

# **Bella Bella/Waglisla:**

## **A Case Study on the Implications of the Closure of Local Maternity Services**

**Submitted by Jude Kornelsen, Georgia Walton & Andrew Kotaska, under the guidance of Louisa Willie, Dawn Wilson, Jennifer Carpenter, Pauline Waterfall, Marie Duperrault, and with the assistance of Wanda Christianson.**



# *Executive Summary*

## *Context*

From October 2005 – July 2006 a research team from the Centre for Rural Health Research, Department of Family Practice UBC, undertook a study of the implications of the closure of local maternity care under the guidance of the Heiltsuk Maternity Care Study Community Research Advisory Committee. The objective of the study was to document the implications of the closure of local services by:

- Undertaking chart reviews to document the maternal-newborn outcomes of women who had left the community to give birth with women who gave birth locally;
- Undertaking an analysis of band travel records to determine costs incurred to the band for medical travel related to maternity care;
- Undertaking a survey to document women's experiences of birth, locally or away; and
- Undertaking in-depth interviews to document women's stories of their experiences of birth.

## *Findings*

Findings from the chart reviews reveal that there were no statistically significant differences in outcomes before and after closures on all variables measured. However, due to the small sample size, there was insufficient power to detect clinically meaningful differences, and hence, it is necessary to interpret this data from within a larger context of maternal – newborn outcomes based on service delivery levels.

Findings from the analysis of band council records revealed women and families spent an average of 29 days out of the community in referral centres costing an average of \$108.07/day and \$3732 per individual for the duration of their stay outside of the community.

Findings from the survey revealed that of the 55 women who completed the survey, 35 gave birth away from the community (the majority at BC Women's) and 20 gave birth in Bella Bella/Waglisla. Themes include influence of care providers in decision-making (higher for those who left the community than for those who stayed), the importance of the presence of family during labour and delivery and the overriding belief that women should be able to give birth in Bella Bella. Of the participants who chose to leave, almost all did so due to the desire for access to pain medication and the belief in the importance of immediate access to technology in case it was necessary. Time of year of delivery was not a significant concern for either women who stayed in the community or women who birthed elsewhere. The majority of

respondents felt local birth was important to the culture and community of Bella Bella.

Results of the in-depth interviews illuminated attributes of birthing locally including the value of emotional and practical support from the community and the importance of local birth both individually to women as members of the Heiltsuk nation and to the wider community. Descriptions of birth away focused on some of the factors that influenced the decision-making process of those who chose to leave and the social, financial and logistical implications for those who had no option. Nine of the women we listened to gave birth in Bella Bella/Waglisla and 3 gave birth in a referral community. All of the women who remained in the community gave birth before 2000, when local services, including cesarean section back-up, were available.

### *Recommendations*

Currently there is ambiguity regarding the future of maternity services in Bella Bella/Waglisla. Current data suggests that the community could support local intrapartum care without surgical capability. Given this, the level of service desired in Bella Bella/Waglisla must be determined honoring an inclusive, community-based process with involvement from key stakeholders. In order to productively move forward, this process should also include a review of the recent history of local birthing services with attention given to describing the decision making process that resulted in the closure of services in 2000.

If the community decides to continue the current program of evacuation from the community for birth, it must be done with a recognition that a comprehensive program of birthing support services must be in place for the prenatal and postpartum period and be integrated with care provided in the referral site. Likewise, supports must be in place in the referral community to ensure the best possible experience for women from the community.

If the community decides to reestablish local birthing services, a community-wide informed consent process must be undertaken that acknowledges the spiritual, social and psychological as well as physiological risks and benefits of local services and services away. A screening protocol as well as an evaluation of the physical infrastructure and competency of medical, nursing and support staff should also be undertaken.

## *The Story of This Study*

In 2002, following the closure of many small rural maternity services in British Columbia, Jude Kornelsen, a medical sociologist, and Stefan Grzybowski, a researcher and family physician who had worked on Haida Gwaii for 12 years, were funded to do a qualitative, exploratory study on rural women's experiences of maternity care. For some women this meant their experience of giving birth in their home community (sometimes without local access to cesarean section) and for some women it meant leaving their community to give birth in a referral centre. The study took us to 11 rural communities including Sparwood, Merrit, Port Hardy, Port McNeill, Haida Gwaii/Queen Charlotte Islands, Tofino, Telegraph Creek, Dease Lake, Iskut and Bella Bella/Waglisla. Through these visits we were able to listen to women's experiences conveyed with a richness and depth that spoke to the importance of giving birth and the importance of community. As the stories unraveled and we began gaining insight into the social significance of birth for rural women, we noted two things: first, that the challenges women faced leaving their communities were consistent across the province, and secondly, that, for a confluence of reasons, these challenges were more deeply felt by First Nations women.

When we talked with First Nations moms we heard of webs of kinship ties among and between families and communities that provided the backdrop for their lives. We talked to many young moms who had to leave this support system when they were most vulnerable, sometimes without enough funding to ensure appropriate food as they waited in referral centres to give birth, let alone enough to bring mothers, aunties, partners or other children with them. And we heard of ties to their land, sometimes ancestral, sometimes through marriage, that formed not just their home, but their identity. The recognition of these differences led to an acknowledgement of the importance of focusing on the meaning of birth and maternity care specifically for First Nations women through a cultural lens. This lens included the historical precedent of local birth for most of the history of First Nations communities in British Columbia, the devastating influence of residential schools on contemporary health and community cohesion, current social challenges faced by many communities, as well as the cultural and spiritual revival and reclamation of First Nations identity currently underway across the province.

One of the values guiding our work is returning findings to the communities so they may be put to local use. After we presented our understanding of the maternity care needs of rural women from across B.C. in Bella Bella/Waglisla in November 2003, we noted several significant responses. We heard that we had captured part of the

experiences of rural Heiltsuk women; we heard that many women in the community had never been asked to talk about their experience of birth and what it meant to them, and that this was an important thing to do; we heard of the importance of birth to the community as a whole, and queries around why services were closed; and we were asked, “What next?”

As we were pondering what was next, we had the opportunity to talk about our findings to a Vancouver colleague, who had practiced as a physician in Bella Bella before returning to school. Hearing of our work in rural communities, Dr. Andrew Kotaska reiterated his keen interest in rural maternity care, his experience in the community of Bella Bella/Waglisla and alerted us to records he had been keeping on the outcomes of women from the community who stayed to give birth or left for referral centres. The ‘what next’ was becoming clearer.

Under the guidance of the community research advisory committee with representation from the Heiltsuk Cultural Education Centre, Hailika’as Heiltsuk Health Centre, RW Large Memorial Hospital and Heiltsuk College (see Appendix A for Heiltsuk Guidelines for visiting researchers and Appendix B for the advisory committee terms of reference) we hired a local research assistant and moved forward with a project to understand the impact of the closure of maternity services on the community of Bella Bella/Waglisla (see Appendix C for project proposal). It was a compelling community to undertake the study in as the population was homogeneous, from a confined catchment and the services were closed within the collective memory of the community. Given the desire to understand different aspects of the implications of the closure of services and take advantage of existing data, we decided on an approach that would consider:

- A comparison of the maternal and newborn outcomes for women who stayed and left the community to give birth;
- A written survey of women’s experiences to be as comprehensive as possible in our understanding;
- An overview of travel costs to the band council to understand part of the financial implications to the community; and
- Women’s descriptions of their experiences of giving birth inside and outside of the community.

Between October 2005 and July 2006, *The Rural Maternity Care Research Team* (housed in the Department of Family Practice at UBC), under the guidance of the community research advisory board, and with the help of a local research assistant, proceeded to collect the data necessary to answer the questions raised. Herein lies our tentative first steps towards documenting part of the story of maternity care for the women of Bella Bella/Waglisla. It is clear that this is a first rendition and that a deep lived

experience of history, tradition and experience of birth in Bella Bella/Waglisla underpins the stories we heard, a history that is, perhaps, waiting for a community member to tell.

*Jude Kornelsen, March 2007*

## ***Background and Context***



The community of Bella Bella/Waglisla on B.C.'s central coast (LHA 83) has a current population of 1250 residents, most of who are from the Heiltsuk nation. The hospital in Bella Bella is governed by United Church Health Services and receives funding from Vancouver Coastal Health. In 2004, a review of support for the United Church Health Service governance of RW Large Memorial Hospital was conducted, and found overwhelming support from board members, hospital staff, First Nations groups and community members (Dowling, 2004). Bella Bella has completed the process of transferring responsibility for health care funding, including non-insured health benefits, from FNIHB. It is this funding that is allocated for patient travel, including but

not limited to travel to referral communities to give birth. Historically, birth has always taken place in Bella Bella/Waglisla, in recent decades through the support of the United Church Health Services. In 1997 there were seven deliveries in Bella Bella and thirteen in referral communities; in 1998 the numbers were 15 and 22 respectively and in 1999 16 women gave birth in the community and 27 birthed away. The year 2000 began the transition away from local birth: 4 deliveries occurred in the community and 17 occurred away. Since 2001, there have been two local deliveries and 53 deliveries in referral communities (usually B.C. Women's Hospital in Vancouver). The change in service delivery is believed to be due to a confluence of factors including difficulty recruiting and retaining a general practitioner with enhanced skills to provide local access to cesarean section, and the reluctance of

physicians to offer maternity care without the availability of such services. The impact of the closure of services has, to date, not been documented.

