VERMONT INFANT SAFE SLEEP QUALITATIVE RESEARCH REPORT

Vermont Department of Health

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Submitted by:
JSI Research & Training Institute, Inc.

Vermont Infant Safe Sleep: Qualitative Research Report

Executive Summary

The Vermont Department of Health contracted JSI Research and Training Institute, Inc. (JSI) to develop an evidence-driven campaign to promote infant safe sleep in Vermont. Building on an environmental scan of existing research and efforts to promote infant safe sleep, JSI also conducted key informant interviews and focus groups to further study the perspectives of Vermont providers and parents. Key findings include:

Knowledge and Practice

- Most parents know the basic safe sleep guidelines (i.e. supine position, in separate sleep space, nothing around the baby), but many parents find them challenging to follow
- The focus group participants' infant sleep practices were similar to the Pregnancy Risk Assessment Monitoring System (PRAMS) data: 83% of parents put their babies on their back to sleep always or often,[i] 71% of babies slept in their own crib, bassinet, or Pack 'N Play always or often
- All parents are concerned about their infants' sleep safety. What they understand about Sudden Infant Death Syndrome (SIDS) is confusing the issue of co-sleeping, suffocation risk, and safe sleep
- Most parents have heard safe sleep information from healthcare professionals, who are perceived as the most trustworthy information source, though healthcare professionals may give conflicting or insufficient information

Populations

- Parents may be broadly categorized as: 1) parents who intend to and successfully practice the American Academy of Pediatrics (AAP) Guidelines for Safe Sleep; 2) parents who intend to and yet fail to practice the AAP Guidelines; and 3) parents who do not intend to and do not practice the AAP Guidelines
- Parents in the latter category typically believe that co-sleeping is safer and/or better
  - It may be cultural
  - They may judge the "SIDS parents," they are the "other" and not them
- Parents in the second category have often attempted to follow the AAP Guidelines, but encountered complications, and saw no other choice but to bedshare
  - Key informants identified the second category as a priority, and one for which they lacked helpful messaging and resources
  - These parents feel like they have to choose between sleep and safety OR they adapt the Guidelines and feel like they are "doing safe sleep"
  - Parents want information to help them when things "go wrong" and they are not successfully able to have their baby sleep "alone,"
  - Most parents feel they are being judged and already feel guilty about something they are doing/not doing

Messaging Implications

- Breastfeeding is contributing to co-sleeping for a variety of reasons – but it is not the largest contributor, lack of sleep/inability to get enough sleep in the largest contributing factor
- While the "ABC" pneumonic may be useful, "Alone" is meeting resistance and confusion

- The idea that there is one correct way to put a baby to sleep safely does not fit with parents' values and beliefs around raising an infant and will be met with resistance
- Making materials to assist parents when things "go wrong" would address an unmet need

Key Informant Interviews

JSI conducted nine interviews with professionals who have diverse types of experience with addressing infant safe sleep. Among the interviewees, there were two pediatricians, a nurse midwife, a nurse clinical manager, two lactation consultants, an assistant medical examiner coordinator, three nurses from Nurse Family Partnership, and three maternal child health coordinators.

Name	Occupation
Amelia Hopkins, MD	**Pediatrician** The University of Vermont Health Network Children's Specialty Clinic
Eliot Nelson, MD	**Pediatrician** Associate Professor of General Pediatrics Department of Pediatrics University of Vermont Vermont Child Health Improvement Program
Meredith Merritt, RN, CNM	**Certified Nurse Midwife** Brattleboro OB/GYN
Sarah Bache, BSN, RNC-OB, CLC	**Nurse Clinical Manager of Women & Children's Services** Rutland Regional Medical Center
Tricia Cassi, IBCLC	**Lactation Consultant Specialist** Vermont Department of Health Division of Maternal and Child Health WIC State Breastfeeding Coordinator
Laura McCormick, IBCLC	**Lactation Consultant**
Lauri W. McGivern, F-ABMDI	**Assistant Medical Examiner Coordinator** Office of the Chief Medical Examiner
Terri Palermo **Becca Rainville** **Kim Rowntree**	**Nurse Family Partnership Nurses**
Jessica Doos **Merideth Plumpton** **Heather Simkins**	**Maternal Child Health Coordinators**

Key Informant Interview Themes

Five main themes emerged from the key informant interviews:

