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UNIVERSITY OF WISCONSIN-MADISON
University Center for Excellence in Developmental Disabilities

Making the Case for Newborn Screening Outreach and Education in Plain Communities



This issue brief shares the results of a survey completed between 2014 and 2016 by 520 Amish and Mennonite families living in rural Wisconsin. The survey helped to identify that these families are open to newborn screening, and rely primarily on the midwives serving them to learn about newborn screening.

The survey and methods to obtain responses were reviewed by a Plain Community Advisory Committee in Wisconsin. Implementation of the survey was supported by grants to the University of Wisconsin from the Wisconsin Partnership program, Genetic Alliance, and the Clinical and Translational Science program. Many people contributed to the project, including the families who responded, faculty, staff, students and trainees at UW Madison Department of Pediatrics and the Leadership Education in Neurodevelopmental Disabilities (LEND) program at the University Center for Excellence in Developmental Disabilities, Waisman Center.

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Issue Statement

The Wisconsin Plain communities, like other separatist populations, have an increased prevalence of autosomal recessive disorders due to genetic homogeneity. Newborn genetic screening (NBS), a mandatory state health program for early detection and intervention of treatable genetic disorders in infants, is performed at a lower rate for children in Plain communities than those in the general population, primarily due to their high rates of out-of-hospital births. While community outreach and education of community members and birth attendants has improved acceptance and rates of newborn screening within Plain communities, there remains room for improvement. Continuing education and outreach to members of the Plain communities, and especially to midwives and public health nurses serving them, has been shown to be a successful strategy to improve rates of NBS for out-of-hospital births.

Background

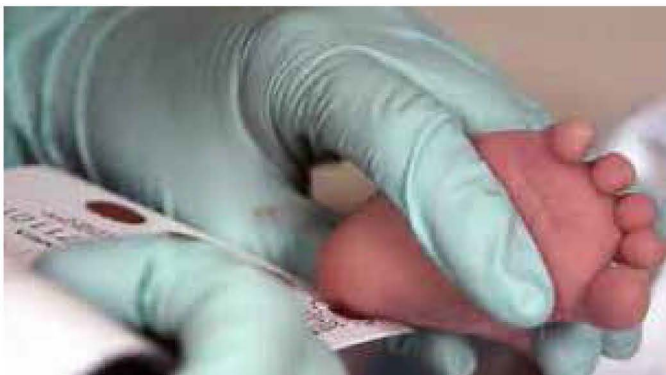
There are a growing number of Plain communities in rural Wisconsin composed of different groups following separatist religious practices, primarily Amish and Old-Order Mennonites. Wisconsin is now home to the fourth largest Amish population in the United States.¹ While Plain communities do not reject modern medicine, they trust in God as the primary healer, and are less likely to seek out medical attention for minor ailments. Plain communities have a much higher rate of out-of-hospital (in-home) births than the general population.² This results in lower rates of newborn screening (NBS), with an estimated

Background, continued

50 percent of Plain babies receiving NBS in 2015.³ Amish populations also have altered health risks compared to the general population. Their isolation results in a genetic homogeneity resulting in higher risks of genetic disorders, including those detected by NBS.

Newborn blood screening for genetic disorders involves a blood sample from a simple prick to the baby's heel, which is spotted on a specialized piece of filter paper called a blood card. The blood cards are then sent to the Wisconsin State Lab of Hygiene for testing. The test is able to identify forty-six disorders that require early intervention to prevent serious health and developmental outcomes. The cost of a blood card is currently \$109, but "fee exempt" cards are provided to midwives serving out of hospital births to ensure all newborns are tested regardless of a family's ability to pay.

Resources such as the Center for Special Children, located in La Farge, WI, have been created to serve Plain and rural populations in western Wisconsin. The center aims to provide low-cost care for children with genetic disorders, which is important for Plain Communities, as they typically do not participate in standard health insurance plans. Approximately 15 percent of patients at the LaFarge Clinic are members of the Plain Community.⁴ Starting in 2011, education to midwives serving Plain communities through group and individual newborn screening training was conducted by the WI State Department of Health Services and collaborating partners. Midwives are supplied with blood cards as well as given access to equipment to perform newborn hearing and critical congenital health disease screening for newborn babies.



Survey Methods

A Plain Community survey, adapted from a similar survey project done in Topeka, IN, was distributed within Plain communities throughout Wisconsin from August 2014 to March 2016. The primary mechanism of survey distribution was providing the survey to midwives and bishops during community meetings, who then distributed the written survey to households in their communities. Survey questions were designed to determine respondents' opinions and beliefs surrounding newborn screening as well as to collect information on family status, diagnosed genetic conditions, undiagnosed conditions and unmet medical needs, deceased children, allergic disease, and contact information. The survey was designed to be completed one per family and was not deemed to constitute research by the UW Institutional Review Board.⁵ A sample question from the survey is provided below:

How much do you know about newborn screening?

