

## ND Medical Home Parent Survey

Your child's health care provider, Dr. \_\_\_\_\_ is part of the North Dakota Integrated Service (NDIS) Medical Home project. Our goal for this project is to increase positive outcomes for children and families and to build effective integrated health services and community systems for children and youth with special healthcare needs.

Several ND primary care providers are working as pilot sites for implementing the Medical Home concept. What is a Medical Home? A Medical Home is a model of providing primary care that is consistent, accessible, and family centered. In this model, the parent is considered the expert on their child.

NDIS is asking you to take part in this brief, confidential survey in order to provide feedback to your health care provider. You do not have to participate if you do not want to. Your decision to participate will not affect your relationship with your health care provider in any way. All information will be kept completely confidential, and no reports will be made that allow an individual respondent to be identified.

We are interested in learning more about the needs and healthcare experiences of families who have a child with special healthcare needs. This includes children with chronic health conditions or disabilities. If you have more than one child who fits this description, please refer to the child with the most severe special health care needs when completing this survey.

Answers will be collected and reported by North Dakota Center for Persons with Disabilities (NDCPD) at Minot State University. Please complete the survey and **return it in the attached addressed, stamped envelope**. Your participation in this study is extremely helpful. If you have any questions, please call Emily Rodacker at NDCPD at: 701-858-3546 or 1-800-233-1737. **Thank you!**

A. This survey is being conducted every 6-months. Have you filled out this survey before?

<sup>1</sup> Yes      <sup>2</sup> No      <sup>8</sup> Don't know

1. What clinic did you receive this survey from? \_\_\_\_\_

2. Is this the clinic that your child regularly receives care from?

<sup>1</sup> Yes → 2a. How long has your child been a patient at this clinic?

<sup>1</sup> Less than 6 months      <sup>3</sup> 1-5 years

<sup>2</sup> 6 months-1 year      <sup>4</sup> 5 years or longer

<sup>2</sup> No      **(GO TO QUESTION 3)**

3. Please indicate your child's age range (if more than one child with special health needs, please choose the child with the most severe needs to focus on for **all** child-related questions in this survey)

<sup>1</sup> 0-2

<sup>2</sup> 3-5

<sup>3</sup> 6-8

<sup>4</sup> 9-12

<sup>5</sup> 13-15

<sup>6</sup> 16-18

<sup>7</sup> 19-21

4. Which of the following statements best describes your child's health care needs?
- <sup>1</sup> My child's health care needs change all the time
- <sup>2</sup> My child's health care needs change only once in awhile
- <sup>3</sup> My child's health care needs are usually stable
- <sup>4</sup> None of the above
- <sup>8</sup> Don't know
5. During the past six months, has your child missed any school due to his/her child's special healthcare needs?
- <sup>1</sup> Yes      <sup>2</sup> No      <sup>9</sup> Not applicable: child not in school or child care
6. During the past six months have you missed any work due to your child's special healthcare needs?
- <sup>1</sup> Yes      <sup>2</sup> No      <sup>9</sup> Not applicable: do not work
7. Does your child have health insurance?
- <sup>1</sup> Yes → 7a. Is your child covered by private insurance?      <sup>1</sup> Yes      <sup>2</sup> No
- 7b. Is your child covered by Medical Assistance?      <sup>1</sup> Yes      <sup>2</sup> No
- 7c. In the past year, was there a time when your child was not covered by ANY health insurance?      <sup>1</sup> Yes      <sup>2</sup> No
- <sup>2</sup> No **(GO TO QUESTION 8)**
8. During the past 6 months, how many times was your child seen by his or her primary care provider?
- <sup>1</sup> None at all      <sup>3</sup> 4-10
- <sup>2</sup> 1-3 times      <sup>4</sup> More than 10
9. During the past 6 months, how many times has your child had a lab or nurse appointment?
- <sup>1</sup> None at all      <sup>3</sup> 4-10
- <sup>2</sup> 1-3 times      <sup>4</sup> More than 10
10. During the past 6 months how many times did your child require care in the Emergency Department?
- <sup>1</sup> None at all      <sup>3</sup> 4-10
- <sup>2</sup> 1-3 times      <sup>4</sup> More than 10
11. In the past 6 months, have you had to delay care for your child because...
- |   | Yes                                   | No                                    |
|---|---------------------------------------|---------------------------------------|
| a. you couldn't get through to your child's health care clinic on the telephone?<br>Please describe:<br>_____ | <input type="checkbox"/> <sup>1</sup> | <input type="checkbox"/> <sup>2</sup> |
| b. you couldn't get an appointment at their clinic soon enough?<br>Please describe:<br>_____                  | <input type="checkbox"/> <sup>1</sup> | <input type="checkbox"/> <sup>2</sup> |
| c. once you arrived at the clinic, you had to wait too long to see the provider?<br>Please describe:<br>_____ | <input type="checkbox"/> <sup>1</sup> | <input type="checkbox"/> <sup>2</sup> |