1. Parents know the safe sleep guidelines, but have a tough time following them
2. Providers disagree on relative safety of bedsharing, particularly lactation consultants and nurses
3. Many providers struggle with how to respond to parents who bedshare instead of following the AAP guidelines
4. Most key informants think it is a good idea to share information about minimizing the risks of bedsharing, though some are concerned it may send a mixed message
5. Recommendations for safe sleep messaging

1. Parents know the safe sleep guidelines, but have a tough time following them

According to the key informants, most parents were aware that babies should sleep on their back in the crib, though parents were less likely to be aware of other safe sleep guidelines, such as not smoking. Bedsharing is the most risky infant sleep practice that parents struggle with avoiding. Most did not bedshare as their first choice, but rather do so after experiencing difficulty getting the baby to sleep in a safe sleep environment:

> *"**The more common thing is, we always put her to bed, at the beginning in the bed, if she's woken up the second time, we're so tired, and she sleeps the rest of the night in our bed**. And the way that I respond to that is to, be, express a little empathy and sympathy with how hard it is to be tired in the middle of the night. And then I… try to explore a little bit with them about how they might be able to get the baby back into bed… It's not a matter of telling what's safest; it's a matter of trying to figure out how can they change what they're doing behavior-wise."*

Some high-risk groups, including those who may have low income, substance abuse issues, or an unstable home setting, may have particular difficulty following the guidelines given the other challenges they face:

> *"We have a lot of families who are staying with friends, relatives, rotating through places… There's a lot of pressure on families to not be disruptive to places they're staying with their infants. And you've got second, third shift folks working as well and there's nothing I see in any of our messaging that's addressing any of that… **Their crying baby disturbs the whole house… And may lose the family their housing**. 'Timmy's losing sleep, his boss is going to fire him, and you've got to go.'"*

These high-risk families may be especially unreceptive to authority figures who tell them what to do not only with regard to safe sleep, but for many other aspects of their lives.

Finally, the key informants felt that there was a certain subgroup of parents that choose to bedshare because they believe it is not only safe, but better for their babies. These parents have had personal experience with bedsharing without consequence, and feel confident that they can continue to do so. The key informants felt that safe sleep messaging did not get through to these parents.

2. Providers disagree on relative safety of bedsharing, particularly lactation consultants and nurses

Parents receive mixed messages about whether bedsharing can be safe. They may hear mixed messages from their family members, friends, peer groups, media sources, as well as providers. The key informants held different opinions about the relative safety of bedsharing and therefore gave different guidance to their patients.

Interviewees who had professional experience with a sudden unexpected infant death (SUID) tended to feel strongly against bedsharing. Nurses and lactation consultants tended to be more amenable to bedsharing, and cited materials from James McKenna, Helen Ball, UNICEF, and the Academy of Breastfeeding as reputable sources of research on how bedsharing can be safely implemented. Research can also persuade providers about the dangers of bedsharing – for instance, Dr. Hopkins successfully changed the minds of OB and VNA nurses by presenting studies on heart rate, apneic events, a meta-analysis (by Carpenter et al in BMJ), and SUPC events in hospitals.

Some interviewees felt that bedsharing was an appropriate choice for some parents, saying:

> *"I really believe* ***we need to tailor our statements for mothers****. I do not agree with the AAP based safe sleep guidelines that give one size fits all."*

Guidance on how to bedshare more safely was delivered depending on context. Interviewees would stick to the AAP guidelines when teaching in a class given certain constraints from their professional role, but they may offer guidance on a one-on-one basis in parents' homes. Particularly, if parents have faced difficulty with following safe sleep guidelines, have already tried bedsharing, were breastfeeding, and there were no other risk factors (e.g. smoking, obesity), providers were more likely to offer advice on how to bedshare.