# *Heiltsuk Women's Experiences Of Birth, 1996 – 2004: Results of conversations and a written survey*

## **Overview**

A crucial part of understanding the impact of the closure of maternity services in Bella Bella/Waglisla was hearing the voices of women who had given birth, either in or out of the community. We undertook this in two ways: through a written survey and through in-depth interviews with community members.

The survey, designed to capture experiences of birth in and away from the community, was developed based on previous interviews in the community and across the province. Three separate forms were generated: one for women who birthed locally prior to 2001, one for women who birthed away, and one for all women who gave birth after 2001 (see Appendix F for sample survey). Potential participants were identified through existing records kept by Dr. Kotaska while providing care, and cross-referenced with a list of all women who gave birth in the study time frame based on the Hailika'as Heiltsuk Health Centre Members List. The community research assistant recruited potential participants by phone to ask them if they would agree to filling out a survey. Surveys were hand-delivered to all participants and retrieved when completed. A total of 55 surveys were returned. Data from the surveys were entered into the Statistical Package for the Social Sciences for analysis. Frequency tables were generated for all questions and correlations were run for all the fields. Statistically significant ones were highlighted. Recounting experiences within the presentation of numbers and charts grounds our understanding of what the data *means*. It answers the question, "So what?" The women we listened to were recruited through the surveys distributed by the community-based research assistant. Twelve 'open-ended', hour-long interviews were conducted by the research team with women from the community either at the Health Transfer House (Nuda Street) or the Board Room at RW Large Memorial Hospital between November 3<sup>rd</sup> and November 5<sup>th</sup>, 2005.

All interviews were tape recorded and transcribed into a word document for analysis. The lead investigator and project coordinator read and coded each transcript separately and compiled a list of key themes. When compared, a high degree of similarity was found between the separate lists of codes. All coded parts of the transcripts were entered into a Qualitative Analysis program, QSR Nudist, for analysis. Below are the results of the interviews, by theme.

## **Findings**

*Demographics* – Fifty-five women volunteered to complete our survey. The average age of women at time of completion was 32 years old. Of the 55 women, 19 indicated that they had lived in Bella Bella/Waglisla all their life, while 32 had lived in the community for over 13 years. Thirty-five gave birth away from the community and 20 gave birth in the community. For those who gave birth away, the majority birthed at BC Women’s Hospital (n=15, 27%) or other Lower Mainland hospitals, while a few gave birth in Prince Rupert, Nanaimo or Victoria. All but one respondent received prenatal care.

### ***Heiltsuk Women’s Experiences Of Birth, 1996 – 2004: Results of conversations with women***

#### **Overview**

## **Findings**

Nine of the women we listened to gave birth in Bella Bella/Waglisla and 3 gave birth in a referral community. All of the women who remained in the community gave birth before 2000, when local services, including cesarean section back-up, were available. Our conversations with women revealed attributes of birthing locally including emotional and practical support from the community and the importance of local birth both individually to women as members of the Heiltsuk nation and to the wider community. Descriptions of birth away illuminated some of the factors that influenced the decision-making process of those who chose to leave and the social, financial and logistical implications for those who had no option. Each of these themes is discussed in detail below.

#### **Birth in Bella Bella/Waglisla**

*‘If you are here, you are not alone’: the Importance of community support*

The most commonly described attribute of staying in the community to give birth was the web of support received from family and friends. Most participants who completed the survey noted family members were present during labour and delivery, ranging from “10 – 20”, to “lots – too many to count”, and “half the village.” While only four (20%) respondents who gave birth in Bella Bella/Waglisla noted that only their physician was present at the time of delivery, 16 (80%) noted

their physician, family members and/or friends were present. When asked why women should give birth in the community, all focused on the availability of family support and the difficulties of being away from family. This extended network of support was seen as part of a larger Heiltsuk commitment to relationships, caught perhaps most clearly by the phrase of one woman, “If you are here... you are not alone.” [006:445] The sense of being part of a larger association was exemplified by many with stories of community members rallying to help each other in difficult times. As one woman said,

And I couldn't believe the support – you get a lot of support here.... If something happens, something goes wrong in one family, the whole community pitches in and helps out to support them, whether it's financial or, you know, if it's death, there's going to be food sent over. [006:86-94]

The sense of support was recognized to be not only material, but emotional as well, with material contributions seen as gestures of deeper emotional support:

And then the nurse said, ‘maybe you should take a walk,’ ... so I get out, take a walk, and there was like, scores of people. I couldn't believe it! And then I started walking down the hall and there were people waiting there, and the waiting room was full and I couldn't believe that, all the support. And do you know how much rice they left us after we had him? Nine bags! And when I had a baby shower I left there with 11 boxes! I couldn't believe the support. [006:68-80]

For some, the importance of this support exceeded concerns about giving birth in the community without immediate access to specialist care: “I would rather take the risk of having my baby here than to have all the high-tech equipment and be in an atmosphere that wasn't familiar.” [007:130-132]

For many women, the support they received included guidance from elder relatives who suggested ways birth may be managed. One noted, “My great grandmother, who birthed 16 children, said it was a natural process. [She said], ‘Don't take pain medication if you don't have to.’ She really coached me in what I should or should not be doing.” [007:79-85]. Another recalled that her grandmother had told her, “You need to put yourself in the mental mind state that everything is going to be okay. You need to relax, prepare yourself, and let the process happen.” [007:121-123] This advice was referred to fondly and seen to be enveloped within a sense of caring.

Within the context of the support received, however, most of the women emphasized the importance of the *celebration* of birth – and life – that being part of a community gave rise to. As one participant said,

When I left (the hospital), I needed a truck, because everyone was bringing gifts and crocheted items... letting (us) know they are happy about the baby. I can't explain it. In Vancouver, there's just probably the mother and the father.

If they are lucky, (the mother's) mother. It's just not the same. They are there alone. No one is celebrating with them. (007:175-181)

For many, the celebration took the form of an 'uplifting' which involved having a hereditary chief present the baby to the community and bestow a name, sometimes within the context of a potlatch.

The most consistent – and dramatically expressed – descriptions of community support were of support during the labor and delivery itself, which, according to all the participants we spoke with in this study, was marked by the presence of family and community members at the hospital. One participant describes her immediate post-partum experiences like this:

When I came out, it was wall-to-wall people. I said, 'What's going on?' Everybody heard that [my baby] was born. And it was wall-to-wall people. It was so nice because my father-in-law was there and I was holding my baby. He was the first and only grandson. [005:84-90]

Another noted,

It was nice because my mom and dad were all there, and my husband was there, so it was really good. You know, it was a lot easier, I think, because now today with guys going down to Vancouver, [its] probably pretty lonely. [009:54-57]

Another woman summarized the richness of support she felt from her family – and its importance to her – in a way that echoes the experiences of most of the women we listened to:

There were so many people... it was just so amazing. I had like, no kidding, probably about ten people in the delivery room. There was his dad, his mother supporting him, and then my mom, my coach, which was a friend. And then there was the physician and a nurse, and then when I was ready to give birth another physician and another nurse came in. And then I think even one of my cousins. But the hallway was packed. His grandpa was there I think my sister was there... It was an awesome experience. [007:42-53]

The importance of the support of family was even more accentuated for younger moms. As one noted, "I was really young, it was a teen pregnancy. It was really important to have my mother with me. She doesn't fly or travel. So I knew that I would have to stay here. So it was really important to have her here. And the rest of the family. [007:15-18]

In the true tradition of support in childbirth, most participants recalled the sense of being embraced during labour and delivery and in the post-partum period. Friends and relatives would care for other children so the new mother could have a break from her usual routine of family care. This was seen to mitigate the stress of the immediate post-partum period and even help combat "the blues":

I think it makes a big difference to have our babies here, because you have all that family support and you really do need it because some mothers go through the postpartum blues here, and just to have all the support...  
[006:423-427]

Several women incisively juxtaposed their in-community experiences with observations of the experiences of women giving birth now in referral communities. As one commented,

I think it just all goes back to having... the family here. My niece is giving birth to another baby [out of the community]. I'm not going to be there. I've never seen any of her kids being born. All my nieces were born out of town and I've never seen any of them. I just wish they would have their babies here.  
[012:205-210]

### *The Importance of Birth in Bella Bella/Waglisla*

All of the women we listened to – whether they gave birth at home or away – expressed the importance of birth in Bella Bella/Waglisla. Our survey data found that 70% of participants responded “Bella Bella” when asked where local women should give birth. Of those who gave birth in the community, 15 (75%) felt it was very important that they birthed at home and 2 (10%) felt it was somewhat important (1 felt it was not important). In addition, when asked if they thought birth was important to their community, 16 (80%) of the women who birthed locally felt it was very important, 1 felt it was somewhat important, and 1 felt it was not important. Of the women who birthed away after the closure of services, 19 (86%) felt birth was very important to the community while 3 (14%) felt it was somewhat important. For most, the importance of local birth was tied to a sense of connection to history and the land itself and gave rise to their identity as mothers but also Heiltsuk peoples. As we discussed with one woman:

Participant: I was glad that [all my children] were born here.

Interviewer: What does that mean to you?

Participant: It felt good. You know, I was born here. I was born in the old hospital. My mom had all of us in the old hospital there. ... We are all from here. [009:44-51]

The sense of a continuation of history underlay many of the women's observations of the roles their mothers, grandmothers or aunts played historically in supporting women through the process of birth. Almost all of the women referred to a family member or friend who they described as a midwife.

