Preventing Inflicted Infant Head Trauma: A Best Practice Implementation

Richard Volpe Christine Davidson Erin Sheard Rosanna Bell & Members of the University of Toronto Research Coordinator Unit

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University of Toronto Research Coordinator Unit

Richard Volpe Christine Davidson Erin Sheard Melissa Biscardi Camilla Todesco Rosanna Bell Shelly Mehta Jeanne Evans Debbilynn Murray Robyn Bourgeois Emily Wujek Dara Sikljovan Era Mae Ferron

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Introduction

The inflicted infant head trauma prevention initiative of the Ontario Neurotrauma Foundation (ONF) is a province-wide adaptation and extension of the Upstate New York Shaken Baby Syndrome (SBS) Education Program. Although many SBS information programs exist, this is the only one that has demonstrated an almost 45% reduction of incidence in a large population study. The ONF slow scale up implementation involves six Ontario sites that include participating hospitals, public health units, and midwife practice groups. The core of the ONF evaluation research is the provision of the standardized health education program. Projects were implemented in the communities of Sudbury, North Bay, Mississauga, Kingston, Hamilton, and Oshawa, Ontario (Figure 1). Data was gathered on the effectiveness of the program and how evidence-informed practices can be disseminated (social network analysis) and implemented (mixed method process evaluation). The intervention aims of the projects were to:

- 1. Provide a consistent educational message to all parents of newborns in selected catchment areas.
- 2. Track the dissemination of information via signed consent forms.
- 3. Assess parents' SBS knowledge and program opinions.
- 4. Assess the impact of the education at 5 to 7-month follow-up.
- Determine the viability and sustainability of site implementations at the close of the first and second phases of the program.

Ontario Neurotrauma Foundation Shaken Baby Syndrome Prevention Program

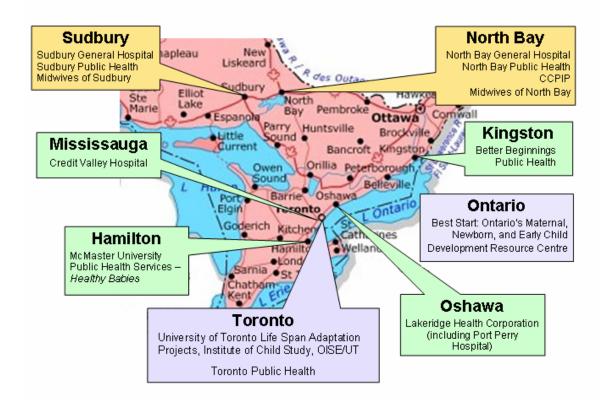


Figure 1: Communities in Ontario participating in the ONF SBS Prevention Program

Inflicted Infant Head Trauma Prevention

Inflicted infant head trauma is a form of violent abuse. In this report, this description will be used instead of the term shaken baby syndrome because it is now recognized, since it was first described by Caffey in 1972 as infant whiplash syndrome, that in addition to shaking, other mechanisms such as banging and hitting are often involved in the maltreatment. Inflicted head trauma is the leading cause of traumatic infant death in North America. Up to 30% of abused infants die from their injuries. Half of the remaining infants experience blindness and various global neurological impairments, including seizures, spasticity, paralysis, and developmental delays. Fewer than 20% of shaken infants escape permanent injury.

In Canada, King *et al.* (2003) finds that 85% of inflicted infant head trauma survivors required long-term multidisciplinary care. Total costs of comprehensive medical care for a single shaken infant can exceed \$1 million. These figures do not even begin to capture the overall burden of inflicted infant head trauma when one considers each victim's loss of social productivity and occupational revenue, the cost of prosecuting and incarcerating perpetrators, the cost of foster care and child welfare agency involvement, and the ongoing mental, physical, and educational therapy that each victim requires. Moreover, inflicted infant head trauma has devastating effects on the personal lives and emotional health of victims and affected family members.

Clearly this destructive and most deadly form of child abuse should be prevented. However, like other forms of intentional injury, we simply do not know enough about the multiplicity of factors that converge in the causes of such trauma. Although some injuries are known to result from specifiable mechanisms, these comprise only a small proportion of what constitutes a preventable injury. Often cited causes, such as a caretaker's anger or a baby's persistent crying, are insufficient explanations. At this point, our best understanding is that abuse arises from a complex interplay of personal and contextual/social determinants (Volpe, 2006). Fortunately, modern prevention science has freed itself from narrow etiological explanations by melding with developmental science. Together, they have been effective in dealing with complex human behaviour and offer hope that the incidence of abuse in human relationships can be significantly reduced. The promise of prevention comes from program designs that mobilize an array of strategies that impact multiple systems and levels. Thus, it is unlikely that the incidence of inflicted infant head trauma will be significantly and consistently reduced by a lone prevention intervention. More likely is the potential of such a program to act as a community-wide catalyst, service integrator, mobilizer, reinforcer, and supporter of positive infant care taking.

Strategic Mobilization and Implementation Evaluation

What follows is a report on the implementation of a well-researched program designed to prevent inflicted infant head trauma. This implementation is part of a strategic Ontario Neurotrauma Foundation knowledge mobilization that aims to reduce the incidence of neurotrauma in Ontario by 20% by the year 2020. The ONF strategy

involves applying rigorous screening to prevention programs that claim to have proven outcome efficacy, and then taking a selected number of these initiatives, adapting them in Ontario settings, and carefully evaluating their implementation. Implementation evaluation then captures and describes how a program operates by identifying the background of a program, the process and procedures undertaken in the development of a program, what resources have been allocated towards its implementation, how the program actually operates, and finally evaluating how, through its delivery, it has made a difference. This form of evaluation adds a qualitative dimension to outcome evaluation and the portions of the best practice monitoring statistics that are replicated in the implementation. In essence, implementation evaluation helps us understand how program plans and objectives are translated into action. Documenting a program in this way provides information for replication and potential to go to scale.

The effort is intended to turn strategy into action by contributing to a new culture of safety. A culture of safety constitutes the institutionalized values, beliefs, attitudes, norms, social relationships, and physical environments that optimally enable people to go safely about their lives. In light of ONF's ambitious goal, such strategic mobilizations involve the implementation of best practice-programs in new ways and in a variety of areas dealing with both intentional and unintentional injury. Use of best practices can have two aims: First, as proven incidence reducing programs they can be implemented in Ontario with a shift of research emphasis from outcome onto the process of their adaptation; Second, they can act as potential service integrators that help tie various relevant service providers and community stakeholders into a more cohesive preventative force. The success indicators for such a dual-purpose implementation evaluation require consideration of both aims.

ONF Prevention Programs as Community Systems Integrators

Communities that focus and combine prevention efforts can achieve holistic system change and contribute to the development of a culture of safety. Community systems oriented best practice-programs can overcome jurisdictional isolation by providing a focal point for the integration of various services. The prevention work of hospitals, public health, and community services is often not coordinated. Only when there is an actual sharing of goals is synergy possible. Multi-level prevention programs such as the shaken baby syndrome best practice can act as a system integrator and professional boundary bridge. Figure 2 illustrates this phenomenon.

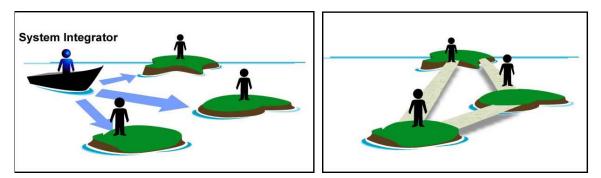


Figure 2 (From Fong et al., 2007): System integrator and boundary bridges

Moving from independent isolated efforts to cooperation, coordination and collaboration increases the effectiveness and potential sustainability of prevention initiatives. The result of this process should be denser social networks that draw on combined competencies and resources to bring about change and advance a community's culture of safety.

Research Values and Assumptions

As noted above, untangling the causes of inflicted infant head trauma or any form of child maltreatment is difficult. Although using what is known about risk and protective factors has been useful in designing prevention programs and targeting areas in need of change, this does not provide enough strict information to design infallible prevention programs. Risk and protective factors interact, and the myriad circumstances that exist in real life elude predictability. These fluid and myriad circumstances require that prevention programs aspiring to alter human behaviour be comprehensive. Because child maltreatment is multi-determined, programs that are designed to prevent it need to be multidimensional. Consequently, efforts to prevent inflicted infant head trauma should involve multiple ecological levels and seek combinatory synergies through service integration. To combat inflicted infant head trauma, service providers such as nurses, social workers, physicians, and teachers need to work together to improve the culture of safety in their communities. Because the collective practice area of primary prevention is characterized by uncertainty, the one constant critical component in an effort to create a culture of safety for infants is the quality of relationship or connectedness of community members. This component is what gives meaning to the pamphlets, videos, and posters that are the visible representations of a prevention program.

Although human connection is a necessary component in efforts to change human behaviour, developing a culture of safety also requires that societal/contextual issues be addressed. Consequently, prevention activities, such as health information, need to be coordinated across ecological levels of influence from individual to institutions. Information about inflicted infant head trauma and the care and comforting of infants is the first level of prevention. Thus, while increasing parents' knowledge and skills at this level is central, it is also important to promote community-wide education and change public policies to create new norms and relationships.

The ONF SBS Prevention Program

The primary goal of the ONF SBS Prevention Program is to evaluate the implementation of the Upstate New York Shaken Baby Syndrome Education Program in Ontario.

Overview of the Upstate New York Shaken Baby Education Program

The major strength of The Upstate New York Shaken Baby Syndrome Education Program lies in its simplicity. The educational program is short and easy to introduce to parents – making it straightforward for very busy neonatal nurses and health educators to put into practice (Dias, et al., 2001; 2002). Another strength of the program is its focus on both parents: close attention to educating fathers, who in fact perpetrate 60% of shaken baby cases. To date, the Upstate New York Shaken Baby Education Program is the only SBS prevention program in the world that has scientifically demonstrated an actual large-scale comparative reduction of the incidence of SBS. During the first six years of the program in Western New York, the incidence rate of shaken baby syndrome dropped by 47% (Dias, et al., 2005). This program has now achieved many years of incidence reduction in New York State and has had widespread use throughout North America. The program has been so successful that it has been launched in multiple states, including Ohio, Pennsylvania, Michigan, Utah, Arizona, and Minnesota. The program has become a best practice in the primary prevention of pediatric neurotrauma.

The entire program requires approximately fifteen minutes of parents' time and less than five minutes of maternity ward nurses' time. Parents are asked to do three simple things:

- 1. Read a one-page brochure that describes the dangers of violent infant shaking and informs parents how to safely vent their frustration and anger over persistent infant crying.
- 2. View a short video that covers the same subject matter.
- 3. Voluntarily sign a commitment statement affirming their receipt and understanding of the information and provide or deny consent for being part of an evaluative follow-up.

These fidelity features of the Upstate New York Program have been identified in the ONF best practice review and retained in the Ontario implementation. Adherence to the what has been determined to be fidelity features of the original program enabled the Ontario implementation to adapt and extend it to service providers both inside and outside of hospitals and in additional formats.

Objectives of the ONF Implementation

Provide a standardized program for hospital-based nurses and then expand it as a radiating series of experimental implementations that will include pre and post-natal public and community health delivery modes that involve midwives, health educators, and general practitioners.

- Track compliance with the program through analysis of the number of forms of delivery, signed commitment statements, and type of signatories.
- Describe the implementation process.
- Profile participating social networks in terms of community coalitions and professional alliances.

Overview of the ONF Shaken Baby Syndrome Prevention Program

The ONF SBS program was divided into three phases. Phase I - Planning Phase; Phase II: Implementation Phase: participating project sites administer the education to parents and families; Phase III – Maintenance Phase: sustainability issues are addressed and program refreshers are administered as needed. This report covers Phases I and II.

Personnel - University of Toronto Research Coordination Unit (UT-RCU)

The UT-RCU included the Principal Investigator and seven part-time team members whose positions were financially supported by the research program:

- research coordinator the role included designing the templates for coding and tracking the consent form data, follow-up call information, and record keeping for contributions in kind; also analyzing the data and providing ongoing reports to the PI
- nurse coordinator –a liaison role; the nurse coordinator was in contact with the SBS site coordinators and worked closely with the two RCU RNs who were hired to provide the follow-up calls; also interested in connectedness, the nurse coordinator conducted several focus groups with nurses to understand relationships nurses develop with patients and families
- communications coordinator built contacts with health care service agencies and organizations in communities where the ONF SBS program was being implemented in order to provide support and/or idea-sharing re SBS awareness and sustainability; interviewed all site coordinators using the BRIO format for case studies
- social network coordinator developed the social networking questionnaires, used Pajek software to create the sociograms to help understand connections between and among the project team members
- research assistant data entry, clerical support
- RNs (2) were hired to assist with telephone follow-ups in sites where the SBS coordinator was unable to do so. These nurses also provided some background documentation one on midwifery in Ontario, and the other on the use of simulators in health care.

The Institute of Child Study's Laidlaw Research Centre provided in-kind administrative support for the program. The LRC's Coordinator, Academic Support

assisted with managing the research award with regard to financial transactions, payroll, reporting, communication with the university's ethics and research services departments, purchasing equipment and supplies, modifying forms, event/conference planning, website design and upkeep, and general communication with sites.

Site Personnel

Each program site was required to have a coordinator who would oversee the research in their community and liaise with the UT-RCU. The Upstate New York program placed importance on the coordinator being a nurse – she/he could relate to nurses by understanding peer interactions, be a credible source of information, and be a leader able to motivate front-line hospital nursing staff. However, in Ontario the ONF SBS program's delivery settings were not limited to hospitals, and in two cases our site coordinators were in the field of social work. All site coordinators had strong support from program administrators at their organizations and were successful at encouraging their colleagues and staff to deliver the SBS education.

Best Start Resource Centre / Toronto Public Health

During the summer of 2006, we were approached by a Health Promotion Consultant with Best Start: Ontario's Maternal, Newborn and Early Child Development Resource Centre who was put in touch with our program through a contact at Kingston Public Health. This Best Start organization presents workshops and consultations to service providers across Ontario that include SBS prevention in general, and talk of Dr. Dias's work in particular. They had been asked to deliver SBS training to 160 staff from the Healthy Babies, Health Children program at Toronto Public Health and were interested in collaborating on this endeavour with our team. The PI joined them in delivering the TPH training as well as presenting the ONF SBS program at a number of conferences and training sessions. The collaboration of our program, Best Start (now Health Nexus) and Toronto Public Health led to the creation of the revised *comforting cards*, professionally designed and translated into 20 languages. This undertaking was an effort to expand SBS awareness to multicultural families across Ontario.

Communications

Team Meetings - The UT-RCU organized two all-site team meetings that took place in Toronto. The first, March 27-28, 2006, was an orientation to the program research. The two nurses from the Upstate New York Shaken Baby Syndrome Education program, Kim Smith and Kathy deGuehery, were the invited guests, attending the event to provide a training presentation, speak of their experiences implementing the education, and offer advice and support to the Ontario project site coordinators. The ONF SBS coordinators had a chance to meet the UT-RCU team, members from the Ontario Neurotrauma Foundation, as well as each other and share their communities' start-up plans and approaches. The proceedings were videotaped with copies available for each site to use in supporting their in-house training initiatives. Kim and Kathy provided their PowerPoint presentation as well, which is available on our website.

The second meeting was held October 1-2, 2007. Guest speaker George Lithco, founder of the SKIPPER Initiative advocacy group (www.skippervigil.com), spoke about shaken baby awareness in the United States and moving education to policy with national and state legislation. He provided a number of handouts and links to electronic documents that are also available on our website. The second day was devoted to site updates, allowing the site coordinators to report on and exchange implementation stories and strategies.

Telephone conferences with all team members were scheduled throughout the program implementation as needed.

Website - Early in the program the UT-RCU created a website that could accommodate information to support the project sites. Although it can be accessed on the internet by the public, the website's design was tailored specifically for the ONF SBS teams and their needs as they moved through the implementation of the SBS education program research. Components of the website were basic as feedback from site coordinators indicated that they preferred straightforward, uncomplicated access to resources.

The website is hosted by the University of Toronto; upkeep is provided through the Laidlaw Research Centre at the Institute of Child Study, UofT (See Figure 3).

We began by providing a Background page that includes links to the original Upstate New York Shaken Baby Syndrome Education Program case study, as well as the program's 2004 implementation plan, model, and literature review. At Implementation Resources, the site coordinators have access to the information they need to provide the SBS prevention education. A

generic copy of the consent form is available in English and French, although for the research, each site had a consent form that was specifically designed and

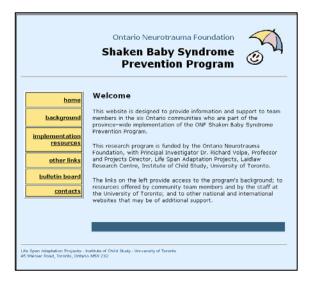


Figure 3: Homepage of ONF SBS Website (URL: www.oise.utoronto.ca/research/ONF-SBSPrevention)

printed for their organization that included hospital/institute logos and printed contact information for the site coordinator(s). The follow-up survey with guidelines for its use are also available to download, as are the data tracking templates, the responsibilities of the nurse-coordinator, and the PowerPoint slides presented by Kim Smith and Kathy deGuehery (RNs from the Upstate New York program) at the March 2006 training session in Toronto. New items continue to be added when they become available, such as the latest translated versions of the *comforting card* and the recently produced SBS Implementation Guide.

The other pages on the website include the contact information for all site coordinators and partners, and links to outside organizations that may be able to provide additional SBS prevention education and support. One final component of the website is a password protected bulletin board area for posting notes and comments and interacting through a web-forum.

SBS materials

Standard materials used by all ONF SBS project sites included a *consent* or *commitment* form, *comforting* card, poster, Portrait of Promise DVD or VHS, and followup questionnaire. The written materials were revised on a site-by-site basis; some sites created additional materials to augment their program delivery.

We started the research by reviewing the written materials produced by the Upstate New York Shaken Baby Syndrome Education Program, which consisted of a *consent form (commitment statement),* a small double-sided *crying card*, a 5"x8" *information card*, and the follow-up form used by nurses who contacted the parents when the baby was between 5-7 months old.

Consent form

The consent form (known as the commitment statement in NY, Figure 4) described the research project and provided a space for the parent(s) to sign their consent that they received the educational material, understand the harm in shaking a baby, and agree to participate in the study. This form also allowed the project to track some basic socioeconomic data about the parents. It was revised slightly for use in Ontario – for example, removing a section on the parent's medical insurance coverage. Space was made available on our consent form for project sites to add their institution logos and specific contact information, as well as the setting in which the education was delivered (prenatal class, dads workshops, etc.). Some of our site coordinators chose to reword the consent form in ways to make it more accessible for their clients; changes such as modifying the level of the written text for better understanding and adding "single fathers living with the baby" as a choice in the socioeconomic tick-boxes (Figure 5).

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Figure 4: Upstate New York SBS Education Program Commitment statement

Figure 5: ONF SBS Consent form-Sudbury

Crying Card becomes the Comforting Card

For the ONF SBS research, we merged the Upstate New York *information card* and *crying card* into what our program initially termed the *crying card*, later to be renamed the *comforting card*, emphasizing the positive aspects of parenting. A French translation was produced.

Information on our comforting card evolved during the first year of the research after receiving feedback from the project sites. We modified the image on the card, removed references both in the graphics and in the text regarding bottlefeeding and pacifiers, creating a "baby-friendly" document in keeping with a move toward Baby-Friendly healthcare in Ontario (see Figure 6). Midway into the project, with the support of the Health Nexus (previously the Best Start-Ontario's Maternal Newborn and Early Child Development Resource Centre), and Toronto Public Health, the comforting card was once again redesigned. This newest version (Figure 7) – now translated into nineteen

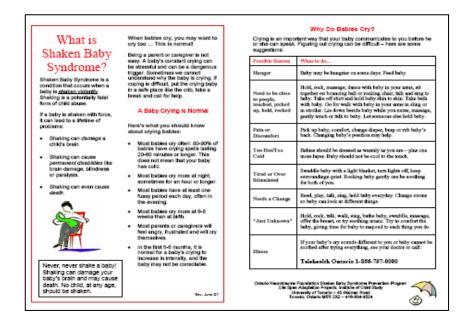


Figure 6: ONF SBS comforting card



Figure 7: Latest version of the ONF SBS Comforting Card - April 2008, in Chinese. Design and translations courtesy of Health Nexus and Toronto Public Health

languages – is available on the ONF SBS website as a Microsoft Word document with text-box space accessible to health care services to input local contact information.