3. Many providers struggle with how to respond to parents who bedshare instead of following the AAP guidelines

All provider interviewees struggled with how to respond to parents who faced difficulty in following the safe sleep guidelines. Providers, regardless of their beliefs about bedsharing safety, described feeling sympathy for the challenges parents faced, and uncertainty regarding how to advise parents:

> *"And then the other thing I hear frequently from pediatricians and nurses is, what do you do – you hear parents who say, my baby will only fall asleep on my chest.* ***I don't know what the right thing is to say*** *to those parents when they're completely sleep deprived and exhausted. I don't know what to say when the baby is screaming once you put them down."*

> *"Some fathers of the babies will not get up and help and some moms are single moms and what do you do? Because the baby quiets when you bring it into bed with you. So what do you do?.. I try to teach them something about sleep behavior. When an infant is fed they'll go into a light sleep and stay in light sleep for half an hour and then drift into a deeper sleep and you might have success. If you have baby into deep sleep you might*

have a better chance then, but might not always work either… It's like, ***what options do these poor moms have?*** *We're telling them not to do so much."*

Providers also struggled with how to respond to the ubiquity of bedsharing, especially when in a group context:

> *"We can't really ever say, 'It's fine, it's okay to do this.' But it is also hard sitting there and hearing these eight women say, this is what we're doing.* ***If the majority of them are doing it, it's silly to say to everyone that they need to get their babies in the cribs on their backs. It's just not the reality of what's happening****, it's not."*

4. Most key informants think it is a good idea to share information about minimizing the risks of bedsharing, though some are concerned it may send a mixed message

Many provider interviewees felt supportive of offering information on how to minimize the risks of bedsharing. Because many parents still bedshare despite knowing the safe sleep guidelines, interviewees felt it was important to address this reality by reducing bedsharing risks:

> *"I don't believe that one size fits all,* ***just like abstinence education doesn't prevent pregnancy –*** *they're tired they're breastfeeding their baby,* ***it's going to happen****."*

> *"We should not say there is a way to safely bedshare. However… I still think there's a huge group of people who are going to bedshare regardless….* ***I believe in a risk reduction model, where we say it's absolutely safest to do follow the AAP recommendations, but if you're going to bedshare, then this is how you minimize the risks****… I liken it a little bit to the vaccine debate… an alternative schedule is better than no vaccines."*

> *"I think we all need to be talking about the realities of sleep and how to make it safer… obviously* ***the reality is that what we're telling parents to do is not happening, and let's not make them feel guilty and scared about it.*** *But I think we are so frightened, myself included, about liability and having this mixed message of saying bedsharing is okay."*

Like in the above quote, some key informants had concerns that caregivers would interpret this information to mean that bedsharing is safe, though others disagreed.

5. Recommendations for safe sleep messaging

Providers found it challenging to deliver safe sleep information given time constraints, and often focused on the key safe sleep recommendations rather than all of them. Many interviewees recommended home visits as a prime opportunity for delivering safe sleep guidance, especially after the baby is a few weeks old, to have the time, parental experience, and physical environment to help address parents' safe sleep struggles in a productive manner. Interviewees also mentioned the importance of repetition of safe sleep information over time from different parties, and that text or email messaging could be one way of delivering this information.

The key informants disagreed on the extent to which safe sleep messaging ought to emphasize the consequences of bedsharing:

> *"I've shown this video of this medical examiner in VA who talks about autopsies on dead babies. It's super frightening. They react to that you know. They find that really, really scary and they feel like whoa I didn't know that, I didn't know that that could happen.* ***It seems to trigger some protective reflex in them*** *to protect their babies."*

> *"The scary stuff where you see the headstone in the bed, it's just upsetting, and it doesn't move the needle.* ***It makes them feel defensive or freaks them out****. And they're afraid to sleep. It's not the most useful approach."*

Providers agreed that the "ABCs" (Alone, Back, Crib) were an easy safe sleep message to remember, though most had criticisms of it. Providers felt that parents needed more guidance on how to get the baby to sleep (e.g. education on deep versus light sleep, how to take turns with one's support system, etc.), rather than more safety recommendations, and tangible resources for high-risk groups:

> *"It's one thing to say a message about how it should be, but* ***if you don't offer concrete supports to pull that off, something gets lost in that messaging****."*

Focus Groups

The purpose of the focus groups was to gather qualitative data on:

- What parents know or have heard about infant safe sleep practices
- What confuses parents about infant safe sleep practices
- How parents decide to put their babies to sleep in terms of location, sleep position, and nearby objects
- How parents respond to existing safe sleep campaign materials
- In addition, a survey will capture parents' demographic information, current infant safe sleep practices, and safe sleep information sources

JSI conducted four focus groups with Vermont parents in Brattleboro (N=11), Burlington (N=21), Morrisville (N=11), and St. Johnsbury (N=12). The total number of focus group was N=55. Focus group participants needed to be at least 18 years old and have an infant under 12 months old. (However, due to the collaborative nature of recruiting for the focus groups, there was one participant under 18 years of age with parental consent and a key informant with a child over a year.)