Feelings of ties to the land were also concretely expressed through unsolicited comments on the importance of having Bella Bella/Waglisla on their children's birth certificates:

I would want my grandchildren to be born here, like other kids. This is where we're from! You know, looking on the birth certificates, they say 'Vancouver B.C.'. You know, they're not from Vancouver. We're from Bella Bella! So when they are born in Vancouver, does that mean they are from Vancouver?  
[012:271-279]

This is congruent with three responses to an open-ended question on the survey about the importance of local birth. Others interview participants noted, "I wanted [my child] to be born in the same place as me. And to say, on the birth certificate, "Born in Bella Bella, B.C. I wanted him to be born here," [006:55-58] and, "Because you know, you see on the birth certificates where the babies are born, right? ... And I think it would mean a lot to have Bella Bella on the birth certificates. [009:158-162] This sense of ties to the community also motivated some women to return to Bella Bella/Waglisla from away to give birth: "I lived in Vancouver... and had just gotten pregnant and came home. I said, 'I want to have my baby born at home,' because all my [other children] were born here." [012:89-95]

Giving birth in Bella Bella/Waglisla was not only important on an individual level for many of the mothers we listened to, but also on a community level, as well. Birth was seen as intrinsically important in itself, but also in conjunction with the honoring of children.

I have done a lot of reading about birth and the whole experience. The one thing that really stuck out for me is that every child is a gift and is to be treasured. ... No matter what, in our culture every child has a gift to share, big or small. You know, you'll hear people say that our children are our future.  
[007:309-324]

Beyond a reverence for children, this participant noted the cultural reverence for *life* as part of the context for birth:

Our culture has always celebrated life. Our children got their first traditional name at birth: it was their child name. At 10, they get another name. As an adult, another name. As they become older, another name. So there was tradition. We've always celebrated life. And uplifted our children. [007:255-260]

For some women, the timing of birth within the life cycles of others in the community was a poignant reminder of inter-connectedness, so when a child was born soon after the death of an elder, the richness of a bitter-sweet time of mourning and celebrating contributed to a depth of the experience. According to many community members, these formative connections reverberate past the time of birth

and into the life of the community, sometimes being acknowledged formally (such as at a Potlatch) and sometimes informally through marking the passage of time by the growth of a child. As one participant noted,

If you had [given] birth here, your life would be marked by experiences, your whole life would be sprinkled by these really positive memories and so that when you saw that child playing you would be like, 'Oh, I remember when you were born.... But now, when you see a child, you didn't participate in that. And the community didn't come together. Cause I am sure there may be people who remember when [I] was born. And that's a really concrete bond you have. [007:412-425]

For some, the absence of birth within the community, like an unbalanced mobile, shifts the weight of experience to death:

I think it's a huge void for people not to be born here, because all we see is death. You've probably heard that before. We're in a small community and it's constantly death, death, death, death. When you don't have birth here, and they're born outside, you know, it's different. There has to be a balance. There's end of life and beginning of life. [007:58-65]

Just as women expressed a desire on an individual level to have 'Bella Bella B.C.' written on their children's birth certificate, so too did elders and leaders recognize the larger importance of this symbolism: "One of our hereditary chiefs got up [at the community meeting] and said, "It's important to be born in our homeland, for your birth certificate to say, born in Bella Bella, born in Waglisla." [007:142-146]

### *Experience of local birth*

Within the context of community support, most women also described positive aspects to the care they received in their community, emanating in part from the ongoing relationships they had with the care providers. Women expressed confidence in the care-providers' skills and abilities and a sense of feeling respected in their questions. The confidence in skills and abilities led to a strong sense of trust in the advice given regarding labour and delivery – including location of birth. As one woman noted,

[The doctor] told me, you know, about the different complications that could happen during labour and delivery and he said, 'But you have nothing to worry about, so I think it is going to be okay to have your baby here.' I said, 'okay.' I took his word on it and I was fine with it. [006:90-94]

## **Birth Away**

### *The Decision-Making Process*

Of the women who gave birth before the closure of services, 41 chose or were advised to leave the community to give birth. Many of those who chose to leave did so when the local maternity service began to decline (1999 – 2000). Those who chose to leave cited issues of safety and the desire for immediate access to technology and specialist care should complications arise. This was confirmed with our survey data by 9 (70%) of the respondents.

As one interview participant said,

[Technology] is important to have nearby in case you need to have a cesarean or anything else goes wrong. I would rather have [access to] the doctors and travel away and have the equipment, everything that you need, in case something goes wrong. [003: 221-228]

Others described their decision in terms of comfort within the context of safety and risks: “I would have preferred [to give birth in] Vancouver in case of complications. I feel safer in Vancouver in case of emergency,” [010:19-20] and “In the end, I want to be safe.” [002: 245] For others, their sense of safety was embedded in their confidence in the local care providers. Once the number of births began declining, women noted the concomitant decline in confidence of care providers. One person said, “You know there was lots of talk in the community about how we didn’t have enough experienced doctors to deliver.” [003: 248-252] Another woman told us of her need for reassurance from the medical staff and what she felt when that wasn’t forthcoming:

You know, like when you are pregnant you want to hear that it’s going to be safe. I wanted to hear that. And I wasn’t hearing the things I wanted to hear so that’s what made me really scared to have my baby here. [003:533-538]

One participant told of her transformation in thought regarding the merits and drawbacks of staying in the community to give birth as, through the experience, she moved from the desire to be close to technological backup to the recognition of the value of having the support of family. Initially, she wanted to leave the community due to concerns around safety and the possibility that the labour and delivery may be complicated:

So I was really upset, really worried. I was thinking, in my mind, something was going to go wrong because my pregnancy was so uncomfortable. I felt something was going to go wrong here. And so I was really upset that I couldn’t have him somewhere else, and I cried and kind of panicked there for a little while. But after I had him, you know, nothing did go wrong. I’m fine, my baby’s fine, and having that family support there... It was a big difference.

I was really glad. I thought about it, it would have just been me and his father in [the referral centre] having the baby, no family, no support there. And I am glad that I did have my baby here. [006:336-346]

The need to hear that ‘everything will be okay,’ was sometimes in conflict with the process of informed consent that women undertook with their care provider when trying to decide where to give birth. Part of the discussion of risks of staying in the community involved an acknowledgement of the unpredictability of transport due to variable weather conditions and influenced women’s decisions to leave the community.

[The doctor said] If something should go wrong then they’re going to have to Medevac you out of here. I said, ‘Well, okay, how long is that going to take?’ And they said, ‘Well it could take an hour, two hours, depending on the weather, depending on the time of day, and depending if there are any hospitals that have space.’ They explained that stuff to me, and they said, ‘Your baby could die by the time you finally get to the hospital or by the time the Medevac gets here.’ And so that’s it. I wanted to have my baby somewhere else. [006:254-263]

For others, the risks inherent in staying to give birth were more acutely expressed to women once services began to be destabilized (1999-2000):

They were talking about [the fact that] they didn’t have any experienced doctors to deliver my baby. They talked about how they didn’t have the right equipment here if anything should go wrong. They just talked about the different kinds of things that could happen, go wrong during delivery or something. And they’re saying, you know, it would be better for you to have your baby somewhere else, because they don’t have the right equipment here. So I did not want to have [my baby] here. [006:399 – 411]

This quote expresses the strong influence care providers or significant others can have on a women’s decision-making regarding location of birth. Our survey data found that when the women who gave birth before the loss of services were asked how much their physician influenced their decision regarding location of birth, 8 (80%) of those who gave birth in a referral centre reported being “strongly influenced” while 1 (10%) was “slightly influenced.” Likewise, 7 (70%) also said their family “strongly influenced” their decision, while 2 (15%) said they were only “slightly influenced.” Interestingly, of those who gave birth in the community 2 participants (10%) reported being “strongly influenced” by their physician, 3 (16%) were “slightly influenced” and 14 (74%) were not influenced at all. In addition, 3 (16%) said their family “strongly influenced” their decision, 2 (10%) reported slight influence, while 14 (74%) said their family did not influence their decision at all

Other factors that influenced women’s decisions to leave the community to give birth prior to 2000 included access to pain medication (found to be an important factor for

84.7% of women who left Bella Bella/Waglisla before services closed), need for privacy during the birth and the desire to ‘have a break’ from the community:

But the thing is, you know, having the birth here and the family visits and my mother... there’s not much privacy. There’s tons of people coming and you just can’t predict how you’re going to feel right after you have a baby. And I was really selfish and I didn’t want anyone to be around. [003:232-237]

### *Experiences of birth in a referral community*

For women leaving Bella Bella to birth elsewhere, time spent in the referral community exceeds the period of labour and delivery to include part of the prenatal period spent waiting for the onset of labour and the immediate post-partum period. According to our survey data results, the average total time spent in a referral community before the closure of services was 2.7 weeks; after services closed women and their families spent an average of 3.7 weeks in a referral community. This requires birthing moms to secure accommodation for themselves and any family members who are accompanying them, either in hotels or hostels. Although the mother’s accommodation costs are covered, via the Band, through FNIHB’s uninsured health benefits program, the costs for escorts are not. Further, if mom is admitted to the hospital for an extended stay, the family must find un-subsidized accommodation on their own. Interestingly, our survey data found a shift in where respondents stayed before and after service closure with more staying with relatives (30%) prior to closure and more staying in hotels/lodges (75%) after closure.

Positive attributes of accommodations that were noted included access to laundry and cooking facilities, especially when moms were accompanied by other children. Some women found it helpful when they were able to go to a referral community where family lived: “It was a lot more comfortable living with my parents for 6 weeks than going to live in a hotel.” [008:90-93] Others, however, expressed stress at the thought or reality of living with family members, or were acutely aware of the burden their presence put on them.