Poster

Each site received posters in English and French to publicly display at their project sites, visibly supporting public awareness of SBS. Known as the Baby Jack posters (Figure 8), they were created in North Bay and distributed through the UT-RCU. Postcard versions of the poster were also produced, and these materials were used in cases where families did not come

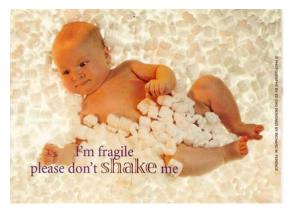


Figure 8: Baby Jack Poster

to a central site, but were visited individually by public health nurses, midwives or community social workers. The postcards were left with the family.

Portrait of Promise

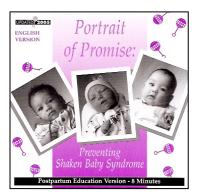


Figure 9: Portrait of Promise DVD/VHS

The film *Portrait of Promise* was used by the ONF SBS Prevention program as it was part of the evidencebased education delivered in the Dias model (Figure 9). Ontario sites had the option of receiving the film in DVD or VHS format, depending on the screening arrangements. Some sites were able to have the film included on inhospital television systems, while others were taking the DVD with a portable DVD player out to an individual's home.

Again, in keeping with a move to Baby-Friendly materials,

we asked our supplier of the film to edit out any images that had bottlefeeding and pacifier use, as well as removing the crib bumper pads in one particular scene. We supported a translation of the film's script into Ojibwe for use in the northern communities.

Other Materials

The Upstate New York program provided guideline documents for the job description of the nurse coordinator role, as well as an oral script for follow-up callers. The UT-RCU also designed a series of questionnaires, filled out by the site partners, to help capture a qualitative history of the program implementation. *RealityWorks, Inc.*, a company that designs and builds simulator dolls, donated a shaken baby simulator that has been used by various sites for demonstration purposes.

Contribution in Kind from Participating Sites

Each implementation partner contributed administrative and management assistance when needed, along with office space, telephone, fax, and computer equipment.

Knowledge Mobilization

The RCU was involved in over fifty SBS presentations as invited addresses at hospitals, community and public health meetings, peer reviewed scientific associations and provided interviews for radio and television coverage of the program.

Research Methods and Procedures

Fidelity Features and Success Indicators

As noted above, the effectiveness of a prevention intervention may be compromised when programs previously found to be effective are not implemented with fidelity, the manner they were developed and validated. Fidelity encompasses adherence, the degree to which the program is delivered as intended with all the prescribed components and processes (Upstate New York Shaken Baby Prevention Implementation Guide, 2008). The fidelity features of the Upstate New York Shaken Baby Syndrome Education Program are as follows: First an education program that employs a video overview of the shaken baby syndrome, related information brochures, and posters as educational materials; Second, a record/performance monitoring system, attitudes, program satisfaction questionnaire, and follow-up survey; Third, the use of a commitment statement that the program had been received and understood by one or preferably both parents.

The ONF program has been faithful to these features. A computerized database was maintained on all parents of the newborns who agreed to receive the SBS program information. The site program coordinators periodically reported the aggregate number of signed commitment statements, and the number of commitment statement signed by mothers, fathers/father figures, or both parents. The proportion of returned statement was used to indicate the scope of program activities in each setting. Data management and analysis was performed in an ongoing fashion. The study tracked the infant's gender, ethnicity, and date of birth.

Internal Evaluation Replication

The results presented include data from five regional hospitals and three community-based settings. Each site tracked the SBS education for an average of 18 months, with a range from 10 to 30 months. In total, we tracked the SBS education experience of 7,433 families and followed-up 26%, 1,920 families, at 6 to 12 months. Of the 7,433 families, 86% were educated in hospital-based settings. At the time of education, 93.57% of the mothers and 64.12% of the fathers/father figures signed the commitment forms.

The demographic variability in terms of parental age, education and child's living situation was broad (see Table 1). The maternal age ranged from 13 to 52 years with a mean age of 27.81 years. Paternal age ranged from 15 to 63 with a mean age of 30.69 years. In terms of education, 51% of the mothers and 45% of the fathers obtained college/university undergraduate or graduate degrees, whereas 16% and 17% respectively did not have a high school degree. At the time of birth the majority of children, 82% overall, lived with both parents, 12% with the mother, and 6% reported an alternate living arrangement (e.g., with grandparents or in the custody of CAS). At the time of follow-up 97.93% of children resided with their mothers and 88.33% with the fathers as well. This difference in living arrangement between education and follow-up may reflect a bias in the follow-up, in that those with more stable living situations were more likely to agree to follow-up. At the time of signing, 74% of respondents agreed to participate in a follow-up phone call.

Site	Number of Families Tracked	Forms Signed by Mother	Forms Signed by Father	Mother's Average Age	Father's Average Age	Mother's Educ	ation	Father's Educ	ation	Baby's Living Si	tuatior
Hospital-Based Sites	6402	89.90%	81.07%	28.63	31.36	Some High School High School Some Post- Secondary Post-Secondary Graduate	11% 14% 17% 53% 5%	Some High School High School Some Post- secondary Post-Secondary Graduate	11% 18% 21% 44% 6%	With Both Parents With Mother Other	89% 8% 4%
Community- Based Sites	1031	98.46%	41.51%	26.72	29.80	Some High School High School Some Post- Secondary Post-Secondary Graduate	23% 23% 14% 36% 5%	Some High School High School Some Post- secondary Post-Secondary Graduate	24% 24% 13% 33% 6%	With Both Parents With Mother Other	72% 20% 8%
TOTAL	7433	93.57%	64.12%	27.81	30.69	Some High School High School Some Post- Secondary Post-Secondary Graduate	16% 18% 16% 46% 5%	Some High School High School Some Post- secondary Post-Secondary Graduate	17% 21% 17% 39% 6%	With Both Parents With Mother Other	82% 12% 6%

Table 1: Participant Demographic Characteristics

Of the participants who completed a commitment form, opinions on the SBS education program at the time of delivery were very positive (see Table 2). Overall, 96.53% found the information to be helpful. Consistent with this finding, 98.99% of the respondents indicated that the information should be provided to all new parents. Although the majority had previous knowledge about shaken baby syndrome, 6.5% of respondents reported that the SBS education was the first time they had heard of inflicted infant head trauma.

	Was the information helpful?	Was this the first time heard about SBS?	Would you recommend this information to all new parents?	Would you like to participate in an education follow-up?
Hospital-Based Sites	96.51%	6.20%	98.77%	65.06%
Community-Based Sites	96.56%	6.84%	99.28%	86.11%
TOTAL	96.53%	6.48%	98.99%	74.08%

Table 2: Opinions on SBS Education at Time of Program Delivery

Note. All responses indicate % of respondents replying 'YES'.

A subset of those consenting to follow-up was phoned between six and twelve months post-partum (see Tables 3 and 4). The follow-up surveyed revealed that 95.18% of parents remembered receiving general childcare information, with 96.31% specifically remembering the shaken baby information. When asked if they remembered speaking with a health care professional about shaken baby syndrome, 90.40% responded yes. The participants also reported sharing the information: 82% shared the shaken baby information with their husband/boyfriend/partner and 16% with someone other than their partner, for example, their mother. If the baby's father was living with the family at the time of delivery 84.91% received SBS information at the hospital, but even if the father was not living with the baby 81.02% of mothers shared the SBS education information with the father; 76.77% of respondents also reported leaving their child in the care of another adult, typically a friend, relative, or babysitter (79%) or at a day care centre (17%), but only 55.18% of respondents shared the SBS information with their caregivers.

Site	Do you remember receiving care of child info?	Do you remember receiving SBS info?	Do you remember receiving a health care professional talk about SBS?	Do you remember receiving SBS materials?	Do you remember the video?	Do you remember the consent form?	Do you remember any SBS posters?	Did receive [site specific] info?	Do you remembe r signing the form?
Hospital-Based Sites	96.02%	98.54%	87.59%	92.27%	89.33%	61.48%	55.13%	50.08%	94.62%
Community-Based Sites	94.07%	93.34%	94.16%	92.18%	91.78%	67.41%	68.27%	64.82%	91.74%
TOTAL	95.18%	96.31%	90.40%	92.23%	90.38%	64.02%	60.76%	56.39%	93.38%

Note. All responses indicate % of respondents replying 'YES'.

Table 4: Supplementary Education and Dissemination of SBS Information

Site	Did you receive SBS materials after leaving hospital?	Did you receive SBS information from your doctor?	If the baby's father/father- figure is living in the home, did he receive information on SBS in the hospital?	If the baby's father/father- figure is <i>not</i> living in the home, did you share the SBS information with him?	Do you ever leave baby in care of another adult?	Have you shared SBS information with your caregivers?
Hospital-Based Sites	31.34%	23.79%	94.51%	81.49%	73.98%	47.39%
Community-Based Sites	49.17%	41.75%	72.11%	80.40%	80.50%	65.56%
TOTAL	38.98%	31.48%	84.91%	81.02%	76.77%	55.18%

Note. All responses indicate % of respondents replying 'YES'.

More direct questions about specific aspects of the education revealed that although only 64.02% said they remembered the consent form, when directly asked if they remembered signing the consent form 93.38% answered in the affirmative. Of those who responded, 92.23% remembered receiving written materials about SBS, 90.38% remembered the video, and 60.76% remembered the posters. When asked to specify which SBS educational material was most memorable, 59% selected the video, 15% the written materials, 9% their discussion with a health care professional and 10% could not specify a single most memorable information source. The consent form, new

parent kits, the posters, and other site-specific materials were each selected as most memorable by less than 2% of participants. Even when asked directly, only 56.39% recalled the site-specific information.

Just 38.98% of respondents reported receiving SBS information from another source (in addition to the SBS education program), and if received it was primarily from their doctor (26%), nurse practitioner (8%) or midwife (4%) and non-specific sources such as the internet, billboards, and TV (50%), with 12% receiving SBS information from multiple sources. When asked expressly if they remembered receiving information from their doctor, 31.48% confirmed that they did receive SBS information from their doctor.

Overall the results are closely aligned with those reported by Dias et al. (2005). Our extension of the program to settings outside of hospital, however, warrants some discussion. For example, striking differences in consent form signing were evident. In the hospital-based settings 89.90% of mothers signed, compared to 98.46% in the community-based settings. In contrast, in the hospital-based settings 81.07% of fathers/father-figures signed, compared to 41.51% in the community-based settings. An explanation for the large discrepancy in father participation is the high-risk status of clientele in many of the community-based programs. In terms of program opinion the findings were very similar for respondents educated in hospital-based compared community-based settings in that essentially all found the information to be very helpful, recommended the education to all new families, and most had prior knowledge of SBS.

At follow-up, however, more differences were evident. When asked the more general opening questions "do you remember receiving child care information" or "do you remember receiving SBS information", parents educated in community-based settings were more likely to say no; but, when probed with specific questions about the SBS education, such as "do you remember a health care professional speaking to you about SBS" or "do you remember the video", they indicated higher rates of recall on all measures.

The Shaken Baby Syndrome Prevention Program has replicated the original hospital-based work by Dias et al. (2005) and extended those findings into a variety of settings. Our findings very closely parallel those of the Dias et al. Upstate New York study with small differences that primarily reflect program administration. For example,

the video was rated as much more memorable in our study, but Dias acknowledged that the video was not always shown in the New York study. In contrast, our video was consistently shown to all participants. Similarly, posters were not as consistently remembered in our study relative to the Dias study, which is primarily a reflection of our poster locations. For reasons of hospital policy, our posters were not always permitted in optimal high-traffic areas. Overall, however, there are no meaningful differences in our findings on program acceptance, opinion, or on memory for the components of the educational program as compared to the Upstate New York study. It is also important to note that, as part of our focus on sustainability, within our study the sites acted very independently and the programs were still administered successfully. This is an important extension to the Upstate New York study, in which the program developers governed much of the administration. This replication is important in speaking to the efficacy of the program.

Another significant contribution of this work is in demonstrating that the educational program is suitable to administration in diverse settings. These findings are particularly important given that the project was originally modeled as a hospital-based prevention program. Our findings show that the program is adaptable in that the core components are maintained across sites, but aspects of the program may be altered to suit better the needs of the community served. The consistency in findings across hospital-based and community-based settings shows that site-specific modifications do not diminish the effectiveness of the education. The pattern of results did not vary dramatically and no strong differences in program acceptance, opinion, or memory were evident among the specific sites or more generally between hospital-based and community-based settings. We strongly believe that adapting the program, while maintaining the fidelity features, leads to improved site suitability, which is critical to the long-term sustainability of the program. The flexibility of the program in allowing for sitespecific customization also had the secondary benefit of developing a sense of ownership and commitment to the program within the site, factors which will also support long-term sustainability.

The Shaken Baby Syndrome Prevention Program is equally suitable for administration within and outside of hospital settings. Adaptations of the education administration to suit the setting do not impact effectiveness, assuming the core features are maintained. Importantly, long-term sustainability is probable when the site is

committed to the education and the method of education delivery is appropriate to the setting.

Implementation Process Evaluation Cases

The implementation evaluation of participating sites required a complex framework. The BRIO Evaluation Model is such a framework. It provides a means of organizing complex information collected via a number of methods into a coherent case by investigating outcome and process measures, demographic target groups, program settings, and evaluation methodology of each policy/service initiatives. The four areas referred to in the BRIO model are Background, Resources, Implementation and Outcome. Background includes policy and program objectives, the environment and events surrounding their development and implementation. Resources deals with the nature and kind of assets developed for and allocated to the strategies/interventions. Implementation refers to the ongoing project/program management such as feedback and priority setting and the provision of service. This section determines how the program is guided at the operational level, what sort of checks on implementation have been made, and what evidence exists as to the relation between what was intended in a program design and what actually exists. Outcome includes the impact and effectiveness of strategies/interventions. The BRIO model provides a consistent way of creating a case so that a comprehensive yet succinct understanding of the structure and operation policies and programs can be made explicit. Information for the SBS Prevention Program case studies was obtained using key informant interviews, focus groups and structured surveys. Data sources also included appraisal of available program documentation, interviews with stakeholders, and a selective review of pertinent literature.

Case Study : Sudbury

SUDBURY & DISTRICT HEALTH UNIT / SUDBURY REGIONAL HOSPITAL / MIDWIVES OF SUDBURY / SUDBURY COMMUNITY MIDWIVES

BACKGROUND

Description of Community and SBS Project Site

Sudbury is the largest city in Northern Ontario. It has the third largest francophone speaking population outside of Quebec, while other community members contribute to its multicultural mix (i.e., First Nations, Finnish, Italian, Polish, Chinese, Ukranian, Croatian). Mining continues to be a mainstay of the city's economy, however, the city's diversity and centrality make it a service hub for all of northeastern Ontario.

Hôpital Régional de Sudbury Regional Hospital (SRH) is one of the largest hospitals in Ontario, providing services to more than 600,000 residents in Northern Ontario in both English and French for acute, transitional, rehabilitation and continuing care. Sudbury & District Health Unit (SDHU) is part of the provincial network of non-profit public health agencies funded by local and provincial governments. The SDHU is a teaching health unit – the northern site of Ontario's Public Health Research, Education and Development Program (PHRED) – and affiliated with Laurentian University. Public health programs offered through the SDHU are geared for all ages and delivered through workplaces, day cares, education environments, homes, health care settings, and community spaces. Sudbury Community Midwives and Midwives of Sudbury provide care to families in the Sudbury area; midwives may attend births at Sudbury Regional Hospital. Services at this site are provided in English, French, and Ojibwe/Ojicree languages in response to cultural populations in the Greater Sudbury area.

A number of local programs, for example the Red Cross, Our Children-Our Future, and the Health Unit's Child & Family Team, have information on shaken baby syndrome available to community members. Midwives have been providing SBS

information to mothers and partners prenatally through their discussions concerning mother self care and baby behaviour.

Neurotrauma Issues in the Community

Members of the SBS team in Sudbury are aware that incidence(s) of infant neurotrauma have occurred within the community in recent years, specifically a confirmed diagnosis of SBS in 2001.

Participation in the ONF SBS Prevention Program

Decision to Participate: Sudbury & District Health Unit - Prior to becoming the ONF SBS public health coordinator for the district health unit, the public health nurse in injury prevention attended the North American Conference on Shaken Baby Syndrome in Montreal (2004). The impact of hearing first hand the personal experiences of families who had endured SBS injuries or death motivated her to mobilize services in the community and seek to implement an evidence-based SBS prevention program through the unit; she then met with members of the Coalition for Child Abuse Prevention who decided to search for a program that would meet this need. The February 2005 NIPPN (Northern Ontario Injury Prevention Practitioners Network) conference in North Bay connected the ONF SBS project's principal investigator with representatives from the Sudbury Regional Hospital, the District Health Unit, and the Midwives of Sudbury, where they proceeded to work towards implementing the ONF SBS prevention initiative.

Sudbury Regional Hospital - A pediatrician at SRH attended a meeting of the SDHU where the shaken baby prevention project was being discussed and later approached the hospital's administrative director of the Family Child program about becoming involved. Subsequent meetings were held with the public health nurse in injury prevention at SDHU where ideas for implementation of the project were explored.

Midwife Groups - Once a decision was made by SDHU to participate in the ONF SBS prevention program, the public health coordinator approached the local midwifery practices about their participation. Both Sudbury Community Midwives and Midwives of Sudbury felt the ONF program would be a worthwhile addition to their practices.

Response in the Sudbury community to the implementation of the ONF SBS research program was one of substantial support by all organizations providing services to children and families, health care services, police services, and the local media.

<u>Original Goals for Participating</u>: By participating in the ONF SBS Prevention program, Sudbury's hospital, district health unit and midwifery groups saw opportunities to raise general awareness of shaken baby syndrome, to increase safety for families in the Sudbury area, and to provide professional enrichment to health practitioners.

<u>Start-Up Process</u>: Sudbury & District Health Unit - The initial partners in the research project - SDHU, SRH and Midwives of Sudbury - had four planning meetings to determine strategies for the launch of the SBS research project in their respective sites. The public health coordinator facilitated the Sudbury Community Midwives to join as the fourth partner. All partners felt the program was simple, portable, and easily incorporated into the parenting support and education services of the participating organizations.

Sudbury Regional Hospital - The administrative director of the Family Child program initiated the planning and design for the ONF SBS prevention education program at the hospital. A part-time nurse coordinator position was required to address the training needs of the nurses who would deliver the program to parents and to coordinate the data collection. As the hospital budget did not have funds available for this position, a request was made to the University of Toronto Research Coordination Unit (UT-RCU) for financial support. A nurse coordinator was hired who reported to the SRH coordinator of sexual assault and domestic violence program. Ethics approval was granted through the hospital's Ethics Committee.

Resources

Personnel

<u>Stakeholders</u>: In this community, stakeholders are identified as Sudbury Regional Hospital staff, Chief of Paediatrics, administrators, coordinators - including the SBS nurse coordinator and the coordinator of the sexual assault and domestic violence program - the nurses on the postpartum floor and the parents using the hospital birthing services, staff of Sudbury and District Health Unit, members of the Sudbury Coalition for Child Abuse Prevention, Sudbury families; Midwives of Sudbury, Sudbury Community Midwifery practice, midwife clients, community social agencies, and professor of Midwifery Education Program at Laurentian University in Sudbury (which offers a Bachelor degree in Health Sciences in Midwifery program).

