

Primary Data Collection Toolkit

RESOURCES FOR SURVEYS, KEY INFORMANT INTERVIEWS, AND FOCUS GROUPS

Introduction

To ensure that the Title V Needs Assessment prioritization process is informed by the community that Title V programs serve, data should be collected from a diverse group of community members and stakeholders. Strategies to efficiently collect detailed and representative data to ensure that everyone has a voice are wide-ranging and require flexibility and a willingness to pivot. This toolkit provides information on three data collection efforts that can support Title V Needs Assessments, but is by no means complete as the best data collection methods are often tailored to specific communities. Surveys that are widespread and targeted to a general audience can collect rich qualitative data that allows for personal experiences to be shared. Key informant interviews can also provide rich qualitative data from subject matter experts that have a valuable depth and breadth of knowledge on specific topics. Focused efforts designed to hear and learn from the experiences of those that are not often involved in public health evaluation efforts through focus groups can give historically left out groups a voice and a seat at the table.

This toolkit was written based on the experiences of the Minnesota Needs Assessment team during the Title V Needs Assessment process. The best practices, processes, and lessons learned could be applicable beyond Title V work to other needs assessments, evaluations, and public health programs; however the information here is intended to support the work of other statewide Title V Needs Assessments taking place throughout the United States.

Getting Started with Primary Data Collection

Convening a workgroup to develop and edit primary data collection materials, methods, and protocols can be helpful to guide the work and establish the scope.

Some initial questions to ask when determining data collection methods include:

- Are there certain communities that we would like to hear more from? Do we have partners that could help us design data collection methods that would reach these communities and build relationships?
- What resources do we have to support staff time to conduct key informant interviews and focus groups?
- What would a representative sample of the population we serve through Title V funds look like?
- What procedures will we use for data analysis? Who will be responsible for this analysis?
- How will we manage the data we collect? What software, storage systems, or other data management processes will we use?
- How will we share back what we learn with the communities we serve?
- In what ways can stakeholders and partners support data collection?

Trauma-informed Data Collection

Reaching a representative sample of the population when completing an assessment of community needs and resources can be achieved through collaboration with service providers, local public health,

and communications experts and supported with innovative data collection projects. Reaching historically under-represented and under-served communities is more difficult and requires thoughtful engagement with members of these communities and a willingness to engage in open, honest dialogue about past injustices and historical trauma. Prior to designing primary data collection tools and protocols, consulting with health equity groups and requesting feedback on language and ways to engage with individuals that have experienced trauma can support developing a needs assessment that is responsive and sensitive to as well as respectful of the experiences of those that have experienced trauma.

Primary Data Collection Activities

Minnesota's Title V Needs Assessment team engaged in three main primary data collection activities:

- Discovery Survey – Summer 2018
- Key Informant Interviews – Spring 2019
- CYSHN Focus Groups – Summer 2019

Specific details on how this activities were carried out, and with what time/resources, are provided below.

Designing and Testing Instruments & Protocols

The **Discovery Survey** was designed in coordination with staff members from sections within the Child & Family Health Division, CYSHN parent work groups, local public health, and community members to develop, test, and distribute the Discovery Survey to stakeholders. The survey was brief and consisted of just 2 open-ended questions so as to keep respondent burden low while also allowing for respondents to provide more detailed responses reflective of their lived experiences.

What is the biggest need among women, children, and families in your community?