In addition, two, New American mothers, one from Bhutan (with her first child) and one from Burundi (with her third child), were interviewed to explore potentially different messaging needs of non-native populations. Overall, these key informants gave similar sentiments as the focus group participant parents.

Survey Results

A survey was administered to focus group participants to collect information about their demographic characteristics, infant sleep practices, and infant safe sleep information sources.

Demographic characteristics

Most of the focus group participants identified as female (87%) and were between the ages of 25-34 (37% were 25-29 years old; 20% were 30-34 years old). Most focus group participants were not Hispanic or Latino (95%) and identified as White (93%). About half of the focus group participants had one child (54%), and about a third of the focus group participants had 2 or 3 children (35%). Parents aged 25-39 reported having 3 or more children while those under 25 years of age or 40+ had 1-2 children, in our sample. This same group of parents (25-39) reported having a child/children that were 6 years of age or older while the other age sets(<25 or >40) did not, respectively.

		N	%
Gender	Female	48	87
	Male	7	13
Age	18-24	10	19
	25-29	20	37
	30-34	11	20
	35-39	8	15
	40+	5	9
	Skipped	1	2
Hispanic/Latino	Yes	3	5
	No	52	95
Race (check all the apply)	White	51	93
	Black or African America	1	2
	Asian	3	5
	Native Hawaiian or Other Pacific Islander	0	0
	American Indian or Alaska Native	1	2
	Other	2	4
Number of Children	1	29	54
	2	11	20
	3	8	15
	4	4	7
	5	2	4
	6+	0	0

Infant safe sleep practices

In terms of infant sleep position, focus group participants typically placed their babies on their back to sleep (83% reported doing so always or often). This proportion is similar to the percentage of infants placed to sleep on their backs in the Vermont PRAMS data, which ranged from 84.1 to 86.3% from 2011 to 2014. Nearly half of focus group participants (41%) reported putting their babies down to sleep on their side at least sometimes, and about a quarter of the focus group participants reported putting their babies down to sleep on their stomach at least sometimes (24%).

How often do you lay your baby down to sleep in the following positions:						
% N	**Always**	**Often**	**Sometimes**	**Rarely**	**Never**	**Total**
On his or side	**7%** **3**	**16%** **7**	**18%** **8**	**9%** **8**	**51%** **23**	**45**
On his or her back	**74%** **40**	**19%** **10**	**6%** **3**	**0%** **0**	**2%** **1**	**54**
On his or her stomach	**4%** **2**	**9%** **4**	**11%** **5**	**11%** **5**	**64%** **29**	**45**

In terms of infant sleep location, most focus group parents said that their babies slept in a crib, bassinet, or pack and play always or often (70%). Most focus group participants said that their babies slept alone

in their own crib or bed (71% reported doing so always or often). On the other hand, 17% of parents reported doing so rarely or never.

How often do you lay your baby down to sleep in the following positions:						
% N	Always	Often	Sometimes	Rarely	Never	Total
In a crib, bassinet, or pack and play	45% 24	25% 13	9% 5	8% 4	13% 7	53
On a twin or larger mattress or bed	12% 6	14% 7	10% 5	10% 5	55% 28	51
On a couch, sofa, or armchair	0% 0	2% 1	4% 2	10% 5	85% 42	50
In an infant car seat or swing	2% 1	8% 4	33% 16	18% 9	39% 19	49
In a sleeping sack or wearable blanket	13% 6	4% 2	8% 4	6% 3	69% 33	48
With a blanket	8% 4	16% 8	26% 13	8% 4	42% 21	50
With toys, cushions, or pillows including nursing pillows	0% 0	4% 2	12% 6	12% 6	73% 37	51
With crib bumper pads (mesh or non-mesh)	2% 1	4% 2	2% 1	2% 1	90% 46	51

In the past 2 weeks, how often has your new born baby slept alone in his or her own crib or bed?						
	Always	Often	Sometimes	Rarely	Never	Total
%	43%	28%	11%	8%	9%	
N	23	15	6	4	5	53

Infant safe sleep information sources

The vast majority of parents reported hearing from a healthcare professional that they should place their baby in on their back to sleep (94%); put them to sleep in a crib, bassinet, or pack and play (87%); place the baby's crib or bed in the parent's room (74%), and about what should and should not go in the bed with the baby (91%).