Community organizations such as Child Care Resources, Healthy Babies Health Children, and Better Beginnings Better Futures, Canadian Red Cross, Child and Family Centre, Child Care Resources, Children's Aid Society, Greater Sudbury Police, Jubilee Heritage Family Resources, Kidshare, Our Children Our Future, Ontario Early Years Centre-Nickel Belt, St. John Ambulance, Supervised Access Centre, Za-geh-do-win Information Clearing House, YWCA Generva House, Infant Development College Boreal, Cambrian College, local media (Sudbury Star, Sudbury TV stations).

Program Personnel: Sudbury Regional Hospital hired a part-time nurse to become the SBS hospital coordinator. The public health nurse for injury prevention in the SDHU took on the role of ONF SBS public health (PH) coordinator for the Sudbury community, working closely with the SBS hospital coordinator regarding program training. As well, a part-time PHN who worked through the Early Years initiative in family abuse prevention at SDHU until December 2006 assisted with the ongoing coordination of the research project for the midwifery groups. Health Unit volunteers put together the parent information packages (comforting info, contact card, etc.) which are given to new parents. Midwives of Sudbury representatives were active in participating in the program by attending team meetings and teleconferences. The Sudbury Community Midwives administrative staff person ensured consent forms were filed once completed and arranged for data to be given to the SBS PH coordinator, as well as provided other general administrative service in support of the program.

Financial Support

Sudbury & District Health Unit / Sudbury Regional Hospital - SDHU received Early Years funding during 2005-06 to assist with the start-up of the ONF SBS prevention project, allowing the SDHU part-time PHN to be involved in program implementation. Financial support from the ONF SBS research program enabled the hospital site to deliver the SBS prevention program with the hiring of the part-time SBS hospital coordinator who provided support and leadership. The UT-RCU also provided

funding for the French translations of the consent forms and earlier versions of the comforting material.

In-kind support from the Sudbury Regional Hospital provided the SBS hospital coordinator with office space and equipment for data collection activities, developing and monitoring the SBS services process and ongoing training of hospital staff; hospital resources, such as the expertise of the communications department and the consultation services of the sexual assault and family violence coordinator were also provided in kind.

Early Years funding supported additional SBS prevention information (Baby Jack banners, posters and cards, congratulations certificate) to be developed and printed in partnership with the North Baby SBS project site, and enabled the Sudbury SBS team to provide a small give-away kit to parents that contained lotion, wipes and a Love Me, Don't Shake Me bib. Other promotional items, such as Never Shake A Baby wristbands, and Does Your Baby Cry, Ask Me for Help pins, were made available for distribution by community agencies. Funding from Early Years ended in December 2006.

Material

Consent and follow-up forms were supplied to the Sudbury team by the UT-RCU. Also provided were DVD players and the Portrait of Promise DVD/videos. Written materials for parents (comforting cards, etc.) and promotional items noted above were used in partnership with the North Bay ONF SBS project site (see Figure 10). The Sudbury site organized a group purchase of the videos Happiest Baby on the Block and Happiest Toddler on the Block; these reference materials were given to libraries through the SDHU's catchment area. The health unit has also purchased six table-top displays, providing one to the SRH, to each branch office location, and to the Early Childhood Development program at a local community college; another is available for loan to community groups.



Figure 10: Sudbury site's displays and promotional items

The SDHU SBS PH coordinator worked in consultation with the SDHU Ethics Committee on SBS materials and protocols proposed for their community, which were accepted after suggested changes were made to the Congratulations and Commitment cards; a protocol was also developed regarding the follow-up calls should a parent wish to decline or withdraw after having signed to say they would participate. Contact listings were included in the parent information packages, and shortly after the program began, at the SBS coordinators' request the UT-RCU put together a page of resource supports that included websites, reading materials, and current videos/DVDs that might be of interest to parents. A special script was prepared for persons doing the follow-up calls should the respondent indicate that the infant had died.

MPLEMENTATION

The Implementation Process

The SBS research project was launched in Sudbury as a full-day event on April 18, 2006 at Sudbury Regional Hospital. The SRH and SDHU collaborated on press releases. Speakers were from the hospital, the district health unit, and Midwives of Sudbury; the ONF SBS program's principal investigator also made a presentation. Local media attended, as did hospital physicians, senior management of the hospital and health unit, as well as the North Bay project site nurses. Displays from partnership member health resources, including posters and handouts regarding SBS, were made available to everyone attending. A highlight of the 2006 project launch in Sudbury was the unexpected attendance of a grandmother, who having learned of the event through the local media, attended with her young grandson who had experienced an SBS injury. The telling of her family story and her support for shaken baby syndrome prevention education made a significant impact on those in attendance.

The four Sudbury partner sites met regularly as a working group to update, review, problem-solve and make decisions regarding the implementation progress of the SBS research program. At Sudbury Regional Hospital, the SBS hospital coordinator nurtured a professional, respectful and supportive mechanism that worked well for the delivery of the SBS education throughout the hospital, from front-line nurses to hospital administration. She trained the nurses in the postpartum unit to teach the SBS education to patients, as well as monitored and analyzed the delivery process, reviewed and updated both the front-line nurses and her manager on an ongoing basis. She also met with the PH coordinator every two weeks to review the research.

The program was piloted at the hospital in such a way that it was built into the daily delivery of services on the post partum unit, and became a "way of life" for the nurses. The SBS education is a component on the "clinical pathway" for care of a newborn. Front-line nurses who teach the education recognized immediately the value of the program for families and were committed to its delivery to parents.

The SBS PH coordinator met individually with the four Sudbury partners, which she found to be important for maintaining communication and support for each other. She attended the team meetings of the midwifery practices, delivering materials they needed to provide the education and collecting any consent form data they had available at that time, which was brought back to the health unit and the data entered by a SDHU clerical support staff. She coordinated community initiatives, such as participating in the annual October Purple Ribbon Campaign, promoting SBS prevention messages with Sudbury's local bus service, inserting a one-time four-page insert into the local newspaper, communicating with local boards of education about the curriculum designed in North Bay, presenting workshops at NIPPN meetings and Best Start, as well as being a consistent member of the Coalition for Child Abuse Prevention. SDHU public health nurses in the Healthy Baby program adjusted their normal prenatal information routine with prospective parents so they were not duplicating information that would be received through the research project - they continued to talk about prevention of SBS injuries and soothing crying babies, but no longer showed a video during the period of the SBS research implementation. Although the SDHU was a valuable partner organization and the PH coordinator was instrumental in facilitating the research study , the public health nurses did not deliver the ONF SBS education to their clients. Implementation was only through the hospital and midwifery practices.

The team at Midwives of Sudbury felt the best time to provide the education was at the 32-week consultation with clients, when partners/supporters participate and the focus is on delivery and post partum care for mother and baby. At this visit, the film was viewed together, materials presented and discussion followed, with midwives conscious of their clients' emotions, literacy skills, life experiences, and timing (for instance, if a client was concerned about another issue, the SBS prevention information was left for a subsequent visit) . A client's reception of the information could impact whether she felt comfortable in participating in the follow-up interview. If a client missed this session, education would be delivered at the group prenatal class and again at the clinic visit 7-10 days following the baby's birth.

Sudbury Community Midwives received orientation on the research from the SBS public health coordinator. This team of midwives chose to deliver the information at the 36th week of pregnancy, as this was the visit that partners attended. They felt delivering the information in the post partum period could be unduly upsetting for the new parents. Clients were prepared ahead of time for the topics that would be covered at the 36-week consultation, at which visit they sit view the Portrait of Promise in a private room, then immediately discuss the information with their midwife. It was noted that the program fit very smoothly into this midwife practice.

The 5-7 Month "Follow-up" Process

The hospital coordinator began follow-up calls with parents who delivered their infants at Sudbury Regional Hospital; however, after several months the volume was too great and nurses from the UT-RCU completed this part of the research.

The SDHU coordinator arranged the follow-up calls for the two midwifery groups; calls were made by research assistants in the health unit's Resource, Research, Evaluation and Development Division (RRED).

Lessons Learned

Sudbury was the first Ontario community to launch the ONF SBS prevention program and, therefore, the site coordinators were first to closely review the materials that had been modified from the Upstate New York hospital-based program. As the Ontario context included various health-care setting delivery methods, the coordinators were instrumental in reviewing and suggesting modifications of the earliest versions of written materials. The proposed changes were discussed over several of the early telephone conferences among ONF SBS program participants; ultimately the revisions were agreed upon and incorporated into the existing consent and follow-up forms prepared by the UT-RCU. Although the fidelity features of the consent and follow-up forms remained intact, site coordinators in all communities took ownership of the forms, creating an evolution representative of their individual settings and clientele.

During the implementation, midwifery groups specifically tailored program delivery to their clients' age, cultural, and literacy needs by using the language and facts that support and would be familiar to the mother-to-be's life experiences. Some availability issues came to light as the midwife groups were documenting their data quarterly, yet the program's coordination unit at the University of Toronto was tracking information monthly, leading to delays in preparing project statistics.

The practicalities of administering the program were challenging at times. The PH coordinator reviewed all data for possible duplication, as it had happened more than once that both the midwife and hospital staff collected the same information - the midwife during the client's prenatal meeting, and the hospital nurse when that client delivered her baby at SRH. A suggestion to overcome any duplication, especially when community

partners work on the same implementation project at the same time, is to create a template that could document data from different sources.

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Program Sustainability

One key to the success of the implementation at Sudbury Regional Hospital is the strength of commitment from those in leadership roles - the nurse coordinator,

administrative director of the family child program, and the hospital's administrative staff, including the Chief of Paediatrics. All recognized the value of the SBS prevention initiative, the potential impact for children's safety, and thus their commitment was a driving force in facilitating the delivery of service at the hospital. The simplicity of the program also contributed to a successful permanent implementation of the SBS prevention education program at the hospital, ensuring it remains on the critical path of services for parents of newborns. The nurse coordinator will be designated one day/month to audit and measure the level of compliance of the ongoing delivery of the SBS program.

The program goals for the Sudbury community were reached – the four partners successfully demonstrated how a committed group of professionals can work together as one voice for the well-being of their community.



Figure 11: Community news re SBS

Shaken baby syndrome prevention awareness has been brought to the forefront here (see Figure 11), and nursing, healthcare, and midwifery practitioners have been professionally enriched through the training. The program has fit well into the models of care used by the hospital, the health unit, and by the midwifery practices. Many families

have noted that they believe the SBS prevention information to be very important and have passed it on to family members, friends, and infant care providers.

Community events have supported the visibility of SBS prevention. The SDHU organized the local purple ribbon campaign in Sudbury (provincially set up by CAS), with ribbons paid for by the CCAP Coalition. Sudbury also participates in the annual "Week of the Child" event, with coordinators placing a focus on SBS. During the ONF project implementation, SBS prevention message were promoted by a one-time four-page newspaper insert and through Sudbury's public transit with posters on the interior and exterior of buses. Financial ability to develop and provide ongoing publicity for shaken baby syndrome prevention education would be helpful in keeping public awareness high; a provincially run campaign would be an added benefit.



Figure 12: Sudbury and District Health Unit



Figure 13: Sudbury Regional Hospital

Case Study : North Bay

NORTH BAY GENERAL HOSPITAL / MIDWIVES SAGE-FEMMES COMMUNITY PARTNERS IN INJURY PREVENTION

BACKGROUND

Description of Community and SBS Project Site

Approximately 350 km north of Toronto is the city of North Bay, one of the two northern communities taking part in the ONF SBS Prevention program. North Bay is an urban/rural mix, home to 54,000 residents of whom one-quarter speak French as their first language. The economy has a high percentage of government/public service sector jobs.

North Bay General Hospital (NBGH) is an acute care community hospital, providing 204 beds and offering a wide range of programs and services to the city and surrounding areas. More than 95% of the city's family physicians participate in patient care. NBGH is in the process of building a new General Regional Health Centre, to be completed in 2010, that will include advanced specialized mental health facilities; a nearby children's treatment centre is proposed that will bring together services for children with special needs. The hospital's medicine, surgery, and obstetrics practices use Care Pathways (Maps) as the multidisciplinary communication tool that inform all members of the health care team, including patient and family, of expected course treatments and outcomes. Midwives Sage-Femmes of North Bay is the only midwifery practice in the community. Midwives have access to the labour and delivery and postpartum services at NBGH.

The **Connecting Community Partners in Injury Prevention** (CCPIP) is an active network of injury prevention practitioners who collaborate on preventative education and programming issues across the life span in the North Bay area. CCPIP has focused on developing and searching for evidence based best practice injury prevention programs for implementation that would increase community safety.

Neurotrauma Issues in the Community

A recent incidence of shaken baby syndrome has made an impact on the community—twin infants of rural area parents received injuries that resulted in severe trauma. Other suspicious SBS injuries have occurred in the region, however due to the current ICD-10 codes under maltreatment, the Canadian Institute for Health Information (CIHI) does not have the ability specifically identify the source of the injury.

Participation in the ONF SBS Prevention Program

<u>Decision to Participate</u>: NBGH was interested in participating as a research site after the principal investigator presented the ONF SBS program at the February 2005 Northern Ontario Injury Prevention Practitioners Network (NIPPN) conference. The NBGH nurse clinician maternal child program submitted a proposal to the hospital ethics committee, which was ultimately approved.

About the same time, the North Bay Partners in Trauma Prevention Network submitted a proposal to the ONF entitled "Developing a High Intensity Injury Prevention Centre in North Bay", the goal of which to increase collaboration among community partners and injury prevention practitioners to address neurotrauma issues. The CCPIP was formed at this time, and one of its many mandates was to focus on programs targeting a range of injury types and injury groups. The ONF SBS Prevention program fit with this focus and was incorporated into the North Bay ONF project, including funds for resources and staff hours. The CCPIP saw this as a two-part prevention effort – to implement the SBS prevention education in a hospital setting, where all parents of newborns would receive the program, and to inform the community at large about shaken baby syndrome by ensuring SBS resources would be made available to all physicians, including those in specific areas (emergency), by promoting the inclusion of SBS information into elementary and high schools through development and piloting of SBS curricula, and by sharing SBS resources throughout Northern Ontario via membership of NIPPN.

<u>Original Goals for Participating</u>: To reduce/eliminate neurotrauma injuries in infants by incorporating the SBS education into the services that parents and families receive in the North Bay community and surrounding environs. To raise awareness of SBS as a preventative injury. To participate in and support the prevention education

project at NBGH by incorporating the program into services provided to families in the maternal child center. To raise staff awareness of SBS; to educate, train and provide the nurses with tools to deliver SBS education to families. To present the ONF SBS Prevention program to all Midwives Sage-Femmes clients.

<u>Start-up Process</u>: October 2005, the CCPIP coordinator hosted a community education blitz on SBS at the North Bay Police Services. Local media covered the event and NBGH administrative staff and representatives of community partners were present.

The NGBH site coordinator and nurse clinician attended the March 06 Site Coordinator's meeting in Toronto, as did the CCPIP coordinator, where training was provided by the two nurses from the Upstate New York SBS Prevention Education program. The site coordinator felt that it was important for staff at the hospital to have ownership of the project – together they reviewed and discussed forms and materials, made recommendations on how to use and present the "tools" successfully to parents and families, and staff role-played to address some questions they had on managing the discussion and viewing of the DVD with the parents.

The NBGH coordinator concentrated on engaging the internal hospital community in the SBS research project, while the CCPIP coordinator introduced and promoted the project to the North Bay community and the northeastern region by contacting community resources. A formal project launch occurred in June 2006, attended by hospital and CCPIP personnel, local family physicians, pediatricians, obstetricians/gynecologists, media, and the UT principal investigator (guest speaker). The CCPIP coordinator also helped to develop additional written materials such as the Baby Jack cards and posters. These were used by the hospital, the North Bay community, and subsequently by other project sites.

The site coordinator invited the Midwives Sage-Femme practice to participate. This group decided to present the SBS information to parents on the prenatal visit at the 37th-38th week; the mother's support system people attend this particular visit.

RESOURCES

Personnel

<u>Stakeholders</u>: Identified stakeholders were front-line hospital nurses, maternal child unit staff, hospital management, administrators, ethics committee members, families, patients, and clients receiving the SBS education; also those who consented to follow up contact, thereby participating in the research. The Midwife group identified the midwife colleagues, office administrator, and the NBGH site coordinator. Community stakeholders were the CCPIP coordinator, North Bay Police Department, Ontario Provincial Police, Children's Aid Society, North Bay Parry Sound Health Unit, Aboriginal Health, Sudbury Regional Hospital, Sudbury & District Health Unit, Nipissing-Parry Sound Catholic District School Board, Amelia Rising, Aboriginal Healthy Babies, Perspectives, Action For Children, Integrated Services Northern Children and the families who participated in the SBS research project.

Program Personnel: The maternal child social worker at NBGH took on the role of SBS site coordinator for this community, working with the support of the Maternal Child Care Centre IBCLC nurse clinician (International Board Certified Lactation Clinician). Although the Upstate NY program identified the importance of the coordinator being an experienced registered nurse, NBGH has a history of significant, cooperative interaction between the nurses and the maternal/child social workers; they work closely on the health teams for antenatal and maternity care, treatment planning, and patient discharge into the community. Maternal/child social workers provide services to clients identified with high-risk factors, and they are actively involved prior to the birth of the child, ensuring that adequate supports are in place. They also provide education in community settings regarding maternal health care. NBGH was confident that the maternal/child social worker would be an effective site coordinator for the SBS Prevention program.

The site coordinator presented the research project to the nurses, trained them to deliver the program in the maternal child centre, followed the progress of the project and monitored the data collection.

Within the midwife group, their office administrator was noted for significantly assisting with the research by reminding midwives to plan for the SBS education (updating appointment calendars and client logs), reminding mothers to bring partners and/or support team for that session, organizing and filing the consent forms, setting up viewing room for the DVD, maintaining communication with the SBS site coordinator at the NBGH re supplies and data collection.

Financial Support

The SBS research supplied funding for the site coordinator's position at NBGH over a 22-month period. The UT-RCU also financially supported the site by absorbing the costs of printing the consent forms, providing the DVDs and DVD players, as well as funding a translation of the script of Portrait of Promise into Cree language for use by the site.

North Bay General Hospital provided in kind the training materials and luncheons for the staff training sessions, paper costs for promotional items available for patients, families, and visitors to the hospital, and the office space for the SBS site coordinator. SBS information was incorporated into a hospital booklet that is available in the antenatal clinic. Consultation services were also provided in kind by the maternal child program manager.

The CCPIP coordinator initiated the production of revised comforting materials for the North Bay community (known as the Baby Jack poster and postcards, and the Tips to Calm Yourself (soothing) cards – available in English and French), through financial support from the ONF "High Intensity" project; the photographer and creative designer involved in producing these materials provided their services at a reduced cost to the research project.

In-kind support was also offered by the Nipissing-Parry Sound Catholic District School Board for the resource education teacher to develop a SBS curriculum for the Parenting Studies course in high school, for grades 7 and eight in the elementary schools, and to pilot the curricula in the classrooms. The teacher presented a trainer-totrainer session with the elementary teachers who are now delivering the SBS program to all grade 7 and 8 students in the Catholic elementary schools.

A number of the stakeholders listed above provided in-kind support through their participation in planning and implementing the community education and launch activities.

Materials

The UT Research Coordination Unit provided North Bay General Hospital with consent forms for the study, DVD players and the DVD Portrait of Promise. The site coordinator in turn passed equipment and materials to the midwives, ensuring that they had what was needed for participating in the implementation. Other materials (see Figure 14), such as the Baby Jack postcards and posters, were supplied by the CCPIP (through the ONF "High Intensity" noted above) with a partnership between NBGH, the North Bay-Parry Sound District Health Unit, and Ed Eng Photography. The "soothing" cards were developed jointly with the North Bay-Parry Sound District Health Unit and the CCPIP, with the health unit providing the funds for the production.