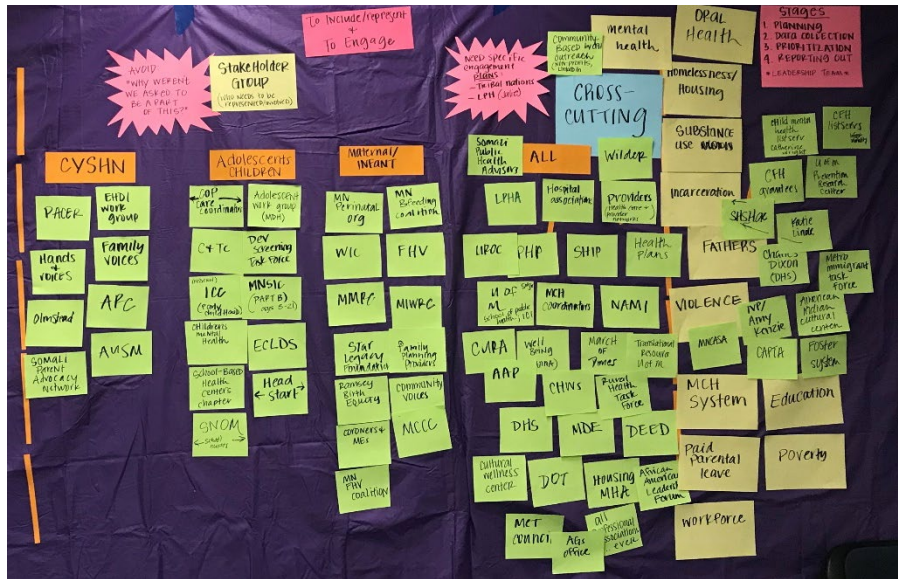
What do women, children, and families need to thrive?

The **Discovery Survey** was distributed electronically to reduce costs and improve ability to distribute across the state. Minnesota did pilot a paper version of the survey at a county WIC clinic in Greater (rural) Minnesota that was provided in three languages. The Discovery Survey included voluntary demographic questions which allowed us to better understand the reach of the survey. The demographic questions were used as a tool to measure if the distribution methodology was inclusive and representative of Minnesotans from across the state with different racial, ethnic, gender identities as well different positions within their communities as a leader, service provider, or member.

Stakeholder Engagement Planning

Minnesota held a structured stakeholder mapping exercise (picture below), the results of which were shared and revised by multiple additional teams/groups. We recommend planning for outreach and engagement ahead of primary data collection activities if at all possible.

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Recruiting Participants and Advertising the Survey

The **Discovery Survey** was distributed electronically with postings on the Title V Maternal and Child Health Needs Assessment website, the internal Minnesota Department of Health website, and social media platforms. All postings included a prompt to share the survey with friends, community, and colleagues (e.g. snowball sampling). With the support of staff members from sections within the Child & Family Health Division, CYSHN parent work groups, local public health, and community members, a list of groups that were thought to be willing to send the survey out to their communities was brainstormed. This method elicited a list of 101 professional organizations, listservs, and groups that were emailed the Discovery Survey. Feedback from the CYSHN parent group that first responders had critical insights into the health of women, children, and families led to the creation of a contact list for all fire and police departments in the state that received the Discovery Survey. Again, the primary contact for these agencies were encouraged to share the survey widely with their staff and communities. The Discovery Survey was available online for 6 weeks during the summer of 2018.

Collecting and Cleaning Data

All complete responses (n=2,716) were subject to a thematic content analysis via an inductive approach. For more details on the qualitative analysis, contact [Blair Harrison](#), Title V Needs Assessment Coordinator.

Sharing Findings

The Minnesota Department of Health's [Title V Maternal and Child Health Needs Assessment Website](#) is home to the materials related to the live webinars that were held to share the results of the Discovery Survey. Accessible to the public are the PowerPoint slides that guided the webinar, a transcript of the presentation, and the full webinar recording.

In addition to sharing the findings (as soon as the qualitative analysis was completed) the team also provided de-identified summary-level data to counties and organizations that had requested results for their geographic service areas.

Maintaining engagement

In addition to updates on the Title V Maternal and Child Health Needs Assessment Website, all survey respondents were able to select an option within the Discovery Survey to receive communications from the Title V team about the ongoing process. Emails were sent to this list of community members that provided their contact information when additional community engagement activities were occurring including the community forums and webinars. Of the 2,716 complete responses, 784 people chose to provide contact information for continued engagement.

Other Primary Data Collection Activities

Minnesota also conducted a series of key informant interviews, subject matter interviews, and focus groups. Examples of protocols and question sets are included as Appendix 5 and Appendix 6.

Best Practices and Lessons Learned

- Including optional demographic questions were very useful in assessing if those that completed the survey were representative of the state's population. However, not having the Discovery Survey available in other languages limited ability to engage with people who do not speak English as their first language and we know that this population has different needs, opinions, and health outcomes than other populations.
- To better collect information on root causes of some needs, changing the language of survey questions or adding additional questions to prompt thinking about the causes of reported needs could be helpful. For example, questions could ask "What is the greatest need in your community?" followed by "Why do you think this is a need?"