Did a doctor, nurse or other health care professional tell you any of the following things?			
% N	Yes	No	Total
Place my baby on his or her back to sleep	94% 51	6% 3	54
Place my baby to sleep in a crib, bassinet, or pack and play	87% 47	13% 7	54
Place my baby's crib or bed in my room	74% 40	26% 14	54
What things should and should not go in bed with my baby	91% 48	9% 5	53

Nearly every focus group participant heard about safe sleep information from a doctor, nurse, or healthcare professional (98%). Family (67%); friends, neighbors, or co-workers (65%); internet, such as websites, blogs, Facebook, and Twitter (61%); and public health materials, such as brochures, posters, and magnets (53%) were also common sources of safe sleep information.

Have you seen or heard information about keeping your baby safe while sleeping from any of the following places (check all that apply):		
	%	**N**
Discussion with doctor, nurse, or other health care professional	**98**	**50**
Public health materials, such as brochures, posters, magnets	**53**	**27**
TV or radio	**22**	**11**
Print media, such as books, newspapers, magazines	**43**	**22**
Internet, such as websites, blogs, Facebook, Twitter	**61**	**31**
Phone app	**16**	**8**
Family members	**67**	**34**
Friends, neighbors, or co-workers	**65**	**33**

Among these information sources, health care professionals were the most highly trusted by far (83% reported trusting them 'a lot'). Public health materials ranked the second highest in terms of credibility, with 31% of focus group participants saying that they trusted them 'a lot,' and 45% reporting trusting them 'some.' Interpersonal sources were perceived as somewhat trustworthy, and internet sources were ranked behind interpersonal sources in terms of credibility.

How much do you trust the information about keeping your baby safe while sleeping from each of the following:					
% N	**A lot**	**Some**	**A little**	**Not at all**	**Total**
Discussion with doctor, nurse, or other health care professional	**83%** **45**	**13%** **7**	**4%** **2**	**0%** **0**	**54**
Public health materials, such as brochures, posters, magnets	**31%** **16**	**45%** **23**	**20%** **10**	**4%** **2**	**51**
TV or radio	**10%** **5**	**45%** **22**	**27%** **13**	**18%** **9**	**49**
Print media, such as books, newspapers, magazines	**21%** **10**	**51%** **24**	**21%** **10**	**6%** **3**	**47**
Internet, such as websites, blogs, Facebook, Twitter	**4%** **2**	**46%** **23**	**34%** **17**	**16%** **8**	**50**
Phone app	**5%** **2**	**39%** **17**	**30%** **13**	**27%** **12**	**44**
Family members	**26%** **14**	**53%** **28**	**15%** **8**	**6%** **3**	**53**
Friends, neighbors, or co-workers	**23%** **12**	**53%** **28**	**19%** **10**	**6%** **3**	**53**

Focus Group Themes

Twelve main themes emerged from the focus group and key informant interviews:

1. Parents are worried about sleep safety
2. Parents find some safe sleep guidelines confusing or conflicting
3. Parents know less about safety guidelines for sleep accessories
4. Breastfeeding can make following the guidelines more challenging, but it is not confusing
5. Some parents believe that co-sleeping is preferable or necessary
6. Parents respect their instincts to make the right choices for their individual situation
7. Babies' needs have a strong influence on parent sleep practices
8. Some parents have had bad experiences with trying to follow safe sleep guidelines
9. Parents want more safety information that is relevant to their experiences with safe sleep
10. Some parents have a strong distrust of authority figures
11. Some parents a highly skeptical of safe sleep research and messaging
12. Some parents who bedshare do so with ambivalence

1. Parents are worried about sleep safety

The vast majority of focus group participants described themselves as worried about infant sleep safety, regardless of their infant sleep practices. They were aware of the risk of SIDS/SUID was low, but were still worried about the possibility it could happen even when following safe sleep practices. Some parents were particularly worried about their baby breathing due to the baby's medical history. A few parents described choosing to follow safe sleep practices out of fear from the potential consequences, though other parents described choosing to bedshare because they felt it was safer.