Figure 14: Baby Jack and Soothing cards created in North Bay





IMPLEMENTATION

The Implementation Process

<u>North Bay General Hospital</u>: At NBGH, the practice on the maternal child unit is for a nurse to be assigned a patient, and that assignment continues through labour, birth, and into the post partum period at the hospital. This practice supports the development of a trusting relationship throughout the birthing experience – an "investment on both sides" – and allows the patient to be receptive to education and assistance. The assigned nurse presents all education, including the SBS program, to the mother and her supporters (father, grandparents, friends).

The site coordinator and nurse clinician developed a PowerPoint presentation on the SBS education program and delivered it to all nursing staff during a mandatory onehour meeting (the presentation was made seven times to small groups in order to reach all nursing staff). The front-line nurses were able to sign up for a specific presentation time of their choice. The hospital provided a pizza lunch for each scheduled meeting. Pediatric and emergency department staff at NBGH also received in-service training from the maternal child program staff. NBGH child protection team members were informed of and updated on the SBS research project process, as were other regional hospitals and police forces.

During program implementation, the site coordinator and nurse clinician met regularly to review progress; they communicated consistently with the nurses, sharing ideas, experiences, and updates. Both were present daily on the floor of the unit, connecting with staff and patients, and sometimes assisting staff with their responsibilities. The unit clerks ensured that patient charts were up-to-date and that the SBS education was documented. <u>Midwife Practice:</u> The midwives felt it was important that clients be prepared for the SBS education ahead of their appointment, and that the DVD viewing was followed by a face-to-face discussion. Written materials could be read at a later time. The midwife would present the SBS education at the office visit when the client was 37/38th week into her pregnancy. At this visit, partners/friends accompany the mother, and the focus is on topics such as building supports when parents come home with a new baby, baby care, and crying. The DVD is watched by everyone together, with the midwife is available for discussion and questions. If a client has not had the opportunity to access the education information with her midwife and subsequently delivers her child at NBGH, the site coordinator will ensure that the SBS program is completed at the hospital.

<u>Community</u>: The CCPIP coordinator entered discussion with the Nipissing-Parry Sound District Catholic School Board about including SBS prevention education into the curriculum of the grades 11/12 parenting studies course. Agreement was achieved and a resource teacher engaged to develop a lesson plan following Ontario Ministry of Education curriculum guidelines. The lesson plan was piloted successfully in St. Joseph-Scollard Hall Secondary School and subsequently the same teacher designed and successfully implemented a curriculum for grades 7 and 8 within the Board's elementary schools. The curriculum has been forwarded to the Ministry of Education, and shared at a number of provincial and regional meetings focusing on injury prevention.

In March 2007, North Bay's Brain Week included one day devoted to shaken baby syndrome awareness and prevention. The St. Joseph-Scollard Hall parenting class students provided an SBS demonstration using the SBS simulator doll, and an egg in a glass bottle. They included a display of SBS information resources and showed a student-made SBS DVD. Nursing students from Nipissing University/Canadore College also provided a powerful visual program. The event was covered by local media and considered extremely successful.

Community awareness and participation in the SBS education program is a continued focus of the CCPIP network. Meetings occur every second month, with SBS program updates being a standing item on the meeting agenda.

A North Bay couple was expecting their third child. The father had an alcohol addiction for which he had been involved in treatment off and on during the couple's relationship. He attended the midwife visit with his partner at which the shaken baby syndrome prevention information was being discussed. He refused to view the Portrait of Promise, finding it too difficult as a friend of his had shaken a baby. However, the mother saw the DVD, saying afterwards that she found it disturbing and "hard to watch", yet felt that it was necessary and the information important.

The 5-7 Month "Follow-up" Process

The NBGH site coordinator began the process of follow-up calls, however, her job description within the hospital changed leaving her with increased responsibilities, and she appreciated that the calling processes would subsequently be taken over by the UT-RCU nurses.

Lessons Learned

At the time the research study was being implemented at NBGH, hospital staff were also entering a period of restructuring that included a reconfiguration of the maternal child unit. This resulted in work space reduction, staffing reorganization, a change in manager of the unit and management style, and addition of a new unit social worker. Both site coordinator and nurse clinician responsible for the SBS program were sensitive to the adjustments that front-line staff were making, acknowledging that it was a difficult time to be presenting yet another change to the unit. Nevertheless, everyone agreed that the research program would enhance the services the nurses provided on the maternal child unit, and the front-line nurses were supportive of how the program could be incorporated into their day; they determined strategies that they would use in educating families and assumed the responsibility for training any new staff joining their team.

The midwives have particularly close relationships with their clients and found it apparent that the SBS information made a direct impact on fathers – they noted changes in body language, facial expressions, and pensiveness followed by questions,

after fathers received the SBS education. Mothers were openly emotional, often in tears, yet willing to engage in discussion, questions, and answers.

OUTCOME

Program Sustainability

The program goals set for the implementation of the SBS prevention education research program have been met. The program has been successfully presented to families and is being sustained at North Bay General Hospital and by the Midwives Sage-Femmes; existing staff are committed to continuing the education to parents and families that pass through the maternal child care unit, and new staff continue to be trained for delivering the SBS prevention education. NBGH has expressed an interest in participating in the second phase of research that is in the planning stage to follow this research study. Injury prevention practitioners and other partnering agencies are using the resources and materials as part of family safety education across communities in the north. SBS project personnel identified the educational materials as an important part of sustaining the visual and oral education received by parents.

The CCPIP and NIPPN memberships have embraced the SBS prevention education program as a valuable tool in their communities. The network established through the University of Toronto Research Coordination Unit with the other ONF SBS Prevention Program community sites has provided contacts and support for colleagues across the province.

Team members in the North Bay community share a concern on the lack of surveillance of shaken baby syndrome across the province. The CCPIP coordinator has made a recommendation to the Trauma Registry Advisory Committee (TRAC) to have the Canadian Institute for Health Information (CIHI) develop a separate code for inflicted head injuries children aged 0-2 years. CIHI will look at the ICD-10 codes under maltreatment for the past two years to ascertain if there has been a decrease in subdural bleeds and retinal hemorrhages and investigate the feasibility of establishing a screen in the Discharge Admission Data (DAD) to capture the cause. These are provincial data records and documents that are used across the province at hospitals. CCPIP and two physicians from the Hospital for Sick Children in Toronto are developing a formal

recommendation for establishing a separate code for this incident that will be sent to CIHI for their consideration.

The SBS high school curriculum, developed for use in the Grade 11/12 parenting studies course following Ontario Ministry of Education curriculum requirements and already piloted in the Nipissing-Parry Sound District Catholic School Board, has since been forwarded to the Algoma District Health Unit, Sudbury DHU, Thunder Bay DHU, Peel Public School Board, Lakeridge Health Centre, Nipissing District, Best Starts, and to the Ministry of Education for formal



Figure 15: Brain Week display by students from St. Joseph-Scollard Hall High School

approval. The CCPIP has also initiated a partnership knowledge exchange with George Lithco of the Skipper Foundation and a secondary school teacher from Monroe-Woodbury High School in Central Valley (both in New York State) as a result of the work from the Nipissing-Parry Sound District Catholic School Board.

Third year nursing students from the Nipissing University/Canadore College performed an evaluative survey on how family physicians and OBGYN physicians made use of the SBS written information that was provided to their practices by the CCPIP coordinator. The nursing students contacted the physicians' administrative staff, 67% of whom reported that posters were displayed and the physicians were discussing SBS with their patients and handing out the SBS information regularly. A professor in the nursing program is also working on having SBS prevention information included in the graduate curriculum.



Figure 16: North Bay General Hospital



Figure 17: NBGH Room on maternal child unit

Case Study : Mississauga

CREDIT VALLEY HOSPITAL

BACKGROUND

Description of Community and SBS Project Site

Mississauga is Canada's sixth largest city, located at the western end of the Greater Toronto Area (GTA). It is a major corporate and financial district in Canada, housing the headquarters for a number of national and international companies; Toronto's international airport, Canada's busiest, is located here. The population is culturally diverse, with almost 50% of the residents considering themselves to be from visible minorities. Many have English as their second language or have limited ability to communicate in either English or French.

Credit Valley Hospital (CVH) provides primary, secondary, and tertiary services to this community. It currently has 392 beds (to increase to 471 by 2011) and provides services and programs that include general medicine, surgery, renal dialysis, oncology, emergency, mental health, continuing care/rehabilitation, obstetrics and gynecology, cardiac services, and a network of support departments. Midwifery practices are unable to use the hospital facilities.

The Maternal/Child program at CVH sees approximately 400-450 deliveries per month, (almost 5,000 deliveries per year). There is an average of 12-15 deliveries per day, with the same volume of discharges. Of the hospital's 392 beds, seven are in labour and delivery (with planned increase to 15 by 2011); the post partum and obstetrics unit holds 35 beds. The staffing ratio is four to five mothers and babies per nurse at the start of the shift, with an average of two discharges and two admissions per shift. If mothers and babies meet established discharge criteria, discharge can occur 24 hours following a vaginal delivery and 48 to 72 hours following a caesarian birth. The goal is to discharge mother and baby together whenever possible. Prior to discharge, families

make an appointment to return to the Post Partum New Family Clinic or the Breastfeeding Clinic one to two days following discharge. On this visit, a registered nurse will perform a general health assessment on both mother and baby, as well as provide a feeding assessment (the RN will ask the mother to nurse her infant). Mothers are encouraged to attend this appointment with their partner or support person.

SBS information is found within the community at Peel Region Public Health prenatal services; in the Peel Children's Aid Society brochure entitled "Positive Parenting of Infants"; in babysitting course curriculum through Canadian Safety Council; and in the Red Cross Ontario Zone's First Aid and National Child Care guidelines.

Participation in the ONF SBS Prevention Program

Decision to Participate: The principal investigator met with the nurse manager, Maternal/Child Program, to discuss CVH as a possible project site. Further discussions included the Maternal/Child nurse educator, who believed the program would be an economical way to impact a positive outcome for parents and that delivering the education to parents before they left the hospital would be valuable. She helped devise the hospital's implementation plan for the research project, and along with the nurse manager, had several meetings with members of the University of Toronto Research Coordination Unit (UT-RCU).

<u>Original Goals for Participating:</u> To participate in the ONF SBS Prevention program and to raise staff awareness of SBS, identify risk factors, and use the prevention program tools to assist parents in avoiding this preventative neurotrauma injury to infants.

<u>Start-Up Process</u>: After initial discussions between the nurse manager and the project principal investigator (PI), the CVH nurse educator attended the first all-site program meeting in March 2006 with the nurses from Upstate New York. The nurse manager then presented the project to the hospital's ethics committee where it received approval in May 2006. Credit Valley Hospital did not have a formal launch of the SBS research project for the internal hospital community or for the external community they served, but began program delivery in the fall of 2006.

RESOURCES

Personnel

<u>Stakeholders</u>: Credit Valley Hospital management, administration, and nursing staff on the post partum unit are considered the site's stakeholders.

<u>Program Personnel:</u> The responsibilities for implementing the SBS program at Credit Valley Hospital were included in the roles of the nurse manager and nurse educator, Maternal/Child services. In September 2007, CVH hired a part-time nurse site coordinator – who shared this role with her part-time colleague, another RN on staff at the hospital – assisting with program administration and delivery. As these two nurses were not in this role from the beginning, the UT-RCU was able to provide the video of the all-site meeting in March 2006 to help with their orientation to the program.

Financial Support

Initially, Credit Valley Hospital did not request financial support. However, midway through the implementation, the nurse manager and principal investigator discussed the possibility of providing funds for a part-time nurse (the site coordinators noted earlier), which was ultimately approved. From this point forward, the site coordinators worked together on the SBS program; they submitted their hours to the nurse manager on a monthly basis, and the hospital invoiced the UT-RCU.

Material

The UT-RCU provided the consent form template to CVH, the hospital preferring to prepare and produce their forms in-house, including adding their logo and contact information. Other materials, such as the posters, comforting cards, and DVDs, were provided to the hospital by the RCU. CVH runs the Portrait of Promise DVD in both English and French at regular intervals on their in-hospital TV channel that is accessible to patients 24 hours a day. The nurses used the translated comforting cards when they became available.

IMPLEMENTATION

The Implementation Process

At the start of program implementation, the nurse educator Maternal/Child Program provided the in-service training to the nurses on the post partum unit. She was able to rotate through all the shifts, presenting the SBS information in a training package she developed for the nurses, which included showing a PowerPoint, viewing together the Portrait of Promise DVD, and reviewing and discussing the DVD and the written information for parents. SBS training was also part of new staff orientations, and the information package provided to other hospital departments such as paediatrics, labour and delivery, and special care nursery. The hospital's media technicians installed the DVDs onto the in-house TV station.

The format for implementation changed slightly with the hiring of the site coordinators, both of whom were already on the hospital's nursing staff working for Ontario's legislated Infant Hearing Screening program. Since all babies must have the screening test, and since the family time in hospital was quite short, it made sense at this site to combine these two initiatives in one nurse visit. The site coordinators included an introduction letter about the SBS research program in the existing maternal-newborn admission package that parents receive for the post partum unit. Babies receive the hearing screening test at the time of hospital discharge, and the nurses took advantage of this opportunity to connect with the parents and go over the SBS information they received in the package and watched on the TV during the hospital stay.

The site coordinators also provided reorientation of the SBS program to all the nurses on the post partum unit, either in small group in-service sessions and moving through the nursing shifts or following up with nurses individually, and discretely role-modeling delivery of the SBS information in front of the nurses. The admission nurse is responsible for providing the patient with a package consisting of the comforting card, consent form, and letter that requests the parents' participation in keeping their baby safe and free from injury. The site coordinators updated the parent education bulletin board with information on SBS, crying, and developing a plan to cope with crying; they also created notices for each hospital room, indicating the times the video would be playing and the channel, and provided monthly email updates and feedback to the

nurses regarding the progress of the program (for example, number of consents, parent comments and reactions). The site coordinators attended the November 2007 all-site meeting in Toronto.

The nurse manager communicated with the post partum nurses at monthly staff meetings and through email and/or memos. The structural division of responsibilities, communication, and decision-making are such that front-line nurses report to the nurse manager regarding any changes to programming or procedures. The nurse manager and the nurse educator at the time of program implementation were peer managers who reported to the same director; they discussed and resolved issues as partners and approached the director and/or the administration team when any questions arose.

The SBS Prevention Program was shared, encouraged, and supported through the Children's Aid Society, the Peel Children's Aid Society, Region of Peel Public Health, Catholic Family Services of Peel/Dufferin, Vita Manor of Peel, Dixie Bloor Neighbourhood Centre, Mississauga Library Services, Peel District School Board, Midwifery Care for Peel/Halton Hills.

The site coordinator and her colleague attempted a strategy for program delivery that proved successful –they encouraged patients to participate in the follow-up telephone survey by introducing this as an opportunity to help other parents in the prevention of shaken baby syndrome and assist in sharing the information with caregivers, relatives, and babysitters. Nursing staff observed this strategy and commented on how different ideas and presentations can work for the delivery of the shaken baby education.

The 5-7 Month "Follow-up" Process

The UT-RCU nurses conducted the follow-up calls for this site.

Lessons Learned

Credit Valley Hospital's high volume of deliveries and short length of patient stay, coupled with the high patient admission/discharge rate of a nurse's assignment, means nurses and administrators must be resourceful in finding ways to provide program implementation that relies to a great degree on the connection between nurses and their patients. At this site, it proved beneficial to have a person(s) dedicated to administering the program – the site coordinators were able to envision the results and outcomes of the program and increase the comfort level of the front-line nurses who were delivering the education. Administrators of the program found that introducing the subject of shaken baby syndrome earlier in the patient's admission helped with obtaining agreement for patient participation in the follow-up calls; it also helped to have the comforting information available in a variety of languages for this culturally diverse community.

Оитсоме

Participating in the ONF SBS Prevention Program was a valuable experience; it brought awareness of shaken baby syndrome to the Maternal/Child community at Credit Valley Hospital, and provided the nurses with tools for prevention. The combination of coordinating and promoting the program with the mandated infant hearing assessment worked well. Consistent communication and support for the nurses in their responsibilities (i.e., discussions, emails, updates, mentoring) results in increased productivity in delivering the SBS education.

Program Sustainability

Shaken baby syndrome education will remain part of prenatal and post partum teaching at Credit Valley Hospital; the program's framework remains in place, and a new nurse manager Maternal/Child services has met with the program's principal investigator and UT-RCU to talk about the flexibility of program delivery in the future.



Figure 18: Credit Valley Hospital Mississauga



Figure 19: SBS information on bulletin board seen when entering the CVH maternal child unit



Figure 20: Room on CVH maternal child unit



Figure 21: Notice in hospital room re viewing the ONF SBS video

Case Study : Kingston

BETTER BEGINNINGS FOR KINGSTON CHILDREN

BACKGROUND

Description of Community and SBS Project Site

Kingston, Ontario is located halfway between Toronto and Montreal. With a population of 153,000, the city's economy relies heavily on public sector institutions (Queen's University and Royal Military College), government (military and correctional services), and manufacturing industries. The Kingston area has the largest concentration of federal correctional facilities in Canada – nine in total, of which seven are located within the municipal boundaries of the city. The Canadian Forces is Kingston's largest employer.

Better Beginnings for Kingston Children (BBKC) is one branch of the Kingston Community Health Centres (sister organizations are Street Health, Immigrant Services for Kingston Area, and North Kingston Community Health Centre). BBKC offers programs and supports for families with children from 0-5 years living within specific boundaries of North Kingston, an area of high density, transient population, and higher than average levels of poverty. All services are free; assistance with transportation and childcare are provided when needed. Programs include prenatal education and support, home visiting, parent-child support groups, parenting programs, and school readiness programs.

Participation in the ONF SBS Prevention Program

<u>Decision to Participate</u>: BBKC staff have strong and lasting relationships with most families using their services and felt that this study was achievable and fit well with their prevention model of services, the philosophy, mission, and goals of the organization. Kingston Frontenac Lennox and Addington Public Health use a number of informational brochures for new parents and also administer a free phone information service called Baby Talk, but none target shaken baby syndrome prevention specifically.

<u>Original Goals for Participating</u>: To provide SBS prevention education to as many families as possible residing within the boarders of service of BBKC; To incorporate the SBS research project seamlessly within the prevention model of service; To deliver the program consistently and track the progress.

<u>Start-Up Process</u>: In 2001, the Ontario Ministry of Health and Long Term Care provided funding for five years of injury and violence prevention activities in Kingston Frontenac Lennox and Addington Public Health. Upon hearing about the ONF SBS Research Program (a radio broadcast on CBC involving the principal investigator), the injury and violence prevention coordinator contacted the PI, expressing an interest in the project for this community. He developed a plan, organized a conference of community group representatives and led the development of the Coalition for the Prevention of Shaken Baby Syndrome. Members of this coalition were Ontario Early Years Centre, Frontenac Children's Aid Society, Hotel Dieu Hospital, Kingston General Hospital, Kingston Frontenac Lennox and Addington Public Health, Better Beginnings, and Childbirth Kingston. The Coalition disbanded when the funding for the injury and violence prevention coordinator position ended.

Start-up process involved the community health nurse meeting with her BBKC family support worker colleague to determine that BBKC was an appropriate service setting for the research. The BBKC family support worker took on the role of site coordinator, which was a mutual decision between the two based on individual work responsibilities and time availability. A budget was drafted, support received from chair and membership of the Coalition, and a plan developed by the community nurse and site coordinator. Program launch in September 2006 included a luncheon and presentation for the front line staff. Further workshops and staff development sessions provided the project's background, BBKC's role in the project, process information, discussion of roles and format, data collection and training.

Resources

Personnel

<u>Stakeholders:</u> The BBKC stakeholders are considered to be site staff – the front line workers, site coordinator, community nurse, Better Beginnings program manager, the members of the Coalition for Prevention of Shaken Baby Syndrome until it disbanded, and the families.