d. you have language, communication, or cultural problems with the provider?

Please describe:

\_\_\_\_\_

\_\_\_\_\_

<sup>1</sup>      <sup>2</sup>

e. you had problems with health insurance?

Please describe:

\_\_\_\_\_

\_\_\_\_\_

<sup>1</sup>      <sup>2</sup>

**Please think about your child's primary healthcare provider**

12. In the past 6 months, when your child was seen by his or her primary health care provider, how often...

	Never	Sometimes	Usually	Always	Don't know
a. did your child's primary health care provider spend enough time with your child?	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>	<input type="checkbox"/> <sup>8</sup>
b. did your primary health care provider help you feel like a partner in your child's care?	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>	<input type="checkbox"/> <sup>8</sup>
c. did your primary health care provider provide you with the information that you needed?	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>	<input type="checkbox"/> <sup>8</sup>
d. did your child's primary health care provider listen carefully to you?	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>	<input type="checkbox"/> <sup>8</sup>
e. was your child's primary health care provider sensitive to your family's values or customs?	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>	<input type="checkbox"/> <sup>8</sup>

13. During the past six months, if you called your child's doctor or nurse for help or advice, how often were you able to get the help or advice you needed?

- <sup>1</sup> Never                                      <sup>3</sup> Usually
- <sup>2</sup> Sometimes                                      <sup>4</sup> Always

14. During the past six months, how often did your child's doctor or nurse explain things in a way that you and/or your child can understand?

- <sup>1</sup> Never                                      <sup>3</sup> Usually
- <sup>2</sup> Sometimes                                      <sup>4</sup> Always

15. Tell us what you think about the following...

	Yes	No
a. I know the different medical treatment options available for my child's health condition	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>
b. I feel comfortable disagreeing with my child's primary health care provider	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>
c. I feel supported by my child's primary health care provider and clinic staff	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>
d. There is someone in the clinic that helps me arrange or coordinate my child's care among the different doctors or services that he/she uses?	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>

16. During the past six months, did your child receive any specialty care services from a doctor other than his or her primary care provider?
- <sup>1</sup> Yes → 16a. Did your child's doctor, nurse or someone from the clinic do anything to help you receive the care from the specialist?
- <sup>1</sup> Yes    <sup>2</sup> No
- 16b. Does your child's primary health care provider or nurse follow-up with you after your child visits a specialist?
- <sup>1</sup> Yes    <sup>2</sup> No
- <sup>2</sup> No (**GO TO QUESTION 17**)

17. Children sometimes need other special medical equipment like a wheelchair, nebulizer, or XXX. During the past 6 months, did your child use or need special equipment?
- <sup>1</sup> Yes → 17a. During the past 6 months, did your child's doctor, nurse or someone from the clinic do anything to help you receive the special equipment?
- <sup>1</sup> Yes    <sup>2</sup> No
- 17b. During the past 6 months, how much of a problem was it to get needed specialty equipment?
- <sup>1</sup> A big problem  
<sup>2</sup> A moderate problem  
<sup>3</sup> A small problem  
<sup>4</sup> No problem at all  
<sup>8</sup> Don't know
- 17c. During the past 6 months, how often did your child's doctor or nurse talk with you about the special services or equipment that your child needed?
- <sup>1</sup> Never  
<sup>2</sup> Sometimes  
<sup>3</sup> Usually  
<sup>4</sup> Always  
<sup>8</sup> Don't know