One of the most stressful parts of leaving the community to give birth was making arrangements for other children, whether they were brought to the referral community or left behind. The emotional anguish of separation was keenly felt by the women we listened to, especially for those who had an extended stay out of the community. As one woman noted,

I was down for so long, I had to leave my two other children here with my parents. And I couldn’t talk to them on the phone. If I did, then I would just cry, cry and cry for days. So I think I talked to them twice. And the second time was an accident – my mom put the phone down and my son went and

grabbed it and started talking on the phone. It was kind of unexpected, you know. It was hard. [011:95-101]

Others observed the effects that a mother's separation from her children had on them:

One girl, she was in grade six or seven, her mother had recently had a baby, and she came to school and she was feeling really sad. She started crying and her teacher didn't know why. She didn't realize that her mom had left to have the baby. And I told the teacher, 'Ask her if she is lonely for her mom, because her mom went down to have the baby,' and the teacher said, 'I hadn't realized that.' [011:334-340]

Just as women who stayed in Bella Bella/Waglisla expressed the sense of support they received from family and friends in the community, so too did the women who birthed in referral communities. Although the intent of the support was the same – to provide encouragement and to help women giving birth – the expression was different. One woman talked about her own initiative to support her sister to bring the expectant father to the birth – an activity she deeply wanted but that exceeded her own financial resources: "If they didn't fundraise enough money I was going to purchase a plane ticket for them and have them deduct [the cost] through my paycheck at work." [006:303-313] Support was also extended between birthing moms or families who were in the referral centres at the same time: "We shared meals with the couple that was down from here at the same time. So it was nice. We kind of supported each other." [006:456 – 458]

Just as several of the women noted a sense of celebration when birth occurred in the community, so too did women note the lack of celebration when birth occurred away:

There are several aspects of it... the celebration has been taken away. Like now, if a baby was being born there would be at least 50 people in this hospital, waiting. And as soon as the baby was born, people would be on the phone, on the radio, celebrating. [007:169-174]

This participant went on to wonder if the high rates of depression in the community were due in part to the celebration of birth being removed from their lives.

Financial concerns were paramount to most of the women who gave birth outside the community after 2000. Women spoke of the costs incurred for themselves and their families above the subsidies available through the band office, and more intangible costs such as missed work for themselves and their partners. One of the most significant extra costs was for escorts – usually family members – to accompany women to the referral community for the birth. Many women expressed the tension they felt in trying to find ways to have their husbands or mothers accompany them, sometimes being forced to choose one to the exclusion of the other due to lack of

available resources. The social support garnered from family members when leaving the community was recognized and valued by all. In addition, some women spoke of the need for an escort for medical reasons at the time of labour and delivery or during the prenatal period:

My sister had to fly down because the doctor was concerned about something. She didn't want to go down by herself because she has epilepsy and she was close to her last trimester of pregnancy. They weren't able to give her an escort. So they fundraised for her husband to fly down with her. [011: 302-309]

Being away from the community was a logistical challenge if one or both parents were on employment insurance:

I believe [my husband] had just started to collect EI. We had to phone them and let them know he was coming with me... 'cause you are not supposed to go away when you're on EI. [008: 199-206]

Some women made compromises in their arrangements – such as traveling by ferry instead of air or staying in cheaper accommodations – so family members could accompany them. This sometimes lead to difficult situations for the new mom, one of whom told us of traveling ten hours by bus and ferry to get home five days after hemorrhaging at birth and receiving four blood transfusions,. [004:236-241] If a woman was Medevacked out during labour, cost-saving strategies were not possible: “He had to pay his own way down: there wasn't room on the Medevac for him” [11:120-122]

For some family members of birthing women, the financial challenges of leaving the community created a situation where they had to choose between traveling with the expectant mother or couple, or using the money to offer financial support:

My daughter delivered my grand-daughter two and a half years ago. And I had to choose between sending her money 'cause she was broke, or going down and being there with her, It was hard! I was on a fixed income. I just sent some money. And she said it was hard for her. She wanted her mommy. [I told her] 'From now on, you gotta tell me [if you might be pregnant], I gotta start saving!' [005: 98-104]

Many women spoke of the basic expenses of the city and also the lure of having access to different shops and activities, and the frustration of not being able to take advantage of them.

You know, it costs so much to do anything in the city. Like to bus it around, cab it around, go shopping, take-out, you know. ... But I know when I go to the city I want to get around to these places. I want to go to a movie. I want to go shopping. I want to order food. You know, all these things I want to do. So, I would have to save up a lot of money, you know. [006: 429-438]

For many, even the basic costs exceeded what the travel subsidy covered and were too much to incur without additional means of support:

There's some people who can't really afford to be down there that long, you know... Like I was fortunate enough that myself and my friends at work were... we did have extra money but there are some people that just can't afford anything. [002: 259-265]

For some, this meant strategic saving ("She was going to save \$25 from every family allowance cheque to put it away" [012:130-133]). For others it required fundraising in the community through bake sales, flea-markets and TV bingo.

For women who had left the community prior to the closure of services or soon afterwards, financial issues were less of a concern as allowable funding was perceived to be adequate to cover expenses.

### *Travel Concerns*

Although our survey data did not find that the time of year of delivery was a significant concern for women who stayed in the community or women who birthed elsewhere, many women voiced concerns about the logistics of travel and the possibility of inclement weather during the interviews. Common concerns expressed included the fear of bad weather keeping them in the community if they needed to leave or preventing them from returning. There were concerns about getting half-way home and then stuck, which precipitated several women to travel by boat instead of plane:

In January, during the winter, I prefer to come on the ferry, even if it's rough... just because the weather turns on a dime. It's really unpredictable during those months. [004: 264-270]

Travel by boat was difficult for some women traveling home after giving birth:

It is a long ride from Vancouver to Port Hardy on the bus. I mean, you're on the ferry for two hours from the mainland to the island and then six hours up the island, stopping everywhere. And you have a five-year-old child and a newborn: it is really tiring. ... And then you have the ferry up to Bella Bella. [004:253-260]

### *The Importance of Family*

The presence of family members – either immediate or extended – often mitigated some of the negative aspects of being in a referral city to give birth.

As one woman noted,

I think... there's some people that don't really like the city or that don't have family there. I mean the family factor, for me, was a big factor when I was there. [2:254-256]

Another described assembling her extended family to provide support while she was in the referral community:

There is no other feeling than having family with you. When I gave birth to [my son], my cousin was with me and he was really helpful because he watched my [other child]. And the next day my uncle and his wife were there and my aunt and her husband and her daughter... [004: 212-216]

The survey results found that 15 (45%) women who birthed in a referral centre were able to have other family members present during labour and delivery. The connection with family and friends extended to the wider community with several women noting the benefits of being able to see band members who lived in the referral centre – often Vancouver – right after they had given birth. As one said,

I love the city and my daughter really loved the city and seeing band members I haven't seen... you know, band members down there are really happy that they're able to see the baby whereas if I was here, they would have to wait. [002:273-276]

For the many women, however, family members were left behind when they left the community to give birth. According to our survey data, 6 (21%) of participants reported only their physician was present at their birth. The absence of family and friends often gave rise to a profound sense of sadness. As one person told us:

So I really didn't want to leave because my whole family is here and I wanted them to be around. My husband came with me and his mother came with me but I wanted my mom to come. There wasn't enough room and she couldn't afford to come. I was lonely. The hardest part of leaving is the family. [011:20-25]

### *The Desire to be home*

Many of the moms who left the community to give birth spoke of the pull they felt to return home as soon as they could. Sometimes this gave rise to travel immediately post-partum, despite physical discomfort some moms experienced, or the need for medical attention in the referral community. As one mom said,

They were going to keep my baby there because his billirubin was a bit high, on the high end of normal. But I was just sort of messed up. I was a wreck. It almost felt like post partum depression, just because I wouldn't stop crying, because I was so worried about him. But they couldn't convince me at all that he was fine. I just couldn't stop crying. I just wanted to be home. [004:244-250]

The draw to things familiar – and comforting – was strong, as many women spoke of longing for day-to-day routines usually taken for granted. The desire for home-cooked meals and foods the women were accustomed to was mentioned by many. One woman told us of a conversation she had with a friend who was awaiting the birth of her child outside the community:

She was saying, 'What I wouldn't do for some rice and fish!' One of our traditional foods. Seaweed and grapes, you know. [She was] so sick of the restaurant foods 'cause they have to eat in the restaurant, right? [007: 208-210]

For many women, the consequences of longing for home gave rise to a sense of exasperation with having to be in the referral centre and difficultly respecting the natural rhythms of the birth process. As one woman said,

You're counting down like, 'I hope its today I go into labour, I hope its today, I hope its today...' While as here, it would just be, 'When it happens, it happens.' So to me a good birth [is] just being able to be comfortable in your own surroundings, not having to worry about, 'What am I going to eat today?' 'What's on the menu?'. Or having to worry about who is going to be there. Yeah, that's a good birth to me. [007: 212-220]

### *Comparison of Services: Before and After*

Several participants had given birth both in Bella Bella/Waglisla before services closed and in a referral centre after closure. The contrasting experiences led to observations of the differences between the two locations from both the perspective of individual experience and the larger community context. Participants spoke of the sense of comfort arising from familiarity of their own surroundings in contrast to the alienation felt in the new environment. Contrasting levels of community involvement in the birth was noted by many participants as well:

We've always celebrated life. But rather than the whole community waiting for the baby to be born, and family members [being] up all night and people in the hospital, you know, it's toned down to, you know, this baby has come home and we need to recognize and acknowledge this baby and celebrate the baby's life. Whereas if the baby's born here, it would be a whole different thing... [007: 267-272]

This participant went on to describe the details that give rise to birth as a cultural event in the community and the concomitant sense of loss when it occurs away:

Let's say that they're coming off the plane and [the mom] is there and her mother and the grandfathers go meet them... There's like two people meeting them, meeting the new baby. While if they delivered here, there would be like 50 people. So to me, it feels like a loss. ... Eventually they will have a baby shower or a tea of whatever, but that's basically it. There's like a disconnect.