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Appendix 1. Email Marketing for Discovery Survey

Email Language

Dear [Stakeholder],

The Minnesota Department of Health is conducting a maternal & child health needs assessment! Respond to this short 2-question discovery survey to make sure the needs of women, children and families in your community are heard! What is a maternal and child health needs assessment?

- As a part of the Title V Maternal and Child Health (MCH) Block Grant, every five years the Community and Family Health Division at the Minnesota Department of Health completes a comprehensive needs assessment to better understand the current state of health and well-being of women, children, and families in the State of Minnesota. As part of the needs assessment, we also look at the capacity of our state and local systems to meet those needs.
- We are currently reviewing existing materials, reports, and data to answer the question, ‘*What do we already know?*’ However, we also recognize the information we already know does not represent all community needs and that things may have changed since information was last collected. For that reason, we are sending out a Discovery Survey.

What is a Discovery Survey?

- The Discovery Survey is being distributed to women, youth, parents, community members, and people who work with women and children across the state.
- The Discovery Survey is short (only two questions!) on purpose: our goal is to make sure we hear about all the needs of women, children and families in Minnesota. Once we have heard back from you, we will compile a big list of needs of this population. After that we will do additional activities to help us narrow down the list to a set of statewide priorities.

How can you help?

- Post the discovery survey link on your website, email it to your program staff, send it out to partners and participants via email distribution lists, and of course, respond to the survey yourself! We also encourage you to send the link to family, friends, and any other social groups you are a part of; we want to hear from anyone who might have thoughts about what women and children in Minnesota need to thrive and reach their fullest potential!
- We appreciate your help and we want to share the information we collect! If you would like to receive a summary of the survey results please let us know. We expect to close the survey in July, and would hope to have information to share with you in late summer/early fall.

Thank you for your engagement and your time!

MDH Community & Family Health Staff

Appendix 2. Social Media Marketing for Discovery Survey

Social Media Blurb

Help the Minnesota Department of Health better understand what women, children and families in the state need to thrive and reach their fullest potential!

Respond to this short 2-question [survey](#).

Listserv Blurb

The Minnesota Department of Health is conducting a maternal & child health needs assessment! Respond to this short 2-question [survey](#) to make sure the needs of women, children and families in your community are heard!

Appendix 3. The Discovery Survey



Discovery Survey

Thank you for taking the time to tell us what you think about the needs of women, children, and families in your community! Please respond with as much information as you'd like to share.

What is the most important thing women, children, and families need to live their fullest lives?

What are the biggest unmet needs of women, children, and families in your community?

Tell us about you! Please note: All demographic questions are optional.

How would you identify yourself? (Check all that apply)

- Mother
- Father
- Other Guardian
- Adolescent or Youth
- Parent/Guardian/Advocate of a Child with Special Health Needs
- Healthcare Professional
- Local Public Health Staff
- MDH Staff
- DHS Staff
- MDE Staff
- Other State Agency Staff
- Other Maternal & Child Health Workforce
- Policymaker
- Community-based Organization or Non-profit Staff Member
- Community Member
- Community Leader

What county do you live in? _____

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What is your age?

- Under 18 years old
- 18-24 years old
- 25-34 years old
- 35-49 years old
- 50-64 years old
- 65+ years old

How do you identify your race/ethnicity? (Select all that apply)

- Black, African American, or African
- American Indian, Native American, or Alaska Native
- Other: _____
- Prefer not to answer
- Asian American or Asian
- Hispanic or Latino
- White or Caucasian

Please further specify your race/ethnicity:

- Ethiopian or Amharic
- Oromo
- Somali
- Hmong
- Vietnamese
- Karen, Karenni, or other Burmese ancestry
- Other: _____
- Prefer not to answer
- Asian Indian
- Mexican
- Puerto Rican
- Other Hispanic or Latino:
- German
- Irish
- Norwegian

Please specify your Tribal Affiliation (if applicable): _____

What best describes your sexual orientation?

- Lesbian
- Gay
- Bisexual
- Other: _____
- Prefer not to answer
- Queer
- Two Spirit/Native LGBTQ
- Straight/Heterosexual

What is your current gender identity?