<u>Program personnel:</u> The SBS research project was supported at BBKC by the office staff, the program manager, the community health nurse, the site coordinator and front-line staff (family and community support workers). The resources from the Better Beginnings staff were in-kind, except for the site coordinator and community health nurse.

Financial Support

The UT-RCU provided part-time funding over a two-year period for the community health nurse and family support worker. The RCU also provided the site with a computer, two portable DVD players, ten copies of the Portrait of Promise DVD, printing of project materials, phone, postage, office supplies, and training costs. Because of the high-risk nature of families in the BBKC programs, the site coordinator included in the budget an allowance for a monetary incentive for the families should they agree to participate in the follow-up telephone survey. The outgoing coordinator of the Coalition transferred remaining modest financial resources to the program to support promotional items for clients, such as pencils. The annual financial base funding received by Better Beginnings has been static for fifteen years.

Material

The UT-RCU provided written materials for the Kingston site that included the poster, comforting card, the consent and follow-forms and the DVDs. The site coordinator and community health nurses felt that the consent form needed rewording to meet the literacy needs of the families. BBKC also created congratulation cards to give out to new parents (Figure 22).

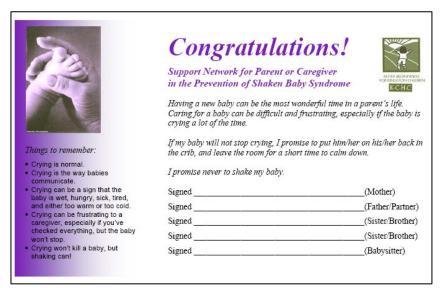


Figure 22: Congratulations card for BBKC

IMPLEMENTATION

The Implementation Process

The SBS education would be provided in three service delivery areas – prenatal classes provided by the community health nurse, through the home visitor program in the family homes by the home visitor worker, and in each parenting group series by the SBS site coordinator. The administrative manager prepared a budget for the program, which she and the site coordinator discussed and approved with the principal investigator.

In September 2006, the site coordinator organized the program launch, which involved a day of presentations including a staff luncheon that gave the occasion special significance for those attending. She presented the Upper New York SBS prevention education model; shared the plan to integrate the program into the BBKC; and outlined what Better Beginnings hoped to gain for the clients (increased opportunities for family safety and education delivered within BBKC services).

Subsequent BBKC team meetings were forums for reviewing and problem solving any issues that arose during the SBS program delivery. The site coordinator

made decisions regarding the program in open consultation with her team and with the community health nurse.

Prenatal classes at BBKC are six-weeks long, with the SBS program initially presented during the final session. It was later moved to the second last session, which typically addresses mother's recovery, newborn care, mood adjustment probabilities and infant crying. The final session then reviewed the entire curriculum and allowed for further follow up on SBS information.

On one occasion, at the request of a corrections officer, the site coordinator presented the SBS education inside a correctional facility to the expectant mother and the incarcerated father-to-be. The dad had initiated this request because both he and the mother had been physically and sexually abused as children, and he did not want this to happen to his child. Both partners expressed hope that the future of their child would be different from their own experiences. The site coordinator was pleased at how portable the SBS education program can be ... "It's easy to take on the road".

The 5-7 Month "Follow-up" Process

Better Beginnings for Kingston Children is the smallest ONF Shaken Baby Syndrome prevention program site in this research study. The BBKC team has close contact with all their clients, and they were keen to continue with the follow-up process; they found it provided another avenue for enhanced connection. At this site, the followup interview was typically in person, not via telephone.

Lessons Learned

The BBKC team were well prepared to deliver the education on shaken baby syndrome prevention to their high-risk clients. They carefully considered the written materials that were provided from the UT-RCU and in some instances made changes to the text, mindful of their clients' literacy levels. However, upon reflection at the project's end, the site coordinator felt the revised form was less user-friendly for the staff. The BBKC team were sensitive of time issues when delivering the education during organized classes, and became resourceful in finding ways to reach out to moms individually during that time to assist with completing the consent forms, and in attempting to include dads/partners, who were often absent, in the education. The site coordinator noted that their home visitor program was a better experience for clients to receive the SBS information than the prenatal class, as the private environment of the home visit increased clients' feelings of safety, allowing them to disclose fears and ask questions in confidence. When several families mentioned that they had already seen a video about SBS on Facebook, BBKC staff encouraged the viewing of Portrait of Promise, as the ONF SBS project approach offered ideas for prevention and solutions for comforting crying babies.

The site coordinator's commitment to the research was evident by her becoming increasingly skilled with computer data entry and file maintenance without having access to specific computer-skills training.

OUTCOME

BBKC services are voluntary and community based, and centre on front-line workers being invited into the client's home or clients attending organized sessions. The BBKC team felt an increased sense of confidence and ability to talk about shaken baby syndrome, and the project gave them a neat package, which helped with consistent delivery of information. The site coordinator felt BBKC had earned new respect from other agencies in the community through participating in the project, and the team were proud to have taken leadership in this prevention endeavour.

The site coordinator felt the shared experience of watching the video with clients strengthened the community support worker–family relationship. Case workers have become more alert to babies on their caseload considered to be "heavy criers". The education materials have provoked discussions on how to deal with crying babies and brought attention to the potential dangers. The program enabled parents to discuss their frustrations and feelings without judgment.

BBKC parents who had taken part in the education became noted advocates, transferring their SBS knowledge to family members, friends, babysitters and caregivers.

They understood and remembered the SBS information and its implications, were aware of their ability to cope and access help, and saw the follow-up as a further support.

The goals for participating in the research project have been met.

Program Sustainability

Better Beginnings for Kingston Children is maintaining the SBS education program as an integral part of the services they deliver to families. Their plan for sustainability includes determining how to assume the internal tracking of program delivery to ensure continuity and consistency, and exploring the possibility of integrating the program into their two sister agencies – Street Health, and Immigrant Services.



Figure 23: Better Beginnings for Kingston Children's location



Figure 24: BBKC Reception



Figure 25: BBKC staff prepare for weekly meeting

Case Study : Hamilton

HAMILTON PUBLIC HEALTH SERVICES

BACKGROUND

Description of Community and SBS Project Site

The City of Hamilton is one of Canada's largest cities; it includes the surrounding communities of Ancaster, Dundas, Flamborough, Glanbrook and Stoney Creek. Hamilton has a culturally diverse population of over half a million people and is a major industrial centre with the local economy based on the steel and heavy manufacturing industries.

Hamilton Public Health Services (HPHS) is governed by Hamilton City Council as the Board of Health. It is funded by the City of Hamilton and by the Ontario Ministries of Health and Long Term Care, Health Promotion, and Children and Youth Services. HPHS provides programs and services in the areas of chronic diseases, injury prevention, family health, infectious diseases, environmental health, and emergency preparedness. Staff work locally with individuals, families, community and partner agencies and organizations in settings such as homes, workplaces, schools, food premises, daycares, and health care settings. Two local midwife groups also participated in the study: The Hamilton Midwives, and Community Midwives of Hamilton.

Over the past five years, reported cases of SBS neurotrauma injuries have occurred in this community and the surrounding region, as identified by the Hamilton Health Sciences Corporation Trauma Prevention Program. Hamilton Public Health Services does not collect this data, but can access statistics relating to children's admissions to hospitals. The data can also be obtained through the Canadian Institute for Health information (CIHI) in its annual reports.

Participation in the ONF SBS Prevention Program

Decision to Participate: An associate professor in the School of Nursing, Health Sciences at McMaster University (and co-investigator of the ONF-SBS study) approached Hamilton Public Health Services management staff about joining the SBS Prevention Education research project in July 2006. HPHS confirmed their interest and met with the co-investigator over a period of time to discuss the partnership. Public health nurses were informed at their regular monthly meeting of the decision to participate.

Agency planning procedures and decision making is in consultation with a department manager, and in some instances the management level group, before a concept would be put into practice. The decision to participate in the SBS research program followed this procedure. The support and involvement of the team members and team leaders, as well as program administration/secretarial staff, is important to the success of any endeavour. Presentation of any internal practice is presented at monthly staff meetings and is followed up at team and site meetings.

<u>Original Goals for Participating:</u> To provide a proven evidence-based practice with measurable outcomes for injury prevention to infants; To incorporate a consistent and evidence-based SBS education program into the injury prevention services Hamilton Public Health Services delivers to families.

<u>Start-Up Process</u>: Following the initial contact by the co-investigator, Hamilton Public Health Services acknowledged their interest in participating in the program. They were keen to deliver a proven, successful evidence-based practice in their injury prevention unit – one where delivery was consistent and in which progress could be easily tracked. HPHS administrators felt that the ONF SBS Prevention Program would enrich the shaken baby syndrome prevention information they were already providing.

Hamilton Public Health Services required a Memorandum of Understanding to be drawn up, agreed upon by parties involved in the research (principal investigator and the University of Toronto, and Hamilton Public Health Services), and signed. This process took approximately 10 months; the MoU was signed in May 2007. HPHS presented the implementation plan at their monthly meeting in April 2007. The principal investigator and members of the University of Toronto Research Coordination Unit (UT- RCU) attended this meeting that included powerpoint presentations outlining the background of the Upstate New York Shaken Baby Education program and the method for implementing the research. More than 50 public health nurses attended this meeting.

Resources

Personnel

<u>Stakeholders:</u> Hamilton Public Health Services staff, including administrators, managers, and nurses, supported the program, along with community partners such as the Ontario Early Years Centres, Grace Haven, St. Martin's Manor, the John Howard Society, and the families who have signed the commitment forms for follow-up in the research program. The program is also supported by the public health nurse liaisons for the two Hamilton Boards of Education and the two child welfare agencies that are in discussion with HPHS regarding incorporating the SBS prevention education into their services (programming and education). One Hamilton hospital and two midwife agencies - The Hamilton Midwives and Community Midwives of Hamilton - have requested information for their prenatal and post partum programs.

<u>Program Personnel:</u> Within Hamilton Public Health Services, the nurses look to the site coordinator for assistance in delivery the program and connecting nurses who can offer mentoring to their colleagues. The site coordinator acts as the "point person" with responsibilities for administration of the program; she also holds other responsibilities within her department that focus on injury prevention, including delivering car seat clinics to new parents.

The public health nurses delivered the program during prenatal classes, the post partum home visit following hospital delivery, in father support groups, ongoing home visits with clients of HPHS, and in partnership parenting classes with other community organizations such as child welfare agencies, adolescent programs and parent support programs.

The HPHS program secretary played a key role by organizing the client lists and supplying the script to help nurses in their presentation of the SBS information.

She assisted in the development of the database, reviewed the data quarterly with the site coordinator and the program manager, assisted nurses needing access to resources and materials for the delivery of the program and/or directed them to the site coordinator for support and direction.

Financial Support

The Ontario Neurotrauma Foundation Shaken Baby Syndrome Prevention Program, through the University of Toronto Research Coordination Unit, provided financial support to this project site for the period of one year, applied to salary plus benefits of one full-time public health nurse for six months and salary plus benefits for one part-time public health nurse for six months. At the outset of the Hamilton site launch, the RCU provided ten DVD players, ten program DVDs (Portrait of Promise), and consent forms, cards, posters and other printed project material related to the program. Additional requests from the site for DVDs and printed material throughout the program implementation were made available by the RCU. Hamilton Public Health Services assumed the planning and staff training activities within their existing operational budgets, and provided office space and furniture.

Material

The UT Research Coordination Unit agreed to supply all sites with SBS program materials. However, Hamilton was one of several sites that developed their own versions of printed material to be used in place of, or along with, the material from the RCU. The new materials were group tested prior to a final decision and reviewed with the RCU. The new comforting cards are considered more attractive and eye-catching for their clients (see Figure 26).

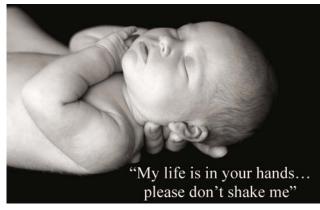


Figure 26: Revised comforting cards for Hamilton



IMPLEMENTATION

The Implementation Process

The SBS prevention education program was implemented in the services of four teams that worked out of three Hamilton Public Health Services locations. Instructions on program delivery were developed by the site coordinator and the program manager and shared with nurses, primarily via email. A number of different strategies were used to establish the program into the nurses' practices and help them with program delivery. These included scripting possible conversations with clients; having nurses who were comfortable and had successfully delivered the program mentor those who were struggling; and providing opportunities to observe home visits. Posters provided by the SKIPPER initiative in the United States were used in presentations for staff and were posted around the office. Nurses were provided with portable DVD players and the DVD to show to clients during their visits. They also took along the printed material, including SBS information and consent forms.

Program delivery and materials were modified at this site according to the specific target client groups. For example, it was felt that the Portrait of Promise DVD did not capture the attention of youth and young adult parents-to-be or parents, whereas another film on the topic of shaken baby syndrome, Elijah's Story, was found to be more appropriate for these clients. The public health nurses adjusted their verbal scripts on an ongoing basis to meet the receptiveness they experienced at any given time.

Each month, the HPHS program manager reviewed the progress of the SBS research with the site coordinator. The program secretary provided statistics and data at these monthly meetings. Information-sharing, decision-making, and communication processes at HPHS follow from the front-line nurses to the site coordinator, the program manager, the director, and to the medical officer of health. Monthly meetings with all nurses provide opportunities for program updates. Members from the UT-RCU visited the site coordinator in Hamilton shortly after she took over the role, and the site coordinator attended the all-site meeting in Toronto in November 2007.

The SBS Prevention Program was shared, encouraged, and supported through: the long-term Healthy Babies, Healthy Children home visiting program; parenting programs targeting parents and caregivers with infants; Parent Link; Beyond the Basics a joint program with the Children's Aid Society and Catholic Children's Aid Society for families involved with these organizations; fathering groups; John Howard Group; Canada Prenatal Nutrition programs; high-risk prenatal (maternity homes, transitional youth sites, teen prenatal) and prenatal series (for couples and singles, not high risk); and the Post Partum Assessment Clinic (PPAC) teams, where appointments are run in hospital settings and program is delivered during post partum home visits. The public health nurses provided the SBS education to all members of these groups regardless of whether the individuals signed the consent form.

The program is being explored for use with by public health nurse liaisons for post-secondary schools, secondary schools, and babysitting courses through the Red Cross.

A story was shared about a young couple with an infant who are mutual clients of Hamilton Public Health Services and one of the child welfare agencies in Hamilton. The family was waiting in the reception area of the child welfare agency for an appointment when their infant began crying and was inconsolable. The father was becoming frustrated at not being able to console the infant. He reported later to his nurse at HPHS that he remembered the information she had given to the couple; he handed the infant to his partner and stepped outside to cool off for a period before rejoining his family.

The 5-7 Month "Follow-up" Process

The follow-up calls were conducted by the UT-RCU nurses.

Lessons Learned

Over the course of the implementation, program personnel modified program delivery as needs arose. The use of an interpreter was approved in cases where language barriers existed; wording of the consent form was revised to include male participants as programs were targeted to father's groups; nurses attempted to book their client visits when other family/household members could be present. Suggestions for the future include lending the DVD to clients to view with household members in the hope that it could relieve some of the time constraints during the home visits; establishing a monthly meeting schedule with the UT-RCU; more frequent teleconferences that include all the project sites.

OUTCOME

The two original program goals have been fulfilled by participating in the ONF-SBS Prevention Program. An evidence-based best practice program to prevent injury to infants has been incorporated into Hamilton Public Health Services as part of the injury prevention mandate, and a consistent delivery of shaken baby syndrome information has been provided to families.

The program is considered easy to administer by an appointed coordinator, straightforward to implement by health care professionals, and can be transferable. The fact that this program is a proven, successful, evidence-based best practice in injury prevention was an important factor for the HPHS and for the nurses who include it in their services. Nurses can balance the needs of their clients (as related to nurses during home visits) with their own professional knowledge to support families. A standardized approach to the delivery of shaken baby syndrome education is now in place, and nurse involvement in the research project has revealed changes in practice – delivering injury prevention information and education is beneficial not only to designated, vulnerable, high risk populations, but also for all parents, caretakers, and family members who may experience the frustrations that could lead to this preventable injury.

Program Sustainability

This community acknowledges shaken baby syndrome prevention education as an important part of the Hamilton Public Health Services injury prevention practice. The program is included in the ongoing HPHS Operational Plan and funded through monies designed for injury prevention. An information system has been developed to provide follow-through for the process, including reminders and updates for program orientation for new staff. The content of the ONF-SBS program will be on the newly created Injury Prevention website page on the City of Hamilton website and will have a link to the Parenting page.

The ONF-SBS program will continue to be supported for implementation in the community resources of the two midwife organizations, the two child welfare agencies and through the two Boards of Education by their respective staff with assistance by the assigned public health nurses.

Work is ongoing to adapt materials to this community site. The revised comforting card is an example, while the showing clients the DVD could be modified to nurses bringing the poster and comforting card to leave with the family, depending on the nurse/client relationship. The HPHS have developed their own consent forms for clients who will receive the information.

Nurses acknowledge that building and nurturing trusting relationships with their clients/families is of the utmost importance in delivering and receiving information and providing guidance, especially with a vulnerable and high-risk population.



Figure 27: The Public Health office from which the ONF SBS coordinator worked - mall frontage on the outskirts of Hamilton.



Figure 28: The Hamilton Public Health Nurse who took on the role of Site Coordinator also had a portfolio in injury prevention that included car seat clinics and the infant bath seat

Case Study : Oshawa & Port Perry

LAKERIDGE HEALTH CORPORATION

BACKGROUND

Description of Community and SBS Project Site

The city of Oshawa is located at the eastern end of the Greater Toronto Area (GTA) in Durham Region. Oshawa's economy is primarily industrial and export related due to the General Motors plant and other manufacturers who support the automotive industry. The fringes of the city are rural-agricultural, and the majority of the population speak English as a first language.

Lakeridge Health Corporation is an amalgamation of four Durham Region area hospitals – Oshawa General located in downtown Oshawa, and smaller hospitals in the outlying communities of Port Perry, Bowmanville, and Whitby. Lakeridge Health Oshawa is one of Ontario's busiest acute care hospitals, providing services that include obstetrics, cancer, comprehensive genetics, laboratory, diagnostic imaging, rehabilitation and base hospital/advanced life support.

Obstetric services are also provided in Port Perry, which lies roughly 25 km north of Oshawa. Port Perry is a 24-bed, Level 1 community hospital; its New Life Centre provides care to low-risk mothers; Oshawa is an advanced Level II hospital, providing services for mothers in the Durham Region who may have complex obstetrical needs. Babies requiring advanced specialty care may be transferred to a tertiary centre.

Lakeridge Health Corporation delivers over 2,500 babies per year. It is a member of the Child Health Network of the Greater Toronto Area, and partners with the Durham Region Public Health Department in the Healthy Babies Healthy Children program and in breastfeeding clinics.

Neurotrauma Issues in the Community

Staff working in the maternal child program would be unaware of potential neurotrauma, such as an SBS injury, as this would be addressed in the emergency services provided at the hospitals, and if suspected, the infant would be transported to a tertiary facility for diagnosis.

Participation in the ONF SBS Prevention Program

<u>Decision to Participate</u>: Lakeridge Health Corporation was contacted about participating in the program as it encompasses a large urban hospital as well as a smaller rural hospital. The director of the maternal child program guided the program through the hospital's ethics review board and the hiring of the nurse coordinator for their site.

<u>Original Goals for Participating:</u> To provide the evidence-based best practice Upstate New York SBS prevention education program to families using the maternal child program at the Oshawa and Port Perry sites; To reduce or eliminate neurotrauma injuries in infants by incorporating the SBS prevention education into the services provided to the families using the maternal child program; To raise staff awareness of SBS, and expand their skills by educating, training, and delivery the SBS education to families; To sustain the SBS prevention education as a best practice service by nurses in the maternal child program.