<sup>2</sup> No (**GO TO QUESTION 18**)

18. Over the past 6 months, how satisfied were you with...

	Very satisfied	Satisfied	Dis-satisfied	Very dis-satisfied	Not applicable
a. the way your child's primary health care provider and other health care providers communicate with each other about your child's care?	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>	<input type="checkbox"/> <sup>9</sup>
b. the way your child's primary health care provider and other health care providers communicate with his or her school?	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>	<input type="checkbox"/> <sup>9</sup>

19. Do you have a written Care Plan for your child?
- <sup>1</sup> Yes    <sup>2</sup> No (**SKIP TO QUESTION 21**)    <sup>8</sup> Don't know

20. IF YES, Please rate the following the statements...

	Never	Sometimes	Usually	Always	Don't know
a. My primary care provider and clinic staff work with my family to create a written care plan for my child...	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>	<input type="checkbox"/> <sup>8</sup>
b. The written care plan is helpful to me and my child...	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>	<input type="checkbox"/> <sup>8</sup>
c. My primary health care provider and clinic staff help me to understand my child's written care plan...	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>	<input type="checkbox"/> <sup>3</sup>	<input type="checkbox"/> <sup>4</sup>	<input type="checkbox"/> <sup>8</sup>

21. I am confident in the knowledge my clinic has about community resources for children with special health care needs

<sup>1</sup> Never

<sup>3</sup> Usually

<sup>2</sup> Sometimes

<sup>4</sup> Always

22. In the past 6 months, I've seen changes at this clinic that are helpful to families of children with special health care needs

<sup>1</sup> Yes

<sup>2</sup> No **(SKIP TO QUESTION 24)**

<sup>8</sup> Don't know **(SKIP TO QUESTION 24)**

23. Please describe the types of changes you have noticed

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24. I would recommend this clinic to other families seeking care for a child with special health care needs

<sup>1</sup> Yes

<sup>2</sup> No

25. Has Medical Home affected your family: (See definition on page 1)

a. Financially? <sup>1</sup> Yes

<sup>2</sup> No (Go to b)

Please describe how

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b. Emotionally? <sup>1</sup> Yes

<sup>2</sup> No (Go to c)

Please describe how

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c. Time savings? <sup>1</sup> Yes

<sup>2</sup> No (Go to d)

Please describe how

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d. Communication? <sup>1</sup> Yes

<sup>2</sup> No (Go to e)

Please describe how

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e. Number of health related visits? <sup>1</sup> Yes

<sup>2</sup> No (Go to Question 23)

Please describe how

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26. Is there anything else you would like to tell us that we have not asked?

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**Please answer a few questions about yourself to help NDCPD generally describe participants. No individual information will be shared.**

These last questions are just to help us understand more about the people completing this survey. Remember, your answers are confidential and will not be connected to you in any report.

27. How far away from your clinic do you live?

- <sup>1</sup> Less than 25 miles                      <sup>3</sup> 50 to 100  
<sup>2</sup> 25 to 50 miles                              <sup>4</sup> More than 100 miles

28. What is your child's racial/ethnic background? (Please answer each section of this question by signifying "yes or no")

	Yes	No
a. African American	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>
b. American Indian	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>
c. Asian	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>
d. Hispanic/Latino	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>
e. White/Caucasian	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>
f. Other (please specify)	<input type="checkbox"/> <sup>1</sup>	<input type="checkbox"/> <sup>2</sup>

29. Last year, was your annual household income

- <sup>1</sup> Under \$25,000                              <sup>4</sup> \$75,000 to less than \$100,000  
<sup>2</sup> \$25,000 to less than \$50,000              <sup>5</sup> \$100,000 or more  
<sup>3</sup> \$50,000 to less than \$75,000              <sup>8</sup> Don't know

**Questions?**

Call Emily Rodacker at NDCPD  
701-858-3546 or 1-800-233-1737  
or email: [emily.rodacker@minotstateu.edu](mailto:emily.rodacker@minotstateu.edu)

**Thank you!**