It's like, 'Oh... they had a baby,' and you know, 'How's the baby doing' versus "how are you recovering? You were screaming away in there – I didn't know you could swear like that." There's a disconnect. [007: 290-302]

Almost all participants expressed a preference for birthing at home for convenience ("I just find it easier to have babies in your hometown rather than having to fly out and then fly back" [011:75-77]) and the support they received. The women who chose to leave the community when local services were available – and those who would have left anyways after they closed – expressed an appreciation for being close to specialist care should any complications arise. This group of women did note, however, a lack of continuity of care with their care provider leading to, in some instances, the sense of having received impersonal care.

The loss of antenatal services in a community often leads to diminished services in the prenatal and postpartum period as care providers become less current with this aspect of practice. The loss of attendant services after the closure of the maternity service was noted by several of the participants. As one commented:

When I was pregnant with [my first child] ... once a month the health centre would drop off all these different kinds of fruit, potatoes, vegetables, milk.... That was something I really appreciated. But they didn't do that [for my second pregnancy]. That stopped. [004: 96-103]

### *Understanding of the Decision-Making Process*

Many of the women we listened to expressed a lack of understanding about why maternity care was no longer available in their community, particularly when their own children were born locally:

I couldn't understand why the women started having to be sent out in the first place. You know, I had my baby here, I had all of my kids here and I don't know why, why did they stop them all of a sudden? There was no explanation to that, And there was no, I can't remember the last person who had their baby here... [012: 149-153]

Some evoked awareness of the historical context for birth in Bella Bella and the perceived irrationality of the change:

It is documented that people have delivered here over 10,000 years. Why change it now? I'm sure that our community, if given that choice, would say, 'Yeah, we want our babies born here. Yeah, we're willing to take that risk.' [007:154-157]

Services in Bella Bella/Waglisla were revoked six years prior to the discussions with women in the community, which allows us to listen to women who had given birth

locally, sometimes in contrast with their experiences away. These stories, experiences and memories are a crucial part of the culture of care for Heiltsuk peoples and reverberations of local birth extend into the life of the community. It was clear, however, from discussions with some of the younger participants that the reality of local birth extends only as far as peoples' memories. As the length of time the community lives with the reality of women leaving to give birth increases, so too diminishes the desire and demand for local birth, foreclosing alternatives. This may be due to changing expectations and desires around birth or simply the lack of awareness of alternatives.

## ***Outcomes of Bella Bella/Waglisla Residents Childbirth Experiences, 1996 – 2005: A Chart Review***

### **Overview**

A chart review of birth outcomes was undertaken for all women from Bella Bella/Waglisla who gave birth between 1996 and 2005, considering key measures including: inductions, cesarean sections, augmentation of labour, and assisted vaginal deliveries (see Appendix D for chart review form). The objective was to compare the outcomes of women who had given birth in Bella Bella/Waglisla with those who had left the community to give birth after the closure of services. The list of charts to be reviewed was compiled through three sources:

1. Personal notation by one of the study investigators who kept records of maternity cases during his tenure as a physician in the community (1997 – 2001);
2. Through the Hailika'as Heiltsuk Health Centre Members List, 2002-2005; and
3. Postal code identification for Bella Bella/Waglisla through Decision Support Services at BC Women's Hospital 2001 – 2004.

We did not seek charts of women from Bella Bella/Waglisla who gave birth at other referral hospitals between 2001 – 2005 due to small numbers and financial constraints on the research process, and did not include women who birthed in Bella Bella/Waglisla after 2004 as the data was not yet available at the time we undertook the study.

We entered 183 charts into the *Statistical Package for the Social Sciences*, a statistical analysis program. Analysis was done to compare outcomes for births prior to and after 2000 (when services closed). Frequency tables (raw numbers) were also created for the key variables that were considered.

### **Findings**

*Demographics* – The average woman in the sample was 26 years old. 151 women identified themselves as Heiltsuk and 32 did not provide an ethnic background. Before the closure of services, more than half the women (56%, n = 52) gave birth in Bella Bella/Waglisla while 32 gave birth in Vancouver, 4 on Vancouver Island, 1 in Prince Rupert and 1 in Bella Coola. Among the women who gave birth in Vancouver, two charts noted “Hotel” as location of birth. After 2000, most women (78%, n = 68) gave birth at B.C. Women’s Hospital, and two gave birth in Bella Bella/Waglisla.

*Outcomes* – There were no statistically significant differences in outcomes before and after closures on the following measures:

- Length of hospital stay (see Appendix E for Table 2);
- Infant birth weight (see Appendix E for Table 3);
- Dilation on admission to hospital (see Appendix E for Table 4);
- Gestational age at birth (see Appendix E for Table 5);
- Apgar scores at one minute (see Appendix E for Table 6);
- Duration of first stage of labour (see Appendix E for Table 7);
- Duration of 2<sup>nd</sup> stage of labour (see Appendix E for Table 8);
- Duration of 3<sup>rd</sup> stage of labour (see Appendix E for Table 9);
- Inductions (see Appendix E for Table 10);
- Spontaneous versus assisted vaginal deliveries (see Appendix E for Table 11).

Due to the small sample size, trends may also be important when understanding differences in outcomes. One trend that was noted in the analysis was regarding vaginal versus assisted deliveries, before and after closure. As per table 11, the percentage of women having spontaneous vaginal deliveries before the loss of services is higher than expected (by 5%), and lower than expected (6%) after loss of services. Furthermore, the percentage of women having assisted deliveries before the loss of services was lower than expected (by 5%), and higher than expected (by almost 6%) after losing services. Although these differences were noted to be statistically non-significant, they may warrant further investigation with greater sample size. Other factors that may have influenced the outcomes include continuity of care that many women had with a care provider outside of the community (45% of women surveyed knew who was going to delivery them) and the mitigating effect of the presence of family at birth (again, 45% of women who delivered outside the community had one or more family members present at their birth). Further, after the closure of services women knew they would deliver outside of Bella Bella/Waglisla so had time to prepare for their departure to and experience in the referral community.

# *Uninsured Health Benefits for women birthing outside of Bella Bella/Waglisla: A financial overview*

## **Overview**

Records of patient travel due to maternity care were access from the band travel clerk for the 2004/2005 fiscal year. Although we initially intended to compare these costs to those prior to the closure of services, we were not able to access financial data prior to 1999. All data was taken from the V0T 1Z0 postal code catchment.

## **Findings**

Travel records were broken down to include food, accommodation, taxi, flights, ferry and gas costs, ferry and bus costs. We calculated cost per day. During the 2004 – 2005 fiscal year, 31 women gave birth outside Bella Bella/Waglisla for a total cost to the band of \$115, 719. Average category costs are as follows:

<b>Category</b>	<b>Average/patient</b>
Days away	29
Total Costs	\$3,732.87
Food	\$839.48
Accommodation	\$1,998.71
Taxi	\$117.42
Flights	\$\$779.28
BC Ferries/Gas	\$434.20
BC Ferries/Bus	\$275.17
Cost/day	\$108.07

## **Discussion**

The findings from this study illuminate the social morbidities associated with Heiltsuk women leaving their community to give birth and are supported by other research on the psycho-social consequences of the routine prenatal evacuation of First Nations women from their home communities (Kornelsen & Gryzbowski, 2005). Although within the context of this study there was no statistical significance in measured maternal and newborn outcomes between women who gave birth in Bella Bella and women who left, this is not surprising given the small sample size. This data must be interpreted, however, within the context of existing research on

maternal – newborn outcomes for women who leave their communities to give birth and women from communities without local maternity services. Several studies have found increased newborn morbidity for both of these populations.

Qualitative findings from the interviews and results of the survey can be thematically summarized by the terse and insightful comment by one of the participants: “If you are here, you are not alone.” The importance of family and community support for parturient women in the perinatal period reflects qualities of culture and being which must be understood differently for Aboriginal women and non-Aboriginal women, and, for Aboriginal women, understood in relationship to the importance of their geographic home. In her article, “Therapeutic landscapes and First Nations peoples: an exploration of culture, health and place,” Wilson (2003) notes:

The identity of indigenous peoples, whose concept of self is rooted in the context of community and place, differs strikingly from the identity of many Euro-Canadians whose concept of self is frequently encapsulated in independence of the individual.” (p. 9).

The idea of providing a *context* for the experience of birth that extends beyond medical needs (e.g., the hospital as a context of birth) has not been given consideration within current health planning. The context expressed by the women in this study was one of family, friends and community but extended to the recent historical context of birth in Bella Bella, evidenced through the many references made to either giving birth in Bella Bella – or others who had – and the symbolic importance of the place name recorded on the birth certificate. For women who birthed locally, these qualities led to a sense of belonging-through-birth; for many (although not all) of those who birthed away, they led to a sense of detachment from the community (and the longing for re-attachment). Snyder (2003) refers to the loss of possession, kinship or belonging as “cultural loss.” (p. 107)

Although we easily understand the therapeutic value of places (i.e., hospitals) and systems (transportation and referral systems) in contributing to health, it may be instructive to also consider the value of therapeutic *networks*. Smyth (2005) and Laws & Radford (1998) describes these as networks through which people receive support and care, though are separate from traditional biomedicine approaches involving families, friends, therapists and kinship groups and an essential part of health. This encourages us to think of health as an integration the physical, psycho-social and spiritual realm and thus of the importance of the context of health care provision.