- Female/Woman
- Male/Man
- Trans female/Trans woman
- Different identity: _____
- Prefer not to answer
- Trans male/Trans man
- Genderqueer/Gender non-conforming

What is your assigned sex at birth?

- Male
- Female
- Intersex
- Prefer not to answer

If there anything else you would like us to know about how you identify yourself, please share it below.

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If you are interested in participating in future needs assessment activities (like focus groups or answering more in-depth surveys) or if you would like to be a part of choosing our statewide priorities, please give your contact information and we will reach out to you with more information about future opportunities.

Your name: _____

Phone number: _____

Email address: _____

Thank you for completing the Discovery Survey!



Appendix 4. Follow-up Email to Discovery Survey

Subject: Thank you for responding to the Discovery Survey!

Good afternoon!

Thank you for responding to the Minnesota Department of Health's Discovery Survey about the needs of women, children and families in your community! As of yesterday, the final count was 2,736 survey responses from across the state. We have carefully read through every answer and deeply appreciate hearing the thoughts, stories and experiences you shared with us. In November we will be hosting a discussion of the survey results and sharing what we learned with you and your communities, and we hope you'll join us! Discovery Survey and Needs Assessment updates can be found on MDH's [Title V Maternal & Child Health Needs Assessment website](#).

We appreciate you providing your contact information so that we can continue to partner with you on this important work! You will receive **two emails** in the future:

- First Email - October/November 2018 - Invitation to join in the discussion and review of survey results (web-based)
- Second Email - Spring 2019 - Invitation to participate in choosing Minnesota's set of statewide priorities for women and children's health (in-person with options for people to participate remotely)

It is possible that we might reach out one additional time to some of you if your responses suggest you might be a good fit for a topic-specific focus group or interview; if this is the case that email will come sometime this fall/early winter.

Again, thank you so much for sharing and participating in the survey. We cannot do this work without our partners and community members, and we are grateful for your continued engagement and partnership!

Sincerely,

The Title V Needs Assessment Team

Appendix 5. Key Informant Interview Protocol

Key Informant Interview Question Set

Key Informant Name: _____

Position: _____

Organization Name: _____

Hi _____ (informant name), my name is _____ and I am a student at the _____ (school name) working with the Minnesota Department of Health. We are conducting interviews because this information will help us understand the needs of women, children, and families in Minnesota as we conduct the Title V Maternal and Child Health Needs Assessment. You were identified as a key person with insight into maternal and child health efforts in Minnesota.

Your responses and the responses from others will be used to write a needs assessment and assist with future public health planning efforts (i.e. programs offered by public health partners in Minnesota). Your responses are considered public data, though we will ask your permission before publishing or sharing anything you disclose during this interview. We expect this interview to take no more than 30 minutes.

Signature: _____ Date: _____

Background

1. Please tell me about your role in [organization].
2. What population does [organization] serve? Please be specific and note any marginalized populations.
3. How do women, children, and families find out about your organization?
4. What services, resources, and information does [organization] provide?

Services/ Resources

5. If women, children, and families ask for resources that [organization] cannot provide, where do you refer them?
6. What are the biggest unmet needs of women, children, and families in your community?- especially subpopulations

Prompt:

- Housing
- Childcare

TOOLKIT TITLE

- Finances/Income
- Education
- Safety
- Paid leave (maternity and paternity)
- Mental health
- Transportation
- Support systems
- Healthy food
- Dental care

7. What actions need to be taken to address these unmet needs?
8. How has your community's needs changed throughout the years?
9. How has utilization of your services changed in the past year?
10. How has [*organization*] adapted to the changing needs of the community?
11. Do you think policymakers are willing to make the necessary changes to improve your community?
12. How have policies impacted the wellbeing of women, children, and families?
13. Can you tell us about some of the strengths of your community and of the people your organization serves?

Wrapping Up

- Are there other concerns you have about the health of women, children, and families in Minnesota? Is there anything else you would like to add?
- Is there anything else that we should know about your community and the population you serve?
- Are there other people/organizations you recommend we talk to?

14. What would be the best way to reach you to follow-up on Needs Assessment activities?

Email: _____ Phone: _____

Thank You

Thank you for taking the time to complete this interview. Your opinions and responses are both valued and respected. Thank you and have a great day.