1	2	3	4	5
A Lot	Some	A Little	Nothing	Never Heard of it

Implications

The majority of families reported their main source of information on NBS came from their midwives.

Therefore, educating midwives may be the most effective method for increasing NBS. Midwives can not only perform the blood test for the screening, but can also educate about NBS throughout their communities.

Given the survey responses, it does not appear the Amish and Mennonite cultures discourage the practice of NBS. However, some families were much more educated on the topic than others, demonstrating a lack of consistent practice regarding education of families on NBS. While many families viewed NBS as somewhat important, only 36 percent of families had all their children screened. The most common reason given for lack of screening was that families were simply unaware of newborn screening or their provider did not offer it.

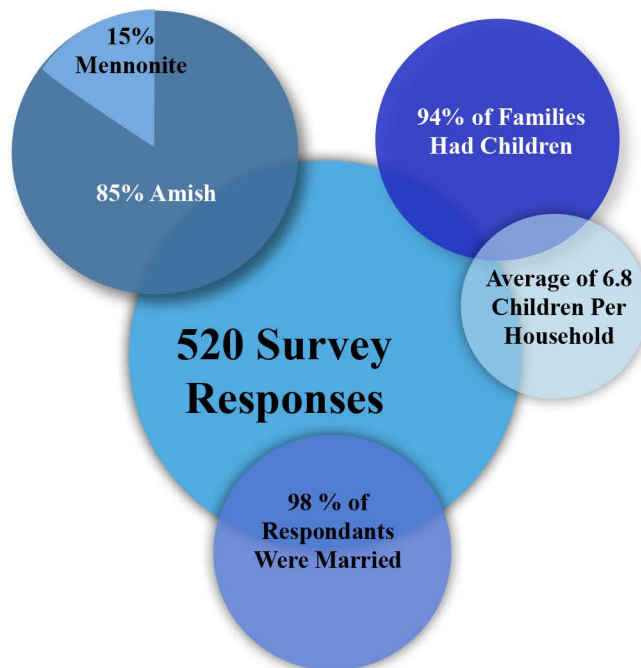
Survey Results

There were 520 surveys returned, with the majority coming from Amish families.

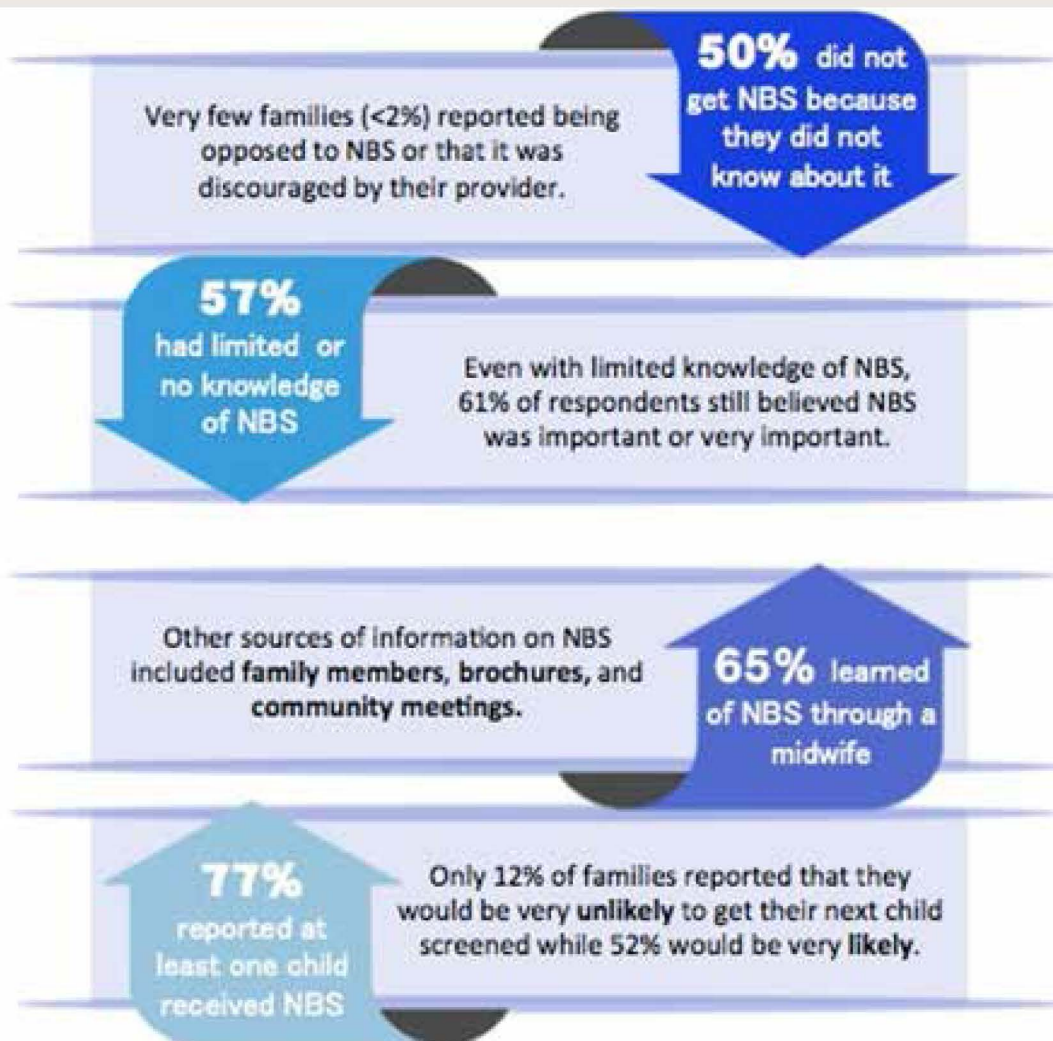
Surveys were received from 22 counties primarily in western Wisconsin with the highest rate of respondents coming from Vernon, Monroe and Clark counties.