The social relationships that women in this study identified as being important to birth occur primarily within the geography of Bella Bella/Waglisla (although some extended outside of the community), which suggests an inter-relationship between social relationships and geography. Snyder (2003) describes this inter-relationship by noting that for indigenous peoples, “relationship to land or resources involves an

intimate bond or sense of place, that take on the characteristics of kinship ties and belongingness, which are inalienable.” (p. 108) Wilson (2003) takes this idea further to suggest that beyond merely *shaping* identity, land is *part of* Aboriginal identity and shapes all aspects of their lives, a notion that Oneha (2001) suggests is consistent with all indigenous peoples on the planet. This gives rise to the sense of spirituality associated with the land by Aboriginal peoples (Royal Commission on Aboriginal Peoples, 1995) which in turn leads to the natural interweaving of culture and geography. When cultural and geography are separated, however, Snyder (2003) notes that cultural knowledge and practices may lose meaning and change the nature of social relationships. This may have disastrous consequences:

Because so much of what constitutes a culture is woven into spatial patterns and localized meanings, to move a culture would be tantamount to destroying it. Much of what is valuable to the culture is embedded in the place.” (Snyder, 2004, p. 109)

Despite the growing literature on the importance of community – both geographic and social – to both Aboriginal cultural and health, this understanding has not been reflected in health services delivery policy. This is due to several reasons including fiscal constraints and the dichotomization of clinical and social concerns, with clinical management (including ensuring access to care) taking precedence. This is evidenced by the devolution of patient travel subsidies and lack of escort support from FNIHB for women who must leave their communities to give birth. However, as the growing body of literature suggests, the social morbidities associated with this policy are significant and may have an impact on the short or long-term health of rural parturient women and their families.

In some instances it may not be possible or feasible to support local birth due to low volume, lack of recruitment and retention of care providers willing to include maternity care within their scope of practice, or the desire of women to be closer to specialist care should it be necessary. In these instances the role of geography and culture need not be overlooked but instead used to inform appropriate practices to support women throughout their childbearing experience (see following recommendations.)

## ***Recommendations***

These recommendations are underscored by research which suggests that based on population and isolation Bella Bella will be able to sustain services at Level A (no local services) or Level B (local services without cesarean section), depending on local and regional feasibility issues and the desire of the community (Grzybowski,

Kornelsen & Schuurman, *forthcoming*). This premise gives rise to the first recommendation:

**RECOMMENDATION:** Level of service desired in Bella Bella/Waglisla must be determined honoring an inclusive, community-based process which at minimum involves representatives from:

- Band Council Health Committee Chair or designate;
  - Health Centre Director or designate;
  - Designate from R.W. Large Memorial Hospital medical staff;
  - Community (inclusive of teenagers, birthing women, and elders with attention given to fathers and other men within the community);
  - R.W. Large Memorial Hospital Chief of Nursing ;
  - United Church Health Services; and
  - Other key community groups identified by community leaders (e.g. Interagency Committee).
- We recommend this process include *a review of the recent history of local birthing services with attention to explicating the decision-making process* around the closure of services in 2000, and an emphasis be placed on informed choice within the context of no immediate access to cesarean section and the unique weather and geography of the central coast; and
  - That this process be facilitated by an external, professional facilitator with a history of working productively with First Nations peoples.

Once the appropriate level of services is determined in response to the community, as well as stakeholder values, needs, and resources, and based on the goal of providing the best possible care for parturient Heiltsuk women and others living in Bella Bella, the implementation of level of care may be guided by the following recommendations based on the local research and drawing also on our experience with other communities across British Columbia.

**RECOMMENDATIONS** If service level A (no local access to labour and delivery) is desired:

1. Recognize that a comprehensive program of birthing support services must be available in the community for the prenatal and post-partum period and be integrated with intrapartum care provided in referral site;
2. A comprehensive evaluation of existing services should be undertaken to clearly identify gaps in services;
3. A focus on local prenatal care emphasizing and providing support for healthy lifestyle choices should be supported. This may include:

- a. Establishing group prenatal care after 12 weeks of pregnancy to develop peer support and learning (Rising, 1998);
  - b. Establishing food voucher subsidies and a delivery program for health food choices;
  - c. Establishing a culturally appropriate physical activities program responsive to an individual's existing level of activity (e.g., "Strollercise", Baby Yoga, pre/post-natal yoga).
4. Develop a framework for a comprehensive approach to risk recognizing the social risks to birthing away from the community (Kornelsen & Grzybowski, 2005) and the effects of this on family and community;
  5. Recognize that a comprehensive program of support must be in place for the post-partum period involving:
    - a. Strategies for re-integrating with family and community upon return; and
    - b. Support for breastfeeding and early newborn care.
  6. Develop a protocol for evacuation from community including identifying the following:
    - a. Timing for departure from community;
    - b. Discussion of potential referral sites;
    - c. Services available in referral community;
    - d. Funding and sources available to support travel and accommodations including limitations and expiration of funding; and
    - e. Strategies for social planning around evacuation.
  7. Ensure appropriate funding by Band Councils for travel funding to cover:
    - a. Escorts and other family members to minimize family disruption caused by prolonged absence from the community; and
    - b. Increased food subsidy (in the form of cash or vouchers) to encourage healthy eating.
  8. Infrastructure to support women in referral communities should be considered including:
    - a. Housing in referral community including facilities for meal preparation and accommodation for other family members;
    - b. Funding for doulas in referral community or local doulas to accompany moms out of the community; and
    - c. Identifying Aboriginal liaison support in referral communities.
  9. Ensure all care providers are current in knowledge and skills required for maternity care so they are prepared for precipitous and premature deliveries, **acknowledging they will occur.**

**RECOMMENDATIONS** If Level B (local access to care without cesarean section) is desired:

1. Develop and implement a community-wide process that acknowledges the risks and benefits of local birth without access to cesarean section to enable
  - a. an informed choice process for the woman and her family;
  - b. an informed consent process for care providers.
2. In the informed consent process, discussion of spiritual, social and psychological as well as physiological risks and benefits must be undertaken.
3. Establish a criteria-based selection process to determine which women are likely to birth safely in the local community which allows an opportunity for input from all members of the local provider team;
4. Undertake an evaluation of the physical infrastructure to ensure appropriate equipment as per BCRCP and previous recommendations (Drury, 2003);
5. Evaluate current competency of medical and nursing staff to provide intra-partum services and develop appropriate maintenance of competency strategy including access to ALSO/ALARM, NALS, and Shoulder Dystocia learning modules;
6. Establish lines of consultant support with referral community including scheduled community visits by referral consultant;
7. Review transfer protocols and update with specific attention given to information for new physicians, nurses, and locums; and
8. Implement a systematic audit and quality improvement framework for ongoing comparison of outcomes to peer hospitals.

# Appendix A: Heiltsuk guidelines for visiting researchers

Heiltsuk Band

Heiltsuk Cultural Education Centre  
Box 880, Waglisla, B.C. V0T 1Z0

## Guidelines for Researchers / Access to Information

Not only in Bella Bella but also in many other First Nations communities, researchers are welcome provided that they commit themselves to observing certain rules of conduct. Those for the Heiltsuk have been developed at the direction and request of our Heiltsuk elders, advisors, and the keepers of our culture.

These rules are meant to ensure clarity and fairness in the relationship between, on the one hand, the researcher and his/her supporting institution and possible funding sources, and on the other, the hosting First Nation, its research and development objectives, and the Band members serving as sources of information to the researcher. The latter include, in addition to informants, the institution and staff of the Band's Cultural Education Centre, and other Band entities such as Heiltsuk Fisheries Co-management, Heiltsuk Treaty Office, as may be stipulated.

In exchange for accepting and abiding by the rules, the Band will support the researcher with, firstly, permission to conduct research on reserve and within its broader traditional territory, and secondly with what pertinent resources it can offer.

The rules and guidelines listed below are intended to ensure that the following basic concerns of the Band are met:

- a) that the research be of use to the Band, as determined by the Band;
- b) that it be conducted according to professional standards and ethics;

With regards to the latter, prospective researchers and supporting institutions are referred to "Ethics Guidelines for Research with Human Subjects," revised xxx by the SSHRC; and the "Statement on Ethics" of the American Anthropological Association, 1971. Two principles basic to all ethical guidelines are i) no harm, and ii) informed consent.

- c) that the interests of the Band and the confidentiality of informants be protected with regard to the dissemination of original research data to any third party (that is, to persons or institutions other than the researcher).

Note: "the interests of the Band...etc." are to be determined in consultation with the Band and are not to be a matter of unilateral assumption on the part of the researcher or his/her supporting institution.

- d) The Band welcomes projects leading to the dissemination of accurate and respectful descriptions of its heritage and culture, especially when native perspectives and interpretations are included in the presentation, but does not support projects that

would lead to the expropriation and exploitation of indigenous knowledge by outside individuals and institutions.

The Band may wish, therefore, to retain copyright of both the research data and any publications (including papers presented in a public or professional forum) arising from the outcome of the research project. This consideration would depend upon the nature of the proposed project, the degree of professional assistance provided by the Band, or local concepts of ownership of certain kinds of cultural knowledge.