Appendix 6. CYSHN Focus Group Protocol- Example Well-Being Topic

CYSHN Focus Group Protocol

Specific Topic: Well-Being

Hello everyone. Thank you for participating in this focus group today. I'd like to start by introducing myself; my name is _____ and I work at Wilder Research. This is my colleague _____ and he'll/she'll be helping me today by taking notes.

We are helping the Minnesota Department of Health's Children and Youth with Special Health Needs Program complete their Maternal and Child Health Needs Assessment.

- This program of MDH works to improve the health of children with special health needs and their families by improving the capacity of the systems that serve them, providing education and support to families and service providers, and shaping public policy.
- MDH is required to complete this comprehensive Title V maternal and child health needs assessment every five years, with the goal of better understanding the needs of families in order to improve the health and well-being of children with special needs and their families and by strengthening partnership that support children and families.

During the summer of 2018, nearly 2,800 people responded to a Discovery Survey to share their thoughts on the greatest unmet needs of women, children and families in their communities, along with what they need to thrive and live their best lives. To further explore topics survey respondents identified as most important, MDH reached out to Wilder for help conducting 9 focus groups that will explore these topics in greater detail by talking with parents of children with special health needs. After completing these focus groups we will write up a summary identifying the themes we heard come out of the groups.

The topic we are going to be focusing our conversation around today is how parents of children with special health needs manage stress and what feeling good and being healthy look like for you. This means that for the next hour or so we are going to take the time for you to think about how you feel and how you navigate caring for your child or children with special health needs.

Before we get started, I just want to note a few things.

- We want to be able to hear from all of you, so thank you in advance for sharing your ideas and for making sure that others also have a chance to give their input.
- We will be putting together a report to share with MDH about what we learn from these discussions. We are including a sign-up sheet near the door if you would also like to be sent a copy of that report.
- In the report we put together, we may use some direct quotes from this discussion, but we will not name you directly. I'd like to record our discussion so that I can accurately

TOOLKIT TITLE

reference all the details of the conversation. The recording will only be used by ourselves and a small team of staff at Wilder. Does anyone have concerns about the discussion being recorded?

- There are no right or wrong answers, and we expect that people might have different points of view. Our role is to listen to ask questions, listen, and make sure that everyone has a chance to share.

Does anyone have any questions before we begin? Let's begin by getting to know about each other more.

1. Briefly share your:
 - a. name
 - b. how many children you have and their ages
2. First I want everyone to take a couple seconds to think back to a time when as a parent of a child with special health needs you felt good, you were coping well with parenting...What made that time particular good?
 - a. As a parent what were you doing, or not doing, for yourself when you felt good?
 - b. Who were you connected to in your family or community when you felt good?
3. Next I want you to think about what you do on an ongoing basis to manage the responsibilities of parenting a child with special health needs?
 - a. Probe: What strategies or resources do you use to help manage the responsibilities of parenting?
4. We know that all parents often feel stressed, however parents of kids with special health needs may feel particularly stressed and isolated. What do you find most stressful about being a parent of a child with special health needs?
 - a. What things do you need (or need more of) to help with the responsibilities of caring for your child or to feel less stressed?
5. As a parent, what do you feel is your biggest strength that helps ensure your child's needs are met?

Thank you!

Post Focus Group Survey

1. What kinds of services do you use for your child with special healthcare needs? (check all that apply)

TOOLKIT TITLE

- Adaptive sports/recreation
 - Assistive technology
 - Counseling/psychiatry or other mental health supports
 - In-home skilled nursing care
 - Individualized Education Plan (IEP)
 - Occupational therapy
 - Personal Care Assistant (PCA)
 - Physical therapy
 - Respite care
 - Speech, auditory, or vision therapy
 - Other services, please specify
-

2. How would you describe your race? Check all that apply

- African American/Black
- Asian American
- American Indian/Alaska Native
- Hispanic
- White/Caucasian
- Other, please describe _____

3. How would you describe your ethnicity?

- Hispanic
- Non-Hispanic

4. Does your family regularly speak a language(s) other than English?

- Yes, please specify the language(s) _____
- No

5. What type of health insurance covers your child's healthcare needs? Check all that apply

- Private insurance
- Public insurance