<u>Start-Up Process</u>: The director maternal child program set up a plan with timeframe that included obtaining approvals of the research project from the Network's Ethics Committee, hiring an SBS nurse site coordinator, developing strategies to inform and educate the staff at both locations as well as the community resources and the public at large.

Resources

Personnel

<u>Stakeholders</u>: The stakeholders at Lakeridge Health Corporation were the chief operating officer, the management staff, the communications and public relations staff, the physicians and nurses, the ward clerks, social worker and front-line nurses in the maternal child program, as well as the families/caregivers who were involved in the SBS research project.

The program stakeholders in the Oshawa/Port Perry communities are considered to be: Children's Aid Society, Durham Region Department of Health-Healthy Babies Healthy Children, Community Care Midwives, Durham District Catholic School Board, Durham District School Board, Catholic Family Services of Durham, Family Services Durham, Rose of Durham, YWC Durham, Oshawa Public Library Services, Girls Inc., Grandview Children's Centre, Durham Region Parents of Multiple Births Association (DROMBA), Umbrellas, Resources for Exceptional Children, University of Ontario Institute of Technology/Durham College Nursing Program, Choices-Childbirth Education & Doula Services, Family Advisory Council, Ontario Early Years, St. John's Ambulance Brigade, Red Cross, Parents Discipline Coalition, Pregnancy Health Centre of Durham, Canadian Auto Workers Union (CAW), Ontario Power Generation (OPG), Port Perry Childbirth Educator.

<u>Program Personnel:</u> The Lakeridge site coordinator is a part-time staff member with responsibilities for administering the program. Hiring for this position was done respecting the collective agreement with the Ontario Nurses Association (ONA). The site coordinator had autonomy in the ongoing administration of the project and relating to community resources. She prepared and conducted the program launch, provided the in-service training for the floor nurses of the maternal child unit, assisted with delivery of the education program to families, and connected with the UT-RCU for one-on-one meetings and the all-site program meeting in Toronto, November 2007. The site coordinator worked in close consultation with the Director, Maternal Child program.

Financial Support

The Ontario Neurotrauma Foundation Shaken Baby Syndrome Prevention Program, through the University of Toronto Research Coordination Unit, provided financial support to this project site for the part-time nurse site coordinator over a period of 18 months. The UT-RCU provided the program materials – posters, consent forms, comforting cards – as well as specialty folders and cards.

The Lakeridge Health Network provided desk space and use of a computer, paper costs for any SBS promotional activities in the hospital and in the community, as well as assistance from the Network's communication department when needed. The Oshawa hospital location purchased an industrial DVD player for showing the SBS DVD.

Material

The site coordinator requested materials in addition to those regularly supplied to project sites. Parents were given the SBS take-home materials in bright yellow folders, in the hope that it would stand out from the many other pieces of information that are given to new parents at the time of hospital discharge. Also created for this site were two different types of Congratulations cards (Figure 29) that allowed parents to list their support network and post at home for caregivers and babysitters. In the Oshawa location, the communications/media department set up a separate channel on the

atulations!

	Congratulations!	hospital TV
	A new baby can be the most wonderful time in a parent's life. Caring for a baby can be difficult and frustrating, especially if the baby is crying a lot of the time.	Promise.
	If	
	Signed (Mother) Signed (Father)	Congr
	Signed (SisterBrother)	
	Signed(Sister/Brother)	Support N
Things to remember:	Signed(Babysitter)	in the Pre-
Cryng is normal. Cryng is normal. Cryng can be a syn that four the syn that the syn set of the syn	Support Network for Parent or Caregiver in the Provention of Shaken Bahy Syndrome. Is adversing that have second stormators on how to cope with a cryste bary can characterize the second stormator or the second stormatic stormatic stormatic stormatic congression with the second stormatic stormatic stormatic congression stormatic stormatic stormatic constraints and stormatic stormatic stormatic constraints stormatic stormatic stormatic constraints stormatic stormatic stormatic stormatic stormatic stormatic stormatic constraints stormatic stormatic stormatic stormatic stormatic stormatic stormatic stormatic stormatic stormatic stormatic stormatic stormatic stor	There is a resource of the second sec
	Name of support person Address Contact Numbers (1)(2)	
LAKERIDGE HEALTH	Contact Numbers (1)(2)	
Better Together	Name of support person	
	Address Contact Numbers (1) (2)	

hospital TV network exclusively for the Portrait of Promise.

Figure 29: Additional materials for Lakeridge Health Corporation

IMPLEMENTATION

The Implementation Process

The site coordinator approached the implementation process as a double focus – presenting the SBS program to the hospital staff and connecting to the community resources/potential partners about the research project. Her first step was to introduce the nursing and ward clerk staff on the maternal child unit to the SBS education as a best practice nursing service that would improve safety for families. The staff were asked for input and what would work for them, with discussions and explanations of what the delivery process could look like. Despite initial concerns about adding to an already busy workload, the nurses were positive about the program and later assumed responsibility for orienting new nurses and student nurses coming into the unit.

A formal launch of the SBS research project was held in Oshawa, with presentations by the director of the maternal child program, the UT-RCU principal investigator, and the hospital's chief of paediatrics. As a morning event, it allowed for better attendance by the hospital physicians, nurses, supervisor of support services, and community agency representatives (local police force and children's aid, etc.).

The Lakeridge childbirth educators included the SBS program in their classes at the hospital. Following admission to the post partum unit, the families were given the SBS information and could view the Portrait of Promise DVD on the hospital network channel. The nurses would then discuss the SBS education and retrieve the signed consent form and follow-up contact information. The discharge nurse was responsible for ensuring that the patient had completed the SBS program before her discharge from the unit.

The site coordinator regularly provided SBS information to the hospital and community by updating displays (including posters and comforting cards) in the hospital lobbies of the two locations; in the emergency departments; in paediatrics, ICU and NICU; at booths on the main floor during any of the Oshawa location hospital events; in hospital newsletters; and at community fairs, forums, and open houses (i.e., Durham Regional Prenatal Fair, and the Aftermath of Domestic Violence on our Youth forum). She also sent SBS information to the major employers in the area, such as General

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Motors and Ontario Power Generation, and the Ontario Teacher's Guide school curricula designed in North Bay went out to the local school boards.

The Ontario Neurotrauma Foundation Shaken Baby Syndrome Prevention Program has invested in a shaken baby syndrome simulator doll, created by RealityWorks Inc and donated to the project. Lakeridge's site coordinator has been instrumental in using the doll for demonstration purposes throughout her community, where feedback has been positive in helping parents and caregivers to understand the effects of violently shaking an infant.

The 5-7 Month "Follow-up" Process

With over 2,500 births in the Lakeridge Health Network, the volume of telephone calls became unmanageable for our site coordinator alone, so ultimately the bulk of the call-backs were carried out by the UT-RCU nurses.

Lessons Learned

The site coordinator initially provided the SBS education to parents and caregivers in attempting to test-out and role-model program delivery to the floor nurses. However, nurses should be encouraged to provide the education from the start, as ultimately they will be responsible for maintaining relationships with the patients and accountable for sustaining the program.

A number of strategies were designed to support program delivery. The site coordinator tracked all admissions and discharges from the unit; kept a consistent presence on the maternal child unit in Oshawa and visited the Port Perry location regularly to follow-up and connect with the nurses; ensured the SBS info packages were supplied and available for distribution; implemented a tracking system that showed nurses which STS education activity still needed to be completed for each patient and the time of discharge, and had that included on the patient's chart.

OUTCOME

Lakeridge Health Network have achieved the program goals with respect to the shaken baby syndrome education, and management report that front line nurses support the program delivery as being successful. The program was routinely implemented, monitored, and data collected by the nurses in the maternal child program at both hospital locations (Oshawa and Port Perry). Parents were given the choice to participate, and some declined. Follow-up contacts with the parents and caregivers receiving the education indicate that they remembered the information, especially when they viewed the Portrait of Promise DVD.

The maternal child program documents on the patient chart that the patient has received the SBS information. The nursing staff became aware of the importance of SBS prevention; they received training in delivering the program and incorporated it into the daily services and charting for patients.

Program Sustainability

The SBS education program continues at Lakeridge Health Network as part of the services provided to patients within the maternal child program. The DVD continues to be offered on the hospital TV network, and discussions between patients and nurses regarding SBS prevention information is documented on patient charts at discharge. The midwives are agreeable to working closely with Lakeridge staff on the maternal child unit in delivering SBS education to their clients.



Figure 30: Lakeridge Health Corporation - Oshawa



Figure 31: Lakeridge Health - Port Perry

Social Network Analysis

A unique feature of this evaluation was an in-depth exploration of human connection as it related to the best practice implementation. The network of connections that made up the implementation was captured through the application of an innovative approach to understanding human interaction and group life known as social network analysis. This method for studying patterns of peoples' interactions illuminated and located the relationships of participants who implemented the program.

The multiple data sources developed in the project include elicited verbal accounts, observations, and a variety of policy, historical and demographic reports. With all this information, words-deeds discrepancies were anticipated, revealed and cross-checked through the sharing in research team meetings within and between programs. The task of the research team was to achieve an independent perspective through research conducted in a manner corresponding with the principles of informed consent, volunteerism, privacy consultation, and collaboration.

The ONF SBS Program consisted of six individual community pilot sites in communities in northern and southern Ontario. It was posited that a major determinant of program sustainability within each site may be the quality and quantity of relationships fostered between SBS Program staff and to their supporting community partners. Built into this hypothesis is the assumption that the initial SBS network would expand from the designated SBS sites into affiliated and independent local, provincial, national and international organizations through pre-existing and new professional relationships. Whether staff was sharing SBS Program information and resources, developing implementation strategies or sharing progress reports, the structure of the initial SBS Program network would invariably evolve into a different and possibly more complex network over the four-year implementation phase.

Given this assumption, a social network analysis (SNA) of the six pilot sites was undertaken to capture a sense of the network evolution, current structure, and community embeddedness of each designated SBS site. Social network analysis is the mapping and measuring of relationships and movement in a given social group. The SNA survey was designed to identify all SBS Program staff and partners and the nature and frequency of the interactions between these individuals. This data was the

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foundation for multiple social network visuals, which represented the entire SBS Program network and the six individual sites. Ultimately, the individual professional relationships fostered in service of SBS education create a unique story and network structure in each site. Identifying these structures may help provide a sustainability forecast for these six pilot communities and, more broadly, for the SBS Program in Ontario.

The data collection tool was a survey designed by the Principal Investigator of the pilot study at the University of Toronto. Prior to administration, seven key staff from all six sites were asked to assess and provide feedback to the Social Network Coordinator on the content and format of the survey. This was done to enhance the accuracy and clarity of the tool. Survey modifications were made based on the feedback received.

The survey was emailed to thirty members involved in the SBS Program in all seven sites including the University of Toronto. Twenty-three surveys were completed and an additional survey was completed by a staff member who was not on the original list, for a total of twenty-four completed surveys.

Results from the survey were input and analyzed in Pajek 1.23 software that is designed for the visualization and systematic analysis of large social networks. The survey consisted of sixteen questions. Each question is represented by a sociogram, which is a network visual displaying vertices, representing individual actors, and lines, representing the actors' social connections. The sixteen sociograms, depicting the connections between all seven sites were then partitioned into the individual implementation sites in order to observe and analyze the connections within each site, within each community, between UT and to other communities.

General Summary of Findings

This summary is organized into two main sections. First, the general summary provides an analysis of the whole-network structure (seven sites), the network structure without the UT site (six sites), the southern sites (Hamilton, Credit Valley, Lakeridge, and Kingston) and the northern sites (Sudbury and North Bay). Second, each implementation

site's network structure is briefly described. The final site summary, North Bay, will be given greater in-depth analysis due to its unique community focus on injury prevention.

The survey gathered that a total of seventy-seven individual members and/or subgroups were involved in the implementation and/or support of the SBS Program throughout the four-year implementation period. These seventy-seven staff were unified by 233 connections throughout the seven sites (six project sites plus UT-RCU). Each connection implies that two staff had made contact and exchanged information regarding the SBS Program at some point in this period. The survey identified that twenty-four individual organizations played an implementation or support role in the program (e.g., Credit Valley Hospital, Sudbury & District Public Health, Best Start Resource Centre, etc.). The Principal Investigator at UT was identified as the primary leader with thirty-one individual connections to various staff throughout the entire network. The "degree" or the average number of connections made by each staff member in the entire network was 6.05.

Removing UT's support role in the program created a dramatic shift in the network structure. In the six project sites, sixty individuals and/or subgroups were involved in the program while the number of connections reduced to eighty. Twenty-one organizations were identified while the primary leaders from all six sites were the CCPIP (Connecting Community Partners in Injury Prevention) coordinator at North Bay and the site coordinator at Hamilton Public Health, both with fifteen individual connections to staff members throughout the six sites. The degree of this network reduced to an average 2.67 connections per member. The two northern sites seemed to forge a stronger support network and considerably greater interconnectivity compared with the south. The leader in North Bay had me seven connections to SBS staff at different sites outside the community, therefore playing a greater role in linking and supporting the larger SBS initiative. Overall, the northern sites appear to have created a denser network in support of the SBS Program than the southern sites.

Sociograms and Site Summaries

A sociogram is a visual representation of a social network, consisting of vertices (the social actors) and connecting lines (the relationships between the actors). The line

between two vertices functionally represents any form of communication that has been made between those two actors. The values on the lines represent the two actors' frequency of interaction during the site's implementation phase. Vectors (the number of lines incident with one vertex) are represented by the size of each vertex (i.e., a bigger vertex implies a greater number of lines incident with that vertex).

The values on the lines connecting the actors may not necessarily represent the frequency of interaction throughout the entire duration of the project (e.g., a "2", representing weekly interaction, may only be representative of the *past year*). Generally, the values are used to represent the most recent or updated relationship between two individuals during project implementation and not typically prior to or during the launch of the project. As well, some values may have changed since data collection, thus they may not represent the current state of this relationship. Also, those who have retired following the pilot project's completion are not recorded on the sociograms. It was also noted directly on the appropriate sociogram if an individual had retired during the project implementation period.

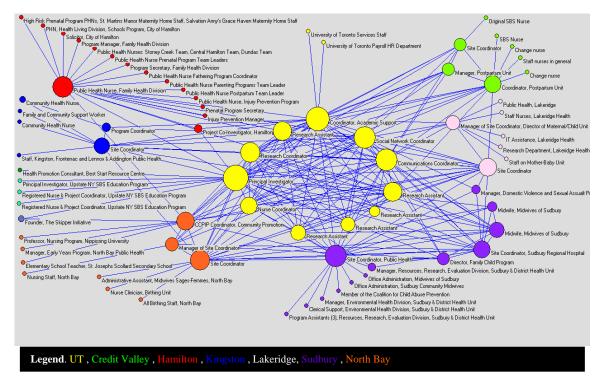


Figure 32: Sociogram of the Whole Network

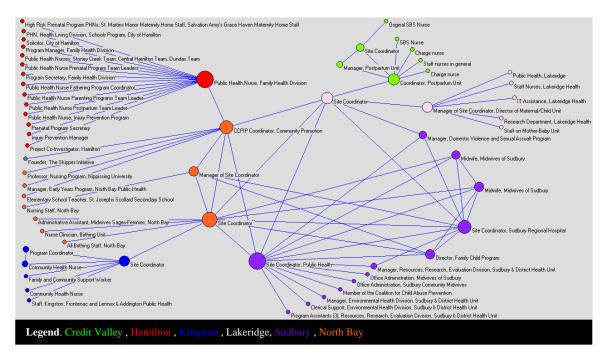


Figure 33: Sociogram: Network without UT

Hamilton

The Hamilton site had considerable involvement of staff at Hamilton Public Health and Community Services, which involved a total of fifteen staff members. A nurse who notably established a connection with fourteen individuals and/or subgroups at public health assumed the site coordinator role. She made eight connections to UT and one connection to the CCPIP Coordinator in North Bay for a total of twenty-three connections throughout the entire network. In addition to public health, two maternity homes and one non-profit agency were involved in Hamilton's Program (Appendix 1). The degree of this site is 1.86.

The Hamilton site's strength appears to be in the strong leadership of the site coordinator within the community and, as a result, the diversity of public health divisions who implemented the program. On a weekly basis, she strategized with the Injury Prevention Manager and an Injury Prevention Nurse at public health, all located in the same building. With the Injury Prevention Manager, they jointly approached other managers in public health regarding implementation within their programs, and helped

plan for ongoing delivery post-study including operational plans. The site coordinator convened monthly with the Family Health Division's program secretary regarding administrative duties, including tracking public health nurses' completed consent forms, coordinating resources and team locations. Also on a monthly basis, the site coordinator and the Coordinator of the Fathering Program collaborated on curriculum for various sites, discussing the implementation for the Dad's groups.

The site coordinator interacted with the following staff on a less than monthly basis: 1) the Neighbourhood Team Leaders (PHNs) in Stoney Creek, Central Hamilton and Dundas regarding equipment issues and resource replenishment, 2) the PHNs from the High Risk Prenatal Program and maternity homes regarding delivery of SBS Program into the homes and the ESL/Newcomer group, 3) the PHNs in the Prenatal Program regarding implementation into prenatal curriculum and presentation at an inservice for school teachers, 4) the PHN Leader in the Parenting Program regarding integration into parent curriculum (Parent Link Groups, Early Years Centres), 5) the PHN Leader in the Post-partum Program, 6) the Prenatal Program Secretary regarding coordination of commitment forms at Prenatal sites, and 7) the Study Co-Investigator in Hamilton. The site coordinator also forged a relationship with the Solicitor for the City of Hamilton and a PHN in the Healthy Living Division who worked in the Schools Program.

The site coordinator had made six connections to UT including to the Principal Investigator, the Coordinator of Academic Support, and Communications Coordinator. Hamilton's Co-Principal Investigator also had a relationship with UT's Principal Investigator and the Coordinator of Academic Support.

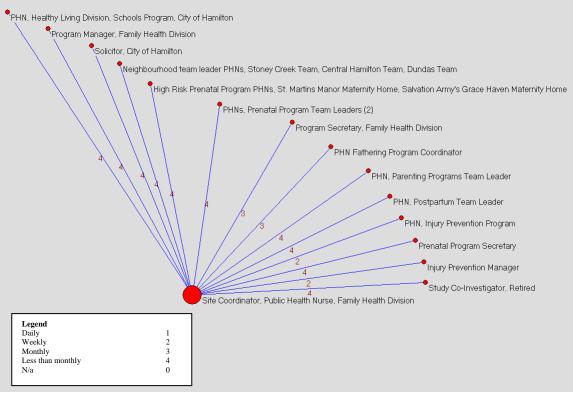


Figure 24: Sociogram: Hamilton

Credit Valley

At Credit Valley Hospital, there were an identified eight staff members involved in the SBS Program. These members forged eight connections within the hospital, one connection to the Lakeridge Site and eighteen to UT for a total of twenty-seven connections throughout the entire network. The primary leader was the site coordinator with six connections. The degree of the Credit Valley network was 2.

Credit Valley had a relatively high number of connections to UT primarily with the site coordinator; she interacted with the Principal Investigator, the Coordinator of Academic Support, the Research Coordinator and Communications Coordinator.

The site coordinator initially was the leading connector of SBS to staff at Credit Valley Hospital. She worked daily with the unit's staff nurses discussing program approaches (e.g., consent form collection, video administration, completeness and confidentiality and looking for the signs and symptoms of SBS) and weekly with two charge nurses and an SBS nurse on the floor regarding the support of nurse discussion

surrounding approaches to administration of the consent form and video. The site coordinator connected on a daily basis with the Nurse Manager of the Postpartum Unit discussing their plan of implementation on the unit, the summary of impediments, language use with parents, comparisons to other health centres, and linking consent form delivery in a package during admission.

The site coordinator interacted less than monthly with the Manager and Nurse Educator as well as one SBS Nurse who all worked on the same floor. The Nurse Educator provided information about the history of implementation, previous questionnaires and previous staff education to the site coordinator. The Manager kept the site coordinator abreast of education and staff numbers.