The matter of copyright and of any restrictions the Band may wish to place on either the dissemination of research data or interpretations derived therefrom, should be discussed or negotiated at the outset of the project. Likewise, any conflict between conditions set by the Band on the one hand, and commitments required of the researcher by any other institution or funding source, on the other hand, should be made known to the Band and resolved at the outset.

## **Appendix B: Advisory committee terms of reference**

### *Bella Bella: A Case Study on the Implications of the Closure of Local Maternity Care Services*

#### **Community Research Advisory Committee Terms of Reference August 9 2005**

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##### **Preamble**

Based on the initial meeting of the Maternity Care Study Community Research Advisory Committee (“the committee”) August 9 2005 (see minutes attached), the following draft terms of reference articulate the committee’s proposed mandate and function.

##### **Mandate**

The Committee will advise and support the study activities initiated by the Rural Maternity Care Research Team (RMCRT) of the proposed project to compare and evaluate maternal health outcomes, band council travel costs and women’s experiences of care prior to and after closure of local services. This will include:

- With support from the RMCRT, recruitment of community-based research personnel including:
  - Advertising the opportunity;
  - Screening and interviewing potential candidates; and
  - Selecting, based on criteria agreed to in the job description, a suitable candidate.
- Guidance on appropriate study process and procedures with special attention given to ethical and cultural considerations;
- Guidance on data analysis with attention given to the process of cultural interpretation of data;
- Guidance on dissemination of findings with attention given to a co-authorship model between the research team and community member(s) and multiple forms of presentation (including community-specific formats);
- Guidance on appropriate actions upon study completion (e.g. presentation to Vancouver Coastal Health Authority, Ministry of Health, Hospital Board).

##### **Membership**

The Advisory Committee will be comprised of volunteer representatives from the following community bodies: Heiltsuk Cultural Education Centre, Hailika'as Heiltsuk Health Centre, RW Large Memorial Hospital and Heiltsuk College.

### **Activities of Advisory Committee**

- Participation in scheduled meetings or video conference calls with the research team starting the week of August 8;
- Providing guidance concerning all research activities of the project either in the form of written or oral feedback;
- Approving all final decisions regarding methods of community engagement, data collection, analysis, dissemination of findings and action that may arise from the research activities.

### **Responsibilities of Research Team**

The research team (sometimes through the community-based research assistant) will be responsible for ensuring:

- Circulation of regular progress reports to the Advisory Committee for their review and comments;
- Seeking direction from the Advisory committee at key decision-making points (e.g., method of community engagement);
- Scheduling meetings with the Advisory Committee, including face-to-face meetings in Bella Bella and video-conference meetings when the research team is not in Bella Bella;
- Recording and circulating minutes of all Advisory Committee Meetings;
- Receipt of the committee's approval before embarking on participant recruitment, data collection and presentation of findings;
- Enough time for the Advisory Committee to review and respond to the research team's final report from the study before it is shared with other community members;
- Training and support of paid community-based research assistant for data collection;
- Facilitation of presentation of findings to relevant health services policy makers if the Advisory Committee and community members so direct.

### **Timeframe**

The Research Advisory Committee's tenure commences Tuesday August 9 and extends to full completion of the project including dissemination of findings to community, health authorities and, where appropriate, academic audiences. It is anticipated that this will not exceed 6 months (February 2006).

## Appendix C: Project proposal

### a) **Prospective Researchers:**

Jude Kornelsen, PhD & Team  
Rural Maternity Care Research  
UBC Family Practice  
#209-1670 West 8<sup>th</sup> Ave.  
Vancouver, BC V6J 1V7  
Tel: (250) 653-4325  
Email: [jude@saltspringwireless.com](mailto:jude@saltspringwireless.com)

Andrew Kotaska, MD  
UBC Obstetrics and Gynaecology  
BC Women's Hospital  
Email: [kotaska@bulkley.net](mailto:kotaska@bulkley.net)

**b) Title of Research Project:** Bella Bella: A Case Study on the Implications of the Closure of Rural Maternity Services

### c) **Project Description:**

#### ***Background***

In 2000, residents of Bella Bella lost access to local maternity services. Since that time parturient women have been referred out the community (primarily to BC Women's Hospital in Vancouver and hospitals on Vancouver Island<sup>i</sup>) for prenatal diagnostics and childbirth. Provincial data suggests that when a community loses its local maternity services, newborn outcomes are worse than when services are maintained, regardless of where women give birth.<sup>ii iii iv</sup> Qualitative research has found that women from rural communities without access to local services experience high levels of stress and anxiety because their perinatal needs are not met.<sup>v</sup> Exploratory qualitative research also shows that leaving the community to give birth incurs significant financial costs to women and their families, even when funding subsidies are available.<sup>vi</sup>

#### ***i. Study Purpose***

Through this study we aim to investigate what the loss of local services means for the health of mothers and their babies, what the costs are to the local band council, and how women evaluate the quality of their birthing experiences. The **goal** of this investigation is to document the health, psycho-social and financial implications associated with the closure of a small rural maternity service. Specific **objectives** include to:

1. Compare newborn and maternal perinatal outcomes prior to and after the closure of local maternity services;
2. Describe the financial costs involved in dislocation of parturient women from their local community;
3. Pilot test a survey of the quality of rural women's experiences of childbirth.

## ***ii. Research Plan***

The three study objectives listed above will be pursued simultaneously but through different methods.

1. Objective: To compare newborn and maternal perinatal outcomes prior to and after the closure of local maternity services;

A comparison of maternal/newborn outcomes will be undertaken through a comprehensive chart review of all residents of Bella Bella who gave birth, locally or away, between 1996 – 2000 (when local services were available) and 2000 – 2004 (when local services were suspended). Categories of analysis include prevalence of:

- |                                  |  |
|----------------------------------|--|
| a. Geographic/social inductions; | h. Hospital length of stay                         |
| b. Cesarean sections             | i. Newborn APGAR scores                            |
| c. Augmentation of labour        | j. Birth weight                                    |
| d. Assisted vaginal deliveries   | k. Gestational age (prematurity)                   |
| e. Post partum hemorrhage        | l. Breastfeeding to 6 weeks, 3 months and 6 months |
| f. Length of labour              |  |
| g. Intrapartum transfer rates    |  |

2. Objective: to describe the financial costs involved in dislocation of parturient women from their local community;

Financial costs incurred to the band council through travel subsidies to parturient women and their escorts (where applicable) will be collected through band travel clerk records.

3. Objective: to pilot test a survey of the quality of rural women's experiences of childbirth.

A survey of resident women's experiences of leaving the community to give birth will be administered to all women from Bella Bella who gave birth 1996 – 2004. The survey will be administered door to door by a community member/research team pair who will verbally ask questions and write down participants' responses.

This survey has been developed based on qualitative research that examined rural women's experiences of maternity care in 11 rural BC communities, including Bella Bella.<sup>5</sup> Findings from the qualitative research revealed a hierarchy of needs in childbirth including the need for access to appropriate care, the need for a sense of safety around the experience of birth, the need for social support during labour and the need for women to actualize their vision for birth. When these needs are not met, women experience high levels of stress and anxiety. The survey has been tested with 10 respondents rural women who have recently given birth away from their communities.

Data from the survey will be analyzed using SPSS. ANOVA's and correlations will be done to compare differences of quality of experience based on geography, parity and age.

### ***Proposed Timeline***

This proposed study will be submitted to the Heiltsuk Cultural Education Centre and Heiltsuk Traible Council for review. If accepted, the study will also be submitted to the University of British Columbia's behavioural ethics review process because the research team is with UBC's Department of Family Practice.

Upon study approval, the research team will consult the Heiltsuk Cultural Education Centre in the recruitment and hiring of a community researcher for assistance with data collection and analysis. This individual will be paid on a short-term contract (2-4 weeks) as a research assistant for the period of data collection and analysis.

Data collection is proposed to begin in Waglisla in July 2005. The research plan described above will be pursued between July and October 2005.

Written and oral reports of the study's findings will be provided to the Heiltsuk Band Council at their convenience.

### ***iii. Application of Research Results***

As this research will be undertaken within the Guidelines for Appropriate Research with Aboriginal Communities and the Heiltsuk Band Guidelines for Research/Access to Information, all data gathered will be property of the Heiltsuk Band thus applied to the Band's chosen purposes (e.g., policy advocacy, public reporting, etc.). Results will also be used by the research team to further understand issues and to identify areas for further investigation regarding the implications of local maternity service closures.

The researchers will seek agreement from the Heiltsuk Band before the findings from this research are shared with other audiences.

### ***iv. Potential Benefits and Risks***

This research will give residents of Bella Bella a comprehensive understanding of the implications of the closure of local maternity health services in terms of health outcomes, economic costs and social perspectives. This information may be useful in community decision making regarding local health services as well as the development of strategies to support local birthing women.

Confidentiality of results will be a priority for the researchers. However, given the small population of Bella Bella and the familiarity of some community member's experiences, study participants' anonymity may occasionally be impossible to ensure. However, disclosure will be the free choice of the participant.

### ***v. Anticipated Date of Project Completion:* October 2005**

**d) Sponsoring Agency:** Rural Maternity Care Research New Emerging Team

e) **Funding Agency:** Canadian Institutes of Health Research

g) **CVs of Applicant Researchers:** attached

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<sup>i</sup> British Columbia Reproductive Care Program. *Deliveries by Maternal Residence, 2002 – 2003*. Vancouver: BCRCP

<sup>ii</sup> Nesbitt T, Connell F, Hart G, Rosenblatt R. (1990). Access to Obstetric Care in Rural Areas: Effect on Birth Outcomes. *American Journal of Public Health*, 80(7): 814-818.