- *"His place to sleep is safe but **just that possibility that he could stop breathing** and we don't know why **is scary to me**."*
- *"I'm an anxious person, so when I was nursing 4-5 times a night all through his newborn stage **I was really serious about not sleeping with him because I was so afraid.**"*
- *"**I used to worry** about it when he was little but **now we co-sleep**."*

2. Parents find some safe sleep guidelines confusing or conflicting

Parents described confusion regarding the safe sleep guidelines, particularly with regard to how they mapped onto developmental milestones such as the baby being able to lift their head or roll over. Parents also described the guidelines as having changed over time, which was a source of confusion and distrust for some parents, while other parents accepted this as part of medical research. Some parents described hearing conflicting information from healthcare providers who offer sleep guidance that did not match AAP recommendations.

- *"Since the day my son was born he would sleep **on his side. The doctor said it was fine.**"*
- *"In 10 more years, **they'll say lay them on their stomachs again**."*
- *"It switches all the time from back to stomach. **I get information from different people** – the doctor, the nurses, case workers, and the pediatrician – **all different**."*

3. Parents know less about safety guidelines for sleep accessories

A common topic of confusion was blankets – if or when they could use them, because otherwise the baby would be cold. Sleep sacks were not well-known among focus group participants. Additionally, parents were confused about the safety of crib bumpers, because they did not understand why an unsafe product would be sold.

- *"After they can pick their head up, **they should be able to have a blanket**."*
- *"**If crib bumpers are so dangerous why do they sell them?** They should be illegal."*

4. Breastfeeding can make following the guidelines more challenging, but it is not confusing

When asked about whether breastfeeding made following safe sleep guidelines more difficult, parents responded with a resounding "yes". Following the safe sleep guidelines as breastfeeding mothers was not confusing, but simply challenging. Breastfeeding parents who bedshared liked that they could sleep while nursing, and believed that being so physically close strengthened their bond. They also saw bedsharing as the best way to support their breastfeeding efforts, which would reduce the risk of SIDS.

- *"He started out in a Pack 'N Play next to me but **late night feedings happened so we breastfed and co-slept at the same time**."*
- *"**I nurse in my sleep a lot**, which is nice.*

5. Some parents believe that co-sleeping is preferable or necessary

Some parents perceived bedsharing as the preferred approach to infant sleep, citing more and better sleep for parents and babies, bonding, and how natural it is. Bedsharing parents believed that they would wake up if the baby moved or stopped breathing in bed beside them. Focus group participants who bedshared often experienced no adverse outcomes after doing so, which reinforced their view that it was a safe practice. Some bedsharing parents with multiple children described having co-slept successfully with the oldest children, and continuing to bedshare with them and their infant.
Other parents perceived bedsharing as a necessity due to concerns about other people in their home environment (e.g. domestic violence, other young children).

- *"**I sleep better when he's in my arms**."*
- *"**I co-sleep** a lot so I think **that's why my children sleep so well**."*
- *"My son sleeps with me, because of **domestic violence**."*
- *"I somehow have to integrate my 3 year old who is super attached to me. If I'm near the baby he wants to take his toys and is territorial. **The baby is safer sleeping in my bed away from the 3 year old** so he can't push the bassinet."*

6. Parents want respect around their instincts to make the right choices for their individual situations

A common sentiment among focus group participants was that every baby and family situation is unique, which was a mismatch from the perceived "one size fits all" nature of the AAP guidelines. Parents valued their instincts to keep their baby safe, and believed that parents should do what is right for their particular situation.

- *"As moms, we all want our babies to be at their safest.* ***It's important for me to be able to trust my instincts.*** *I'm glad to hear that is what others are doing, too."*
- *"I've put a lot of thought into it and I think it comes back to intuition about what is going to work. Even though there is pamphlet after pamphlet and wise tales,* ***it comes down to a mom's intuition.****"*

7. Babies' needs have a strong influence on parent sleep practices

Many parents described having to get their baby to sleep in particular ways, such as needing to be on someone's chest or sleeping with a blanket. These did not always match with safe sleep recommendations. Parents also expressed a desire to be responsive to their baby's need for physical closeness. Some parents felt that letting babies cry themselves to sleep was cruel, which is what they would need to do if forced to follow the safe sleep guidelines.