Results showed that low NBS utilization among Plain families who responded to the survey is due primarily to a lack of knowledge and awareness. This information gap extended to both the availability of NBS, and benefits of the screening test for their children. While many families stated they were unaware of NBS, very few reported being opposed to or having negative views toward it. Survey responses also revealed that the majority of information families have about NBS comes from midwives in the community.

Demographics of Respondents

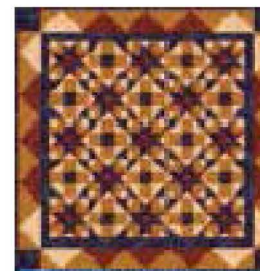
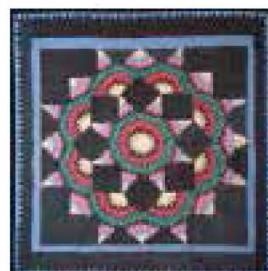
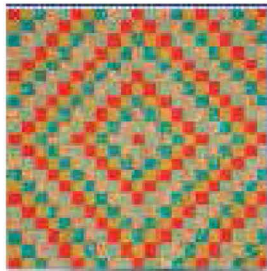
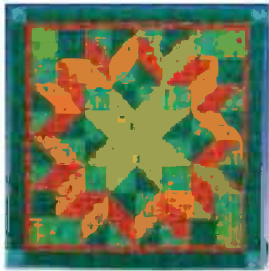


Awareness of Newborn Screening



Monitoring Newborn Screening Rates

As education and outreach efforts are continued, an important step in improving NBS rates in Plain communities is the ability to monitor changes in screening rates. Currently in Wisconsin, birth certificates do not identify babies as being a part of a Plain community. In order to accomplish this, an algorithm was developed to identify which birth certificates belong to an Amish baby. A birth is considered Amish if the mother is non-Hispanic, white, adult, married, from the U.S. or Canada, and has a 6th grade-level education. This algorithm has very high sensitivity and specificity (both over 98%). Identification of Amish birth certificates allows state epidemiologists to more accurately quantify rates of NBS among Plain communities. This is useful in monitoring the effectiveness of outreach efforts as well as to identify communities where NBS rates are low. Further investigation is necessary to determine if this method can be used to identify Mennonite births as well as Amish (unpublished data, Angie Rohan, WI Department of Health Services).



Conclusion and Recommendations

Newborn screening ensures early detection and treatment for a variety of treatable genetic disorders. Given their unique risk factors, NBS is particularly important for babies born in the Plain communities. Their genetic homogeneity puts babies at greater risk for certain recessive genetic disorders that can be identified during newborn testing. High costs associated with the consequences of untreated genetic conditions make NBS especially important for Plain communities due to their lack of insurance coverage. One study found that the costs-savings of early detection to be 15:1.⁶

Based on the Plain Community Survey results, we recommend continuing outreach and education efforts to Plain communities. Using an algorithm to identify Amish births and monitor newborn screening rates will allow for the verification of progress in education and outreach to improve newborn screening rates. Most Plain communities welcome education efforts in order to improve the health of their children and community. We expect that with continued education and support of follow up services, the number of screened newborns in Plain communities will continue to increase.

References

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