<sup>iii</sup> Larimore W, Davis A. (1995). Relationship of Infant Mortality to Availability of Care in Rural Florida. *Journal of the American Board of Family Practice*, 8: 392-9.

<sup>iv</sup> Grzybowski, S et al. (in-progress). Rural maternity care: access to services and birth outcomes. In write up prior to submission for publication. Funded by the Telethon Foundation at Children's and Women's Health Center of BC.

<sup>v</sup> Kornelsen J, Grzybowski S. Safety and Community: The Maternity Care Needs of Rural Parturient Women. *J Obstet Gynaecol Can* (forthcoming 2005).

<sup>vi</sup> Kornelsen J, Grzybowski S. (2005) Is Local Maternity Care an Optional Service in Rural Communities? *J Obstet Gynaecol Can*, 27(4):327–329

# Appendix D: Chart review data form

## Bella Bella Delivery Data Sheet

### Personal Information

Case ID #:

Mother:	Age:
Delivery Date:	Grav:
Gestational Age at delivery:	Para:
EDC:	Weight:
DOB:	Ethnic background: Heiltsuk Yes No
Other:	
Antepartum Risk:	Low Med High

### Location

Planned:		
Actual:		
Intrapartum Transfer?	Yes	No
Reason for delivery at other site	Indication:	Patient choice:
	Unkown:	

### Labour

Duration 1 <sup>st</sup> Stage:	Induction:	Yes	No
Duration 2 <sup>nd</sup> Stage:			
Dilation on Admission:			
Analgesia:	Narcotic	Epidural	Pudental Local

### Delivery

Delivery Type:	SVD	Forceps	Vacuum	C/S
Hosp. LOS::				
Complications:				

### Infant

Gender:	Breastfed:	Yes	No
Birthweight:	Duration (weeks):		
Apgars: 1 min:			
5 min:			
Complications:			

Comments:

## Appendix E: Comparison of outcome measures before and after closure

Table 1: Breakdown of the Number of Births Before and After Hospital Closure in Bella Bella

	Before	After
Number of Local Births	93	87
Births in Bella Bella	52	2
Births away from Bella Bella	41	82

Table 2: Comparison of Means for Hospital Length of Stay by Hospital Closure in Bella Bella

	N	Mean	SD	t	DF	p
Before	69	2.928	1.465	-1.40	133	0.163
After	66	3.303	1.645			

Table 3: Comparison of Means for Infant Birthweight by Hospital Closure in Bella Bella

	N	Mean	SD	t	DF	p
Before	89	3584.618	645.990	-0.39	158	0.697
After	75	3618.533	464.746			

Table 4: Comparison of Means for Dilation on Admission by Hospital Closure in Bella Bella

	N	Mean	SD	t	DF	p
Before	43	3.856	2.325	-0.05	86	0.960
After	45	3.878	1.768			

Table 5: Comparison of Mean Ranks for Gestational Age at Birth by Hospital Closure in Bella Bella

	N	Mean Rank	Sum of Ranks	Z	p
Before	87	84.16	7322.00	-0.94	0.346
After	74	77.28	5719.00		

Table 6: Comparison of Mean Ranks for Apgar Scores at 1 Minute by Hospital Closure in Bella Bella

	N	Mean Rank	Sum of Ranks	Z	p
Before	86	75.24	6471.00	-1.67	0.095
After	74	86.61	6409.00		

Table 6: Comparison of Means for Apgar Scores at 5 Minutes by Hospital Closure in Bella Bella

	N	Mean	SD	t	DF	p
Before	86	9.163	0.457	0.63	157	0.529
After	74	9.122	0.368			

Table 7: Comparison of Mean Ranks for Duration of Labour Stage 1 by Hospital Closure in Bella Bella

	N	Mean Rank	Sum of Ranks	Z	p
Before	62	55.04	3412.50	-1.49	0.136
After	56	66.44	3608.50		

Table 8: Comparison of Mean Ranks for Duration of Labour Stage 2 by Hospital Closure in Bella Bella

	N	Mean Rank	Sum of Ranks	Z	p
Before	64	63.57	4068.50	-1.41	0.159
After	54	54.68	2952.50		

Table 9: Comparison of Mean Ranks for Duration of Labour Stage 3 by Hospital Closure in Bella Bella

	N	Mean Rank	Sum of Ranks	Z	p
Before	15	33.23	498.50	-0.18	0.860
After	49	32.28	1581.50		

Table 10: Induction

		Induction		
			Yes	No
Delivery Before or After Loss of Services	Before	Count	11	73
		Expected Count	10.6	73.4
		Percent	13.1%	86.9%
	After	Count	8	59
		Expected Count	8.4	58.6
		Percent	11.9%	88.1%
Total	Count	19	132	
	Expected Count	19.0	132.0	
	Percent	12.6%	87.4%	

$$X^2(1, N=151) = .045, p > 0.05$$

Table 11: Spontaneous versus vaginal delivery

		Type of Delivery		
			Spontaneous	Assisted
Delivery Before or After Loss of Services	Before	Count	70	18
		Expected Count	65.3	22.7
		Percent	79.5%	20.5%
	After	Count	54	25
		Expected Count	58.7	20.3
		Percent	68.4%	31.6%
Total	Count	124	43	
	Expected Count	124.0	43.0	
	Percent	74.3%	25.7%	

$$X^2(1, N=167) = 2.73, p > 0.05$$

## Appendix F: Survey of Experiences of Childbirth



# Experiences of Childbirth In Bella Bella prior to year 2000



We would like your help to understand what it was like to give birth in Bella Bella. Please answer these questions thinking about the birth of only one of your children. If you have given birth to more than one child in Bella Bella before 2000, please fill in a separate survey for each one. This survey will take approximately 15 minutes to complete. It has 21 questions. Please take your time to read the questions carefully. There is a space for additional comments at the end. A summary of results will be sent to the health centre and hospital in the spring. Thank you very much for taking the time to fill out this survey. The information will be presented to policy makers to help them make decisions about where maternity care services should be provided.

### Section I: Demographics

This section asks for general information about you. This helps us get a better sense of who you are. Please take some time to answer these questions.

1. In what year and where was your child born? \_\_\_\_\_
2. What is your age? \_\_\_\_\_
3. Are you of Heiltsuk heritage?       Yes       No
4. For how many years have you lived in Bella Bella? \_\_\_\_\_
5. a) Do you have any family members living in Bella Bella?       Yes       No
5. b) If yes, how many family members live here? \_\_\_\_\_

### Section 2: Questions about your Birth Experience

This section will help us understand your experience of birthing in from Bella Bella before the year 2000. There are 28 questions in this section.

6. Did you receive prenatal care  Yes  No
7. What kinds of prenatal care did you receive?  
 Prenatal doctor's visits  Tests and diagnostics (e.g., ultrasound)  Referred to specialist
8. From whom or where did you receive advice during your pregnancy? \_\_\_\_\_
9. When you learned you were pregnant did you know where you would to give birth?  Yes  No
10. Did you plan on giving birth in Bella Bella?  Yes  No
11. Was the time of year when you would deliver a concern for you?  Yes  No
12. How important was it to you to have access to pain medication (e.g. epidurals)?  
 Very Important  Somewhat Important  Not at all Important
13. To what extent did your doctor influence your decision to give birth in Bella Bella?  
 Strongly Influenced  Slightly Influenced  Did Not Influenced
14. To what extent did your family influence your decision to give birth away from Bella Bella?  
 Strongly Influenced  Slightly Influenced  Did Not Influenced
15. Did the doctor talk about any risks you would face if you delivered in Bella Bella?  Yes  No
16. Did the doctor talk about risks you might face if you delivered in a referral hospital?  Yes  No
17. Who was present at the birth?  
 Physicians  Midwives  Friends  Family Members # of Family Members \_\_\_\_\_
18. Did you breastfeed after giving birth?  Yes  No If Yes, How long did you breastfeed for? \_\_\_\_\_
19. How important was it to you to have your baby in Bella Bella?  
 Very Important  Somewhat Important  Not at all Important  
 Why? \_\_\_\_\_  
 \_\_\_\_\_
20. How important do you think local birthing is to your community?  
 Very Important  Somewhat Important  Not at all Important
21. Where do you think women from Bella Bella should give birth? \_\_\_\_\_  
 Why do you think they should deliver there? \_\_\_\_\_  
 \_\_\_\_\_

Please add any additional comments about your experience of birth in Bella Bella prior to the year 2000 in the space below

Thank you very much for taking the time to fill out this questionnaire. Your comments are highly valued. If you would like to talk further about any issues raised in this questionnaire, the Rural Maternity Research Team from UBC will be in Bella Bella from Wednesday Nov. 2 to Saturday Nov. 5 2005. In order to set up an interview time with members of the research team, please write down your name, telephone number and the best time to contact you. If you do not want to participate in an interview, please leave this section blank and your survey will remain anonymous.

**Name:** \_\_\_\_\_

**Telephone Number:** \_\_\_\_\_

**Best time to contact you:** \_\_\_\_\_

### **SURVEY DRAW**

Tear off the portion below that says PARTICIPANT NUMBER 1. Keep this number with you as we will be conducting a draw with all the surveys returned by Monday October 31<sup>st</sup> 2005. The draw will be conducted randomly, as your survey number is recorded below:

**Survey Number 1**

Tear Off Here - - - - -

**Participant Number**  
**1**

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