- *"My other baby will sleep on his belly on my chest and* ***he won't sleep any other way****. I'll just sit there with him on my chest for hours."*
- *"****Every baby is different****. They want to sleep in a certain way, and it can change. Next month maybe she will want to be in Pack 'N Play.* ***It's based on what their needs are****."*
- *"****One of my pediatricians said to let them cry it out and I don't agree with that****, so we switched."*

8. Some parents have had bad experiences with trying to follow safe sleep guidelines

Some parents described having bad experiences when attempting to follow the safe sleep guidelines. For instance, some babies needed to sleep when propped up due to medical issues like reflux. Other babies would get their body parts stuck in the bars of the crib, and other babies simply would not sleep in safe sleep environments.

- *"We had a b ad experience with formula,* ***sleeping on her back, she'd choke in her sleep*** *(the nurse just pat her on the back) but she'd choke and turn blue."*
- *"They say* ***no bumpers*** *in the crib, but my baby would get his* ***arm or leg stuck in the crib bars****."*
- *"At 2-3 weeks old, we decided* ***the bassinet didn't work****, so we took him in the bed."*

9. Parents want more safety information that is relevant to their experiences with safe sleep

Many parents already knew the basic safe sleep guidelines, and wanted more information on how to sleep safely given their particular situation. Particularly, many focus group participants asked for information on how to co-sleep safely. Some parents proposed the idea of a safe sleep consultant, like a lactation consultant, who would have expert knowledge on safe sleep and would be able to offer tailored guidance to different circumstances. Many focus group participants commented that they enjoyed the opportunity of the focus group to discuss sleep issues with other parents, and that a peer community would be helpful.

- *"There too many stipulations on **what safe sleep has to look like versus actual parenting**."*
- *"It would be nice to talk to the pediatrician and have them say, this isn't recommended but **if this is what works for you this is what you could do to make it safer**."*
- *"Maybe have **a person who can consult** on breastfeeding **and someone in safe sleep** and how I can learn more and tips can be helpful. My oldest and youngest sleep great on her back but with the breathing issue with my second, she sleeps on her stomach and it opens her airways and I wouldn't have known that if it weren't for someone telling me that."*

10. Some parents have a strong distrust of authority figures

Some parents who bedshared had a strong distrust of healthcare providers, WIC staff, and other professionals. They felt they were always being told what to do, and were being judged by them. These parents would say "yes" to authority figures in response to questions asking about compliance (e.g. safe sleep guidelines) in order to leave as quickly as possible. Some parents were frightened by the idea that co-sleeping would lead to Child Services taking their child away. Several parents reported changing their doctor so they could be honest without fear of judgment.

- *"**You have to lie to the doctor**. I agree so they leave me alone."*
- *"You can't trust the doctor. They are mandated reporters and they will call DCF. I almost didn't come because **I didn't want to tell everyone I co-sleep and get reported to Child Services**."*
- *"**We switched doctors because we felt we couldn't be honest** with the doctor anymore… Why should you have a doctor you can't be honest with if they are going to be judgmental?"*

11. Some parents are highly skeptical of safe sleep research and messaging

Some parents expressed great skepticism of safe sleep research and messaging, and wanted statistics presented with the guidance given. For some parents, the statistics would not be persuasive, as they criticized the research that found bedsharing to be unsafe as fake, outdated, and/or not representative of reality. For other parents, the statistics were irrelevant because they did not apply to them as individuals. Several parents were adamant that nothing their doctor could say could convince them that bedsharing was unsafe.

- *"If I'm listening to my EES worker or home nurse and they tell you to do this, **I wish they'd cite sources or put in statistics**. How does it make a difference? You're telling them just do it – no explanation, why is it not safe to sleep with your baby?"*

- *"**Maybe one mom rolled over. Supposedly there is research** from the CDC and state departments. You couldn't hand this [safe sleep message] in as a high school paper – no sources – where is the research? They think people are stupid."*
- *"Research is based on statistics and statistics don't represent individual people, they represent groups of people. **It's hard to say the research is best** for the majority."*

12. Some parents who bedshare do so with ambivalence

Focus group participants who bedshared sometimes felt conflicted about the practice. Some parents felt as though they had no other option but to bedshare, and felt guilty and fearful when bedsharing. Some bedsharing parents viewed risk as unavoidable but acceptable if they took precautionary measures, such as removing pillows and blankets from the bed.

