of any accidents that are the result of driving without wearing a seatbelt?
11. If you don't wear seat belts what are some of the reasons?

12. What risks do you think teenagers associate with driving without wearing seatbelts?
13. Do you know teenagers that talk on their cell phone while driving?
14. What do you think are the dangers?
15. Has there been a cell phone related accident (crash, death, injury)?
16. What are your suggestions for solving this problem?
17. Do you know teenagers that text while driving?
18. Do you know of any accidents that are the result of texting while driving?
19. What should be done to inform teenagers of the dangers of texting while driving?
20. What are the biggest problems that affect teenagers in your community? What can be done to solve those problems?
21. If you or your friend has a problem with drinking or using drugs do you know where to go for help?
22. What agencies are there to help?
23. How can the community help to let you know what is available?
24. If you have a disability where do you go to receive information that could help you transition into adulthood? What types of information would be most helpful to you?
25. In your opinion would it be helpful to have a youth advisory group in ND that understand you and can help you with what you may be going through?

Appendix G

Focus Group Questionnaire

Young Adults, Ages 18-24 Years

1. How would you describe a healthy and successful young adult? What are some of the characteristics? Who are your role models?
2. What are your goals? What are your greatest supports and biggest barriers to achieving your goals?
3. Where do you see yourself in 2-4 years? (college/work?)
4. Is health care a serious problem in your community?
If yes why? What are your suggestions for solving this problem?
If not, in your opinion what systems are in places that have eliminated this problem?
5. How important is health insurance to you? Why? Do you have health insurance? If you do, is it through your employer or did you purchase it yourself?
If you don't have health insurance what would help you to get health insurance?
6. What are some of the reasons that you and others you may know might not buy health insurance or sign up for coverage?
Probe: Healthy? Too expensive? Can get care anyway?
7. Why do you think young adults engage in risk behaviors such as drinking and driving, not wearing seatbelts, texting while driving etc? What are your suggestions to help change those behaviors?
8. What are your biggest fears /concerns about leaving your parent's home or when you left your parents home? What kind of supports will make or made the transition easier for you?

9. How do you access services that you may need (housing, health care coverage, mental health, food stamps)? What would make it easier for you to access those services?

10. What activities are available in your community to support young adult health? Do you participate in these activities? If not what are some of the barriers that prevent you from participating? What kind of activities would you like to see your community providing to people your age?

11. What are the biggest problems that affect young adults in your community? How can these problems be solved?

12. If you have a disability where do you go to receive information that could help you transition into adulthood? What types of information would be most helpful to you?

13. In your opinion would it be helpful to have a youth advisory group in ND that can assist you and understand what you may be going through?