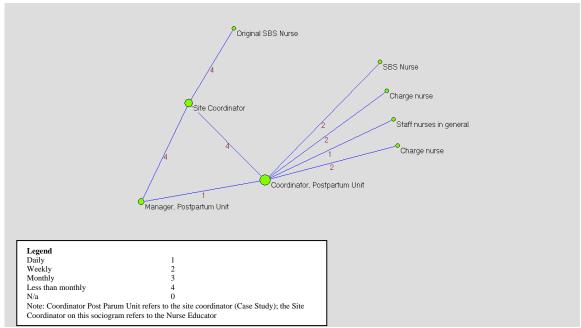


Figure 35: Sociogram: Credit Valley Hospital

Lakeridge

Lakeridge Health was one of the more modest sites with seven identified members involved in the implementation, with all but one located at Lakeridge Health Corporation. Twenty-five connections were made within the whole network: six within the site, thirteen to UT, and six to other SBS Program Sites outside the Lakeridge community. Lakeridge Public Health provided support to the Lakeridge Health Corporation via one identified member. The degree in the Lakeridge site was 1.71.

The Director of the Maternal Child Unit (the site coordinator's manager) appeared to play the leading role for the SBS Program in the Lakeridge community, while the site coordinator connected to members outside the community. The Director worked with the site coordinator at least weekly for the initial approval of the implementation plan and for successive updates on the project. Prior to project implementation, the Director prepared by liaising with the IT Department on a daily basis and the Research Department on a weekly basis. During implementation, the Director worked with the IT and Research Departments on a less than monthly basis while connecting with staff on the Maternal Child Unit at least weekly and liaising with Public Health.

The site coordinator played a vital part in gathering resources for the Lakeridge site from external sources such as UT and other SBS sites. She made nine connections with UT while the Director had created four connections, both with the project's Principal Investigator, the Coordinator of Academic Support, and the Communications Coordinator. On a less than monthly basis, the site coordinator worked with a group of health care professionals outside of the Lakeridge site who were directly involved in the SBS Program including: 1) the site coordinator at Credit Valley Hospital (discussing implementation and dissemination strategies, encouraging nurse participation and tallying the number of forms signed), 2) the site coordinator at North Bay General Hospital (who provided a copy of her launch handout materials) and, 3) the CCPIP coordinator (who provided the Teachers' SBS Guide). The site coordinators at Lakeridge Health Centre, North Bay General Hospital, Sudbury Regional Hospital and Sudbury Public Health and the CCPIP Coordinator all maintained less than monthly contact through conference calls regarding their implementation agenda. The site coordinator at Lakeridge also maintained less than monthly contact with the Manager of Sexual Assault and Domestic Violence Program at Sudbury Regional Hospital.

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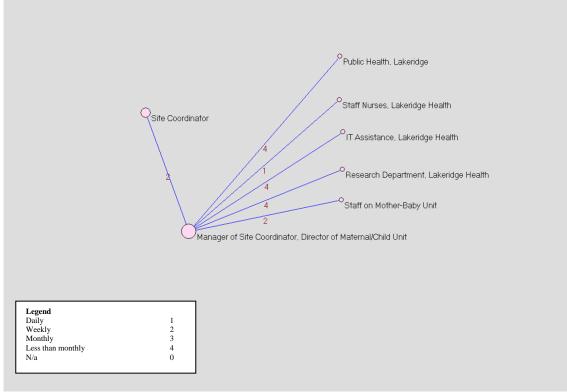


Figure 36: Sociogram: Lakeridge

Kingston

The Kingston site, implemented at the Better Beginnings for Kingston Children (BBKC), is the smallest of all six sites with total of six individuals involved in the program. The site coordinator made five of the six total connections within the site. Kingston had made nine connections to UT and one connection to North Bay for a total of sixteen whole-network connections. Better Beginnings also received support from Kingston, Frontenac and Lennox and Addington Public Health. The degree in the Kingston network was 2.

All staff at Better Beginnings worked on the same floor of their organization. The site coordinator and a Family and Community Support Worker at Better Beginnings Kingston interacted weekly regarding scheduling for delivery of the SBS Program at the Infant Group. A Community Health Nurse also worked weekly with the site coordinator

regarding planning, project implementation and training of nursing staff, however, she had retired from the project in 2007. On a monthly basis, the site coordinator and a second Community Health Nurse discussed data collection issues. The site coordinator also discussed budgeting, planning and implementation with the Program Coordinator of Better Beginnings on a less than monthly basis and interacted on a monthly basis with Public Health prior to the implementation of the SBS Program. Finally, the Program Coordinator and Community Health Nurse conferred less than monthly.

Outside the community, the site coordinator maintained seven connections to UT including the Principal Investigator, Research Coordinator, Academic Support Coordinator, Communications Coordinator, Social Network Coordinator and several Research Assistants. Additionally, the site coordinator at BBKC connected with the site coordinator at North Bay site in group meetings on a less than monthly basis.

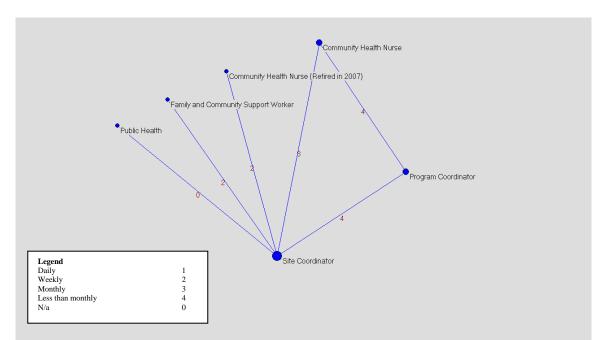


Figure 37: Sociogram: Kingston

Sudbury

The Sudbury site is unique in having two major organizations involved in the SBS Program who are also highly supportive of one another - the Sudbury Regional Hospital (SRH) and the Sudbury & District Health Unit (SDHU). Collectively both sites had thirteen active members. The entire network was comprised of fifty-eight connections; nineteen within the site, twenty-eight to UT, and eleven to other SBS sites outside of Sudbury. Additional participation and supports were provided from two midwife agencies and one child advocacy agency (see Appendix 1). The public health coordinator at SDHU made twelve within-site connections, while the hospital site coordinator made six. The Sudbury network's degree was the highest of all six sites at 2.92.

At the Sudbury and District Health Unit, the public health coordinator was exceptional at liaising within her own organization, to the regional hospital, to UT, to the midwife groups and to other SBS sites. Prior to implementation, she interacted weekly with the Manager of Resources, Research and Evaluation Division to exchange research advice on tool development. During implementation, the she connected with this Manager and three program assistants in the division monthly regarding follow up calls for the midwife group. She also maintained monthly interactions with the Manager and clerical support person in the Environmental Health Division and the office administration at the Midwives of Sudbury. The public health coordinator provided program resources to the Midwives of Sudbury group, picked up their completed surveys and was available for assistance by phone.

The site coordinator at Sudbury Regional Hospital worked with the Director of the Child and Family Program and the Manager of Domestic Violence and Sexual Assault Program on approaches for program implementation. She met individually with the public health coordinator on a weekly basis to strategize, organize and share resources for their respective pilot sites.

The hospital site coordinator had made six connections in the community: two within SRH, two with Public Health, which included the public health coordinator, and two with the Midwives of Sudbury group. The hospital coordinator reported monthly to the Director of the Family Child Program and the Manager of Domestic Violence and Sexual Assault Program in the hospital by sharing progress about the program and to discuss sustainability strategies. She was also the hospital representative for one midwife at Midwives of Sudbury group. During their monthly individual meetings they discussed strategies for implementing the program at both sites. After North Bay, the Sudbury site made the highest number of partnerships to SBS sites and organizations outside of their community, particularly with North Bay and Lakeridge. Public Health and SRH had made ten connections to UT individuals respectively while the Midwives of Sudbury created a total of eight connections to UT. Sudbury's public health coordinator connected with the site coordinators at Lakeridge and North Bay as well as the CCPIP coordinator in North Bay. Similarly, the hospital site coordinator connected with the site coordinator s at Lakeridge and North Bay as well as the CCPIP coordinator s at Lakeridge and North Bay. The Director of the Child Family Program at SRH connected with North Bay's site coordinator and her manager. The Manager of the Domestic Violence and Sexual Assault Program at SRH connected with the site coordinator. Within the Midwives of Sudbury connected with the North Bay site coordinator. Within the Midwives of Sudbury group, two midwives who were directly involved in the implementation of the program would communicate daily through individual meetings.

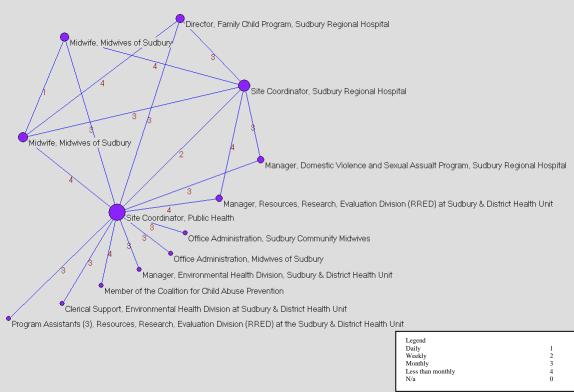


Figure 38: Sociogram: Sudbury

North Bay

North Bay's SBS network will be discussed in two parts: 1) the structure detected through the SNA survey, 2) the aforementioned structure integrated with the CCPIP Coordinator's additional network connections. It is critical to include these additional connections, which the SNA survey did not capture, due to North Bay's unique focus on injury prevention. The CCPIP is mandated to create a High Intensity Injury Prevention Centre driven towards cohesively integrating the strong pre-existing injury prevention infrastructure through new best practice community initiatives. Thus, this data will help describe a more comprehensive picture of North Bay's site.

According to the survey, North Bay's site was composed of eleven SBS staff members. North Bay staff made forty-two connections within all seven sites; eleven within-site, nineteen to UT, and twelve to other SBS sites outside of North Bay. The CCPIP coordinator played a central role in the community with six connections to the main implementation site at North Bay General Hospital (NBGH) and to other community partners. A total of six organizations were identified as being involved in the program. The degree of North Bay's network was 2.0.

The site coordinator and the CCPIP coordinator had a key relationship in the North Bay SBS Program, both working in the same city for affiliated organizations. They had consistent though less than monthly interaction prior to the implementation and during the launch of the SBS Program at NBGH. Their discussion focused on program implementation, brochure development, and SBS material dissemination developed by the community. However, during implementation their interactions were less consistent.

Within NBGH, the site coordinator fostered a number of key support relationships. She and her Manager convened on a weekly basis about the SBS Program during the implementation phase, discussing strategies for program coordination and implementation, dissemination strategies and their SBS resources. She also met daily with all birthing staff at NBGH and a nurse clinician on the birthing unit, both of whom were located in the same building and department. On a less than monthly basis, the Manager of the site coordinator convened with the nursing staff at NBGH. In addition, staff at Midwives Sages-Femmes, a midwife organization in North Bay, met on a monthly basis with the North Bay site coordinator.

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According to the SNA survey, the CCPIP coordinator liaised with six individuals in the community in support of the program. Daily discussions with one nurse focused on strategies to enlist the North Bay Parry Sound District Health Unit (NPPSDHU) for the program. A second nurse from the NBPSDHU, also the Manager of the Early Years Centre, conferred on a monthly basis with the CCPIP coordinator, discussing the utilization of SBS resources in community programs.

Additionally, a professor and head of the nursing program at Nipissing University had weekly conversations with the CCPIP coordinator concerning how to get the nursing students involved in the evaluation of physicians' utilization of the SBS resources. The coordinator also talked weekly with an elementary school teacher at St. Joseph Scollard Secondary School, who had developed the SBS curriculum, delivers it in the North Bay Catholic Secondary School Board, and who trained the trainers of the program. The Founder of the Skipper Initiative shared information on SBS and provided a teacher contact in the US for the North Bay school to interact with via video conferencing to the CCPIP coordinator. It was also noted that the Chief of Staff at NBGH played a key role in promoting the use of resources with their physicians and attended the launching event.

Outside the community, the site coordinator at NBGH connected with all but one of the UT SBS staff. The CCPIP coordinator maintained connections with all but two of the UT staff while the Manager was also in touch with the Principle Investigator, the Coordinator of Academic Support, and the Communications Coordinator during implementation. Both the CCPIP Coordinator and North Bay Site Coordinator maintained connections with the site coordinators of Lakeridge and Sudbury. The CCPIP coordinator connected with Hamilton's site coordinator at Public Health while the North Bay site coordinator connected with her counterpart in Kingston. North Bay's site coordinator had also made four other connections to Sudbury while the Manager of the site coordinator had made two to the Sudbury Community.

Centre of High Intensity

North Bay's large and unique SBS network is in part due to it being an experimental ONF Centre of High Intensity, an effort to coordinate and integrate community injury prevention programs. The Connecting Community Partnerships in Injury Prevention (CCPIP) program was developed to help build on the strong presence

of pre-existing injury prevention initiatives in the area and to forge new community partnerships and programs. The CCPIP Coordinator has played a central role in the SBS Program in North Bay, connecting with individuals at the main implementation site, North Bay General Hospital, and with various community organizations and agencies.

As a result, the North Bay site is an excellent model for injury prevention community integration and involvement demonstrating the potential capacities and settings in which the SBS program and resources can function and thrive. By including the CCPIP Coordinator's additional connections, the North Bay network is considerably larger and more organizationally diverse. The network consists of forty-four staff members, with seventy-five connections within the entire network: forty-four within-site, nineteen to UT, and twelve to other SBS Sites outside of North Bay. The CCPIP Coordinator had forged a total of 39 connections throughout the entire network and partnered with twenty-eight organizations in support of the SBS Program both within and outside the North Bay community. North Bay's network degree remains at 2 because its inter-connectivity does not increase with these added partners.

Thus, the CCPIP coordinator reported on these additional key connections that were made throughout implementation to enhance our view of North Bay's diverse and complex network structure. At minimum, there were a reported twenty-two additional organizations involved in supporting resource dissemination and public education and/or program implementation at their site (see Appendix 1). Some of these organizations included: health units in and around North Bay, (i.e., Temiskaming, Algoma, Thunder Bay), as well as North Bay Police, Ontario Early Years Centres, several high schools in New York, Illinois and in Peel and Durham.

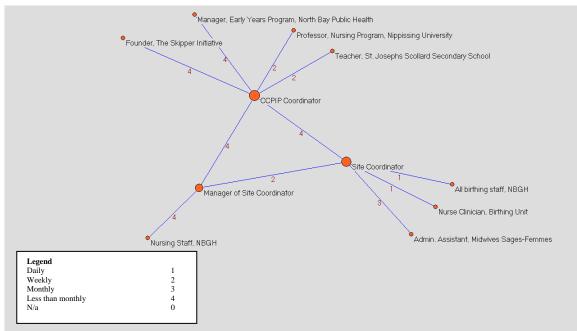
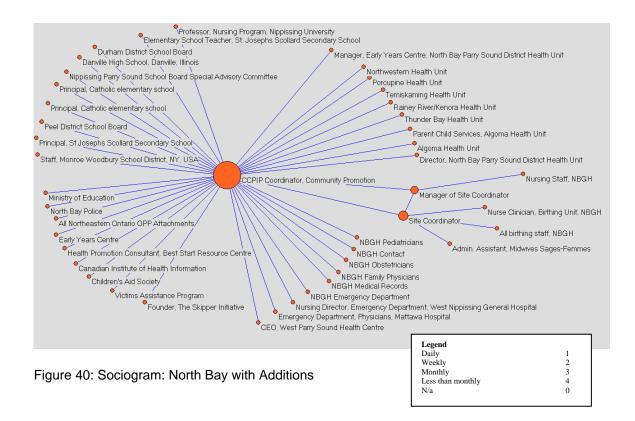


Figure 39: Sociogram: North Bay



This social network analysis has revealed that the SBS Program network has grown and diversified across organizations, disciplines, and geographical borders during its implementation. However, each site presents a unique profile in terms of the number of staff on board, their connectivity within and outside of their community, and the quality of relationships that were fostered. While there are undoubtedly numerous factors affecting the long-term sustainability of a program, it is strongly held that this program is more likely to thrive in the sites that support "champions" who are working towards embedding the program in the community through relationships to a diverse group of professionals and organizations.

Conclusion

The main aims of educating parents about SBS and infant comforting, increasing the connection of service providers by using SBS prevention as a community system integrator, and creating a sustained program after the project ended were achieved. The implementation also advances the program's use in a variety of settings (hospitals, midwives, public and community health agencies), at different times (pre and post natal), and incorporates a range of educational materials (neurotrauma focus and comforting/crying emphasis) that will benefit new parents and caregivers. This program was also unique in the range of adaptations made to the original hospital-based best practice through the involvement of a number of stakeholders in both implementation and reinforcement of SBS information. Along with its accomplishments, the program has some limitations and issues that need to be addressed.

Program sustainability is not the same as effect sustainability. There are two aspects of effect sustainability to consider. The first has to do with how the program evolves and is understood by successive cohorts of nurses and health educators. Health education efforts that lose their ability to meaningfully connect to people become mere mechanical information transmissions. Closing the gap between words and deeds is ultimately the goal challenging any primary prevention effort that targets knowledge and beliefs. This will be the major challenge of the third maintenance phase of the program. The second aspect has to do with actual incidence reduction. Good implementation

* * *

evaluation should be cognizant of both process and outcome. Although this implementation used a program with demonstrated success in reducing the incidence of inflicted infant head trauma elsewhere, the impact it may have had in reducing actual incidence in Ontario is unknown. We found the means to obtain proper surveillance information to be inadequate. We also found that monitoring advances, such as the new ICDA 10 trauma codes, were not extensively employed. Our hope is that this situation will be corrected as attention to information needs in this area becomes more widespread.

The density of social networks and the effectiveness in human connection recorded in the northern sites did not come as a surprise. While there was extraordinary leadership in these sites, there was also the reality of northern community cohesiveness that could account for much of what was found to be different in the large and small, urban and rural implementations. As one practitioner put it, "this is known by anyone who practices nursing in a small town who then works in a big city hospital". The issue of community connections is also important as a consistent observation of our call-back nurses – that program information was not as relayed in as much detail by participants in less densely connected communities. Moreover, there was agreement that physicians were generally not reinforcing program messages, whereas the existence of the post-partum clinics were reported to be effective in providing continuity in messaging and considered a valuable supplement to the initial education session.

Finally, some light was shed on the question of what are the best education materials to use in this inflicted infant head trauma education program. It appears that the answer is that it depends on the audience. Because the fidelity of the implemented program did not require the use of specific videos or written materials, a whole range of information tools were employed. While some parents found some of the materials disturbing and a "downer" at what was supposed to be a happy event, others found that a certain level of drama was necessary to make the education event memorable. Likely it is important for the health educator to choose and ultimately utilize the materials that they find to be most effective and comfortable to use.