- *"I co-sleep. I never intended to co-sleep. He started in a crib, but late night feedings are awful. It's conflicting because I know what's best and I know he is supposed to be in his own crib, but he won't sleep in a crib and will not sleep through the night. **It's hard for me going with what's best and recommended, versus what's best for me and the baby**."*
- *"There's ways around it. **I put the pool noodles under the sheets to separate the baby and me**."*

Interviews with New Americans

The interviews with the New Americans had similar themes to the focus group participants. There was a strong worry about and desire for the babies' safety. They understood and practiced the guidelines, though with some modifications. Co-sleeping was a cultural norm associated with safety and bonding, and leaving the baby to sleep alone was perceived as risky. These interviewees were not necessarily getting information or support from healthcare professionals. Different messaging may be needed for non-native populations, or low-literacy level materials if not translated.

Overall, these key informants gave similar sentiments as the focus group participant parents. They felt very strong worry about their baby's safety and understood and practice the guidelines – also with modifications. Both women:

- Had a strong desire to take care of their baby correctly and asked questions to clarify if they were (despite one mother being an experienced parent)
- Were not necessarily getting information or support from health care professionals, even when seeking it
- Identified co-sleeping as a cultural norm that equals safety and bonding

> *"**Normally parents from Africa have their baby sleep in their bed**. When I had my first baby it was all new. I had the crib and whatever the providers were telling me to do I did. **I also have family members that tell me that I need to create a connection between my child and me. I need to keep the baby with me when they sleep**. I believed them and they [the baby] didn't like to sleep in the crib"*

Additionally, these participants identified that leaving a baby alone is not what you do when you want your baby safe, indeed, it could be what puts the baby at risk. While one woman was interested in breaking away from family cultural norms and identified the ideas of her husband's parents as "old ways", the other key informant was closely tied to the ideas and traditions of her family – both women used family for childcare and felt family gave them a lot of advice on child rearing. One of the two

women, who works with people in her community, stressed the need for different messaging for non-native populations – and for low literacy level materials if not translated. Both women felt the ABC's were easy to understand, if you were someone who spoke and read English.

> *"I have never heard of a baby dying because of sleeping in my country. It would be so hard to convince this to them."*
> *"The NY one [brochure] is more detailed and explained more clearly. The ABC's is easy to remember. It is clear that they can see on this on the paper"*

Both women stated that they felt empowered to tell family who were watching their children how they felt the babies should be cared for. This was consistent with other parents who were in positions where they could control their environment, unlike parents who might be "couch surfing", staying at a partner's home, or with friends.

> *"I always tell them what to do and what not to do when we go out and they babysit and they listen.* ***It is my baby and I have a right and I tell them what they can and can't do****."*

Conclusion

Parents are highly motivated to do what is best for their baby. The vast majority of parents know what the basic safe sleep guidelines are. Though some parents choose to bedshare out of preference, other parents may bedshare or otherwise not follow the guidelines due to challenges in getting their baby to sleep “alone.” Parents who struggle the follow the guidelines feel they must choose between sleep and safety, or adapt the guidelines as their version of “safe sleep.” Parents want assistance to get their babies to sleep while keeping them safe and this assistance must be grounded in the reality of the challenges and choices they face.

Currently, there is little guidance on the challenges parents may face when implementing safe sleep guidelines and how to address those challenges. Providers also do not know how to advise parents on how to get their babies to sleep in safe sleep environments. The guidance given to parents must be respectful of parents’ values, including the views that babies have unique needs, and parents should be the ones to decide what is best for their family situation. The guidance should also be sensitive to the finding that many parents already feel judged and/or guilty, which may lead to parents not disclosing actual infant sleep practices or rejecting strong directives.

The qualitative research findings suggest that the Vermont Department of Health has an opportunity to address an unmet need for a significant target audience: helping parents overcome the safe sleep struggles they face. Healthcare providers will also require education on how to best assist these parents. An infant safe sleep campaign that focuses on the knowledge and skills required to adhere to safe sleep guidelines can be an effective way to support Vermont parents and reduce sleep-related infant deaths.

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[i] June 2015 Vermont Department of Health PRAMS: Infant Safe Sleep, 2009-2011