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Appendix 1

Organizations identified in the section on Social Networking:

Hamilton

- Hamilton Public Health
- St. Martin's Maternity Home
- Salvation Army's Grave Haven Maternity Home
- The John Howard Society of Canada (Kingston)
- •

Sudbury

- Sudbury Regional Hospital
- Sudbury and District Public Health
- Midwives of Sudbury
- Sudbury Community Midwives
- Coalition for Child Abuse Prevention

North Bay

- North Bay General Hospital
- Connecting Community Partners in Injury Prevention (CCPIP)
- Nipissing University, Nursing Program
- North Bay and Parry Sound District Health Unit, Early Years Program
- St. Josephs Scollard Hall Secondary School, Nipissing Parry Sound Catholic District School Board
- Midwives Sages-Femmes
- The Skipper Initiative
- Best Start Resource Centre
- Porcupine Health Unit
- Rainey River/Kenora Health Unit
- Thunder Bay Health Unit
- Northwestern Health Unit
- Temiskaming Health Unit
- Emergency Department, Physicians, Mattawa Hospital
- Emergency Department, West Nipissing General Hospital
- West Parry Sound Health Centre
- Monroe Woodbury School District, NY, USA
- Nipissing Parry Sound School Board Special Advisory Committee
- Canadian Institute of Health Information
- Children's Aid Society
- Victims Assistance Program
- North Bay Police
- Ontario Early Years Centre
- All Northeastern Ontario OPP Attachments
- Ministry of Education
- Parent Child Services, Algoma Health Unit
- Durham District School Board
- Peel District School Board
- Danville High School, Danville, Illinois

Appendix 2

Inflicted Infant Head Trauma (Shaken Baby Syndrome) Prevention Program Implementation Guide

Introduction

This guide was developed for health professionals wanting to implement the ONF Shaken Baby Syndrome (SBS) Prevention Program in an effort to prevent head injuries sustained by young children after being violently shaken. The original Upstate New York Shaken Baby Syndrome Education Program has been operating for about 10 years and has been deemed by the Ontario Neurotrauma Foundation (ONF) as an effective evidenced-based "Best Practice" (Volpe & Lewko, 2006). The SBS Education Program was the only program to achieve this status in the latest ONF review of head and spinal cord injury prevention programs (Volpe & Lewko, 2006). Although many SBS information programs exist, this is the only one that has demonstrated an almost 45% reduction in incidence of SBS in a large population study (Dias et al., 2005). The program is now a legislated part of SBS education in New York and a number of other US states. Hence, the program has demonstrated transportability to new community and cultural contexts. Due to the support of the ONF, the latest locale to which the SBS Prevention Program has been transported is Ontario.

Description

SBS describes a cluster of brain and eye hemorrhages. Perhaps better described as inflicted infant head injury, this act of commission permanently injures or kills more children than any other form of physical abuse, with a 15-35% mortality rate (ONF, 2007). Previous research has documented the extensive personal and economic costs associated with SBS (e.g., King, MacKay, Sirnick, & the Canadian Shaken Baby Study Group; Smith, 2003).

The Upstate New York Shaken Baby Syndrome Education Program is cased by Hunchak in the Casebook of Evidence-based Practices (Volpe & Lewko, 2006) as a simple, time-limited program that can accommodate nurses' busy schedules. The program offered a consistent message about the seriousness of SBS, with a non-threatening approach, to every parent who had a baby in an 8-county region of western New York State (Dias et al., 2005).

Ontario Context

The general goal of the Ontario SBS prevention program is to provide a comprehensive implementation evaluation (ONF, 2007). This research will be used as a base for province-wide SBS education and a part of ONF's knowledge transfer activities--to generate, acquire, apply and make accessible the knowledge needed to reduce the incidence of SBS. This program also provides an opportunity to study SBS education in settings specific to Ontario (e.g., public health, midwife services, and medical offices) and to examine carefully the role of the care provider-client relationship in health education (ONF, 2007).

Specific Tasks

The main objectives of the ONF SBS Prevention Program are as follows (ONF, 2007):

- Provide educational materials about shaken baby syndrome to new parents.
- Verify parents' comprehension of the dangers of violent infant shaking,
- Track success of program through returned commitment statements,
- Describe the implementation process,
- Provide knowledge for sustainability and scalability

Fidelity Features

Research suggests that effectiveness may be compromised when programs previously found to be effective are not implemented with fidelity, i.e., in the manner they were

developed and validated (Elliott & Mihalic, 2004; Schoenwald, Sheidow, Letourneau, & Liao, 2003). Fidelity encompasses adherence, the degree to which the program is delivered as intended with all the prescribed components and processes. The following fidelity features of the original New York SBS Prevention Program are the result of practice experience and research on the distribution and determinants of SBS between 1992 and 1996 (Dias, 1996; Hunchak, 2006):

The incidence of shaken baby syndrome appears to be modifiable with timely parental education.

Education efforts must be targeted at parents, and particularly, at males, since 71% of perpetrators are parents and paramours, and males comprise the majority.

Many parents are already aware that violently shaking an infant is dangerous. Therefore, the aim of the education campaign should be to remind parents about shaken baby syndrome at the appropriate time –during a mother's post-natal stay in the hospital – after which both parents will soon be immersed in the challenges of infant care.

Parents are optimal advocates for infant safety and care and may be most effective at disseminating information about shaken baby syndrome to caregivers that will be in contact with their child.

In addition, an important fidelity feature of the original SBS Parent Education Program is its simplicity and ease of implementation. The program is a relatively short and straightforward way for busy health care professionals to introduce the topic of SBS to mothers and fathers after the birth of their child (see Volpe & Thomas, 2004).

Key Elements:

The simplicity of the SBS Prevention Program is manifested in the following key elements:

The program can be administered by almost anyone. It takes approximately 15 minutes of the parents' time, and asks them to do three simple things:

- read a short brochure in which the dangers of violent infant shaking are described and which provides alternative options to parents needing to vent their frustration and anger over persistent infant crying;
- view a short video that covers the same subject matter; and
- voluntarily sign a commitment statement affirming their acknowledgment and understanding of the information, and agreeing to participate in a follow-up.

Both parents are asked to view the information and sign the commitment statement. The commitment statement is designed to accomplish two main objectives: 1. To actively engage parents in their own education about SBS; and 2. facilitate program data collection and tracking. The timing of the instruction is an important factor in the program's success: the physical presence of the newborn infant is a significant focal point during program delivery. The program designers recommend that the educational material be provided to the parents after the child's birth but before the baby's discharge from hospital (Volpe & Thomas, 2004).

Program materials include posters to place on the walls of the maternity wards so visitors can also be educated about violent infant shaking, and information cards about that teach parents and caregivers how to handle prolonged infant crying. Implementation Guidelines

Initial Implementation Plan

The program designers have identified three implementation phases that are detailed in Volpe & Thomas (2004) and discussed further in this guide.

Phase I: The Planning Phase Phase II: The Implementation Phase Phase III: The Maintenance Phase

Phase I (About 3-6 months) Start Up

The SBS Prevention Program can follow the same implementation model employed in another program, Stay on Your Feet [SOYF]/Ontario. The first phase of implementation encompasses start up. First, recruit a volunteer SBS Advisory Group consisting of seven or eight individuals with diverse professional backgrounds who have experience in SBS and paediatrics (Corlett & Warren, 2006). Ensure the group is in place to direct the SBS team. Sustainability of the program should be an overriding objective of this team.

The important tasks during this phase are to learn about and promote the issue of SBS. Assess what SBS prevention resources already exist in the community. All important constituents must be recognized and their input and support secured. These may include (among others) relevant government and political leaders; children services, and other public and private agencies; hospital administrators and/or medical directors; regional obstetricians and pediatricians; and most importantly, nurse managers at all the hospitals that will ultimately provide the program (Volpe & Thomas, 2004). Define the scope of the issue by consulting literature and relevant organizations (See links in Web Resources section). Put together an Implementation Plan.

Once the Advisory Group reviews the Implementation Plan, the first step is to hire and train the project nurse coordinator. Ideally, a full time coordinator could deal with the many issues that arise during the implementation of the SBS prevention program. However, the nurse coordinator could work part-time if her jurisdiction area is small. The granting agency will also hire a research associate to work with the coordinator. The requisite number of hospitals/services will be selected (Volpe & Thomas, 2004).

Role of Coordinator:

The program designers recommend that a nurse coordinator be hired to coordinate the program and interact with nurse managers and others at each hospital (Dias et al., 2002). The role of the nurse coordinator has been described as follows:

1) to educate the nurse managers and their staff about the program, its importance, and its implementation;

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2) to serve as a regional resource for education, dissemination of materials and other supplies;

3) to act as a conduit for ongoing communication with the nurse managers at each hospital to troubleshoot problems as they arise, provide supplies as necessary, and maintain records of the number of parents reached;

4) to track the success of the program if desired, identifying cases of abusive head injury as they arise by interacting with paediatricians or other physicians at hospitals that provide emergency services to these infants, regional coroner's offices, state child abuse agencies, and state child death review teams.

The importance of this person as an experienced registered nurse has been highlighted in a number of publications (Dias, 2002; Dias, 2003; Dias, 2004). Since most of the people who will administer the program are nurses, the nurse-to-nurse interaction is extremely important as the nurse is a credible source of information.

Tasks of Coordinator:

Volpe and Thomas (2004) provide instruction for the nurse coordinator in their Implementation Plan as follows:

Define the community by identifying all hospitals that provide maternity care, as well as the name and phone number for the nurse manager for maternity or mother-child services. Each nurse manager should be contacted to introduce the concept and arrange a face-to-face meeting to give a brief presentation to the administrative staff. Once contact has been made and support enlisted from the nurse manager or designee, training of the maternity and neonatal nurses can begin. This can be done by either the nurse coordinator or nurse manager, depending upon the individual circumstances. A standardized educational curriculum with slides and video is used in educating the nurses.1 During the training it is important to present the program in an enthusiastic

¹ The New York program and ONF SBS program implementers may be able to provide guidance with respect to the educational curriculum (see ONF contact information).

manner and to emphasize the important role that they play in the success of the program and in saving children's lives.

Depending upon the circumstances, the appropriate ethics review committees or hospital Institutional Review Boards need to be contacted at each hospital to ensure that any research and/or privacy issues are taken into account. Medical Records committee clearance may be necessary if the commitment statements will be entered into the patients' medical record.

Finally, materials must be ordered, translated into appropriate languages, and distributed to participating hospitals. Once materials are in place and nurses are trained, the program is ready to begin. A program start date is set. The time required for Phase I is generally 3-6 months depending upon the size of the region, the number of hospitals, the speed with which support can be obtained, and the schedules for training nurses. Each hospital must find a reliable way to provide the educational video. Hospitals have either used a handcart with a video/television/DVD unit that can be wheeled into individual parents' rooms, a centralized viewing area where several parents can view the video together, or educational channels where the video can be shown continuously or at predetermined times. Again, it is important to be flexible in finding a solution for each hospital.

Suggestions:

Make a case for the program. An SBS prevention program is generally noncontroversial—people want to prevent child abuse. The challenging task is to convince the various stakeholders that the strategies that you want to use are effective. Establish a web site (Cost/benefit should be evaluated here—perhaps link with the already existing healthcare agency to decrease costs). Remember: Document your progress!

Recommended Documents to Distribute to Hospital During Phase 1 (For Examples See Appendix):

Job Description for Nurse Coordinator Commitment statement Follow up Survey Follow up Survey Guidelines Parent resource list Parent information pamphlet Educational Poster Educational Video Literature Review Reference List

Phase II (About 18-24 months):

Phase II and III are characterized by the maturation of the program. Thus, there is more difficulty in prescribing defined tasks at these phases. The experience, expertise, and local knowledge of the nurse coordinator and other stakeholders become integral to the program's operation.

According to Volpe and Thomas (2004), Phase II starts when the participating hospitals begin to administer the education to parents and families – written material is handed out, the video is viewed, and commitment statements are collected. During this time, frequent contact with the hospital nurse managers helps to iron out various problems as they arise and to answer questions. Repeated nurse education may be required for those who did not initially receive it or for new hires. Reinforcing the central message to nurses and managers is important during this time so that they begin to incorporate the educational program into their daily routine and the program becomes second nature. New problems may arise as unforeseen circumstances change the nature or administration of the program.

Responsibility may be handed off to another nurse or educator, or even other hospital personnel such as a social worker or lactation specialist; it is important that these people have the resources, education, and training to effectively administer and coordinate the program. Phase II ends when greater than 75% of the commitment statements are being signed by parents; by this time, the program has become incorporated into the culture of the maternity ward and becomes a matter of routine for the nurses. Make an effort to establish the regional baseline incidence rate of SBS by tracking incidence data at your hospital from the program's inception (Hunchak, 2006).

Tasks of Nurse Coordinator during Phase II

The nurse coordinator, once trained, will deliver a standardized in-service training program to maternity and neonatal intensive care nurses at all hospitals. The training program emphasizes the nature, purpose and importance of the program; provides information about the consequences of violent infant shaking and long term medical and developmental outcomes; reviews the results of the pilot programs; trains nurses how to approach parents with program information to educate them in a consistent manner, engender their support for the program, obtain their signatures on the commitment form, and answer any questions. It emphasizes the importance of seeking out both fathers and father figures for education; if that is not possible, having a mother share this information with her partner (if not present) and with other child care providers.

Nurses on the maternity wards will administer the program to parents. Nurses will be requested to ask both parents to read the brochure and view the short educational video. Nurses will be asked to provide the SBS program information separate from other discharge planning information and child safety information that might detract from the central message. They will be encouraged to discuss issues with parents and answer any questions. Hospitals will be asked to display educational posters (Never, Never, Never, Never, Never Shake a Baby) in the halls of the maternity wards to provide additional public information for families and visitors. Both parents will also be asked to sign voluntarily a commitment form affirming their receipt of the information. All educational materials are being provided in community-relevant languages. The hospital nurse managers will report monthly to the study coordinators: 1) the total number of deliveries, 2) the aggregate number of signed commitment forms, and 3) the number of commitment forms signed by mothers, fathers/father figures, or both parents. The proportion of returned commitment forms will determine each hospital's compliance with the program.

Phase 3 (Maintenance of program):

Phase III: The final phase begins the program has become routine and the nurses generally are educating each other about its requirements (Volpe & Thomas, 2004). The

program should be firmly established and consistently meeting targeted program performance goals.

The role of the nurse coordinators shifts primarily to involve data input, follow up calling, incidence tracking, and public relations (Hunchak, 2006). Ongoing input and communication by the nurse coordinator is still necessary for educating new hires; alleviating disruptions in program operation when there is a turn over in a nurse manager or other person responsible for coordinating the program (in some instances, this can result in the dissolution of the program within a hospital); and when other barriers or complications arise that make it difficult to administer the program. Nurses need to be reminded periodically about the whole purpose of the program and their tremendous importance to its success. This last point cannot be overemphasized. Continuous feedback to the nurses is extremely important: it is essential that they understand their efforts are in fact bearing fruit, that they are saving a baby's life, and that they are participating in a program with demonstrated success. Ongoing short face-to-face meetings or periodic newsletters to the nurse managers and their staffs with updates will provide continuous positive reinforcement and continued success. Altogether, it takes approximately two years for the program to be up and running smoothly with good active participation from all involved hospitals (Volpe & Thomas, 2004).

Appendix 3

Contact information for site personnel participating in the ONF SBS Prevention Program:

Credit Valley Hospital

Mary Anne Van Os Coordinator Nurse Educator 3C Maternal/Child Credit Valley Hospital 2200 Eglinton Avenue West Mississauga, Ontario L5M 2N1

ph: 905-813-1100 ext 5728 fax: 905-813-3831 email: mvanos@cvh.on.ca Kelly Falzon, R.N. Manager, Maternal/Child Credit Valley Hospital, 2200 Eglinton Avenue West Mississauga, ON L5M 2N1 ph: 905-813-1100

Hamilton Public Health

Georgeanne MacGregor-Fox, RN, BScN Public Health Nurse Family Health Division Public Health Services City of Hamilton 2255 Barton Street East Hamilton, ON L8H 7T4 ph: 905-546-2424, ext: 2328 fax: 905-546-3156 email: gmacgreg@hamilton.ca

Better Beginnings for Kingston Children - Kingston, ON

Karen Laidlaw Better Beginnings for Kingston Children Kingston Community Health Centres 730 John Counter Blvd Kingston, Ontario K7K 2P4 ph: 613-542-2835 email: karenl@bbkc.kchc.ca Wendy Christopher Program Coordinator Better Beginnings for Kingston Children Kingston Community Health Centres 730 John Counter Blvd Kingston, Ontario K7K 2P4 ph: 613-542-2835 Fax: 613-542-3861 email: wendyc@bbkc.kchc.ca

Lakeridge Health Corporation - Oshawa & Port Perry, ON

Donna Brownlee Lakeridge Health Centre 1 Hospital Court Oshawa, Ontario L1G 2B9 ph: 905-576-8711 4209 email: dbrownlee@lakeridgehealth.on.ca

North Bay General Hospital - North Bay, ON

Leslie Ryan Coordinator Maternal Child Social Worker North Bay General Hospital 720 McLaren St North Bay, Ontario P1B 3L9 ph: 705-474-8600 ex 4110 email: ryanle@nbgh.on.ca

Joanne Laplante, R.N., Bsc.N., IBCLC Nurse Clinician Maternal Child Care Centre North Bay General Hospital 720 McLaren Street North Bay, Ontario P1B 3L9 ph: 705-474-8600 4159 Cell:705-497-5767 fax: 705-495-3683 email: laplaj@nbgh.on.ca

North Bay, Ontario - Community

Pat Cliche CCPIP Coordinator 1270 Hwy 17 East RR#3 North Bay, Ontario P1B 8G4 ph: 705-472-8172 email: pat17@sympatico.ca

Sudbury, ON - Hôpital régional de Sudbury Regional Hospital

Angelina Wiwczor Nurse Coordinator Hôpital régional de Sudbury Regional Hospital 700 Paris Street Sudbury, Ontario P3E 3B5 ph: 705-674-3181 or 705-523-7100 ext 6018 fax: 705-671-7378 email: awiwczor@hrsrh.on.ca Diane Belanger Gardner Administrative Director Family Child Program Hôpital Régional de Sudbury Regional Hospital 700 Paris Street Sudbury, Ontario P3E 3B5 ph: 705-523-7100 ext 1553 email: dbelangergardner@hrsrh.on.ca Mary Carter Manager - Sexual Assault, Domestic Violence Hôpital régional de Sudbury Regional Hospital 700 Paris Street Sudbury, Ontario P3E 3B5 ph: 705-523-7100 ext. 1028 email: mcarter@hrsrh.on.ca

Sudbury, Ontario - Community & Midwives

Laurie Fraser Coordinator Public Health Nurse Sudbury & District Health Unit 1300 Paris Street Sudbury, Ontario P3E 3A3

ph: 705-522-9200 ext 391 fax: 705-677-9607 email: fraserl@sdhu.com

Janette Mishibinijima Registered Midwife Midwives of Sudbury Ekwe-ebaa-jaaget-ikwe, Sages-femmes-de Sudbury 435 Notre Dame Ave Suite 201 Sudbury, Ontario P3C 5K6 ph: 705-671-2229 fax: 705-671-2074 email: midwivesofsudbury@bellnet.ca Susan Snelling Manager - Research and Evaluation Public Health Research, Education and Development Program Resources, Research, Evaluation and Development Division 1300 Paris Street Sudbury, Ontario P3E 3A3

ph: 705-522-9200 ext 353 fax: 705-677-9602

Kim Cloutier-Holtz Registered Midwife Midwives of Sudbury 435 Notre Dame Ave Suite 201 Sudbury, Ontario P3C 5K6 ph: 705-671-2229 fax: 705-671-2074 email: midwivesofsudbury@bellnet

Resources

American Academy of Pediatrics See policy statements at http://aappolicy.aappublications.org/)

Canadian Pediatric Society See position paper at <u>http://www.cps.ca/english/statements/pp/cps01-01.htm;</u>

National Center on Shaken Baby Syndrome (NCSBS) http://www.dontshake.com/

Ontario Neurotrauma Foundation (ONF) http://www.onf.org/

ONF Shaken Baby Syndrome Prevention Program Home Page http://www.oise.utoronto.ca/research/ONF-SBSPrevention/index.htm

ONF Shaken Baby Syndrome Prevention Program Contact Information http://www.oise.utoronto.ca/research/ONF-SBSPrevention/Contact%20Info/Contact%20info.htm

Public Health Agency of Canada See health promotion pages at <u>http://www.phac-aspc.gc.ca/dca-dea/prenatal/shaken_e.html</u> See joint statement on SBS at <u>http://www.phac-aspc.gc.ca/dca-</u> <u>dea/publications/jointstatement_web_e.html</u>

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