1+1= A Healthy Start to Life - Research Report

The *1+1 = A Healthy Start to Life Project: Targeting the year before and the year after birth in Aboriginal children in remote areas* is a three stage baseline, intervention and post-intervention study designed to improve maternal and infant health for remote dwelling Aboriginal families in Maningrida and Wadeye. We are investigating how services can be better designed to increase community involvement in improving early detection of problems and increase the effectiveness of multidisciplinary practice during pregnancy and the year after birth. This study is funded by the National Health and Medical Research Council, the NT Research and Innovation Board and the Helen and Bori Liberman Family. An Australian Research Council funded project in partnership with the Department of Health and Community Services and Danila Dilba Aboriginal Medical Service is looking at Indigenous families and birth which is also informing this work.

Dear Colleagues

The 1+1 study is progressing well and we are not just over half way through our funding period. On 6th November 2009, we held a half day advisory committee meeting at Charles Darwin University. Twenty-five people attended, eight from NT Department of Health and Families (DHF), nine clinicians from RDH and remote outreach health services, and eight researchers from USYD, ACU and CDU. We presented the preliminary infant health data collected by Sarah Bar-Zeev from an audit of records, observation and interviews and also Suzanne Belton's and Sue Kruske's qualitative data following families over the first year of life. I guess, despite knowing the field, and others work showing heavy use of services, we were all concerned and surprised not only by the rate of use, including very heavy use of the neonatal nursery, but ineffective use of time and services. We have been sharing this work with staff and leaders in the health system who also share these concerns. As a result, we will work with them and other clinical leaders as they work out how they can apply these findings to restructuring modes of delivery of remote services to pregnant women, mothers and families of infants.

The early publications from this study are about to come out with our first 2-3 papers being reviewed now. What is so good about the 'action research' approach is that people are aware of these findings and have already worked extremely hard to improve things where our data show less than optimal the services are provided.

We are delighted and honoured to have the opportunity to work with you all to try to help with these important improvements.

Lesley Barclay AO PhD
Director and Professor; Northern Rivers University Department of Rural Health; University of Sydney and Chief Investigator

on behalf of the project team

Advisory Committee Workshop – what happened?

Audit data – more preliminary findings of an analysis of maternal health services for remote dwelling Aboriginal women and infants from the Top End of Australia

Sarah Bar-Zeev presented an interim analysis of the health service utilization by infants from two remote communities in their first year of life. A retrospective review of all infants born between 2004 and 2006 from two remote communities (n=404) was undertaken between January – August 2008. Data was collected from medical records at the Royal Darwin Hospital and the Remote Health Centres.

Preliminary findings from the retrospective review included:

- High rates of birth complications (approx 40% infants identified with one or more complications) and admissions to the neonatal nursery at birth with preterm birth and low birth weight identified as the major reasons for admission.
- High rates of infant hospitalization within the first year of life (1.14 admissions per infant) primarily for respiratory infections and gastroenteritis.
- Frequent presentations to the remote health centre within the first year of life (higher numbers of presentations ascertained in 1st year of life than previously documented). The leading reasons for presentation were for respiratory, gastrointestinal and skin symptoms. Approximately half of all presentations were for an acute reason whilst the remainder were for recall visits, 'well baby' or routine checks and paediatric reviews.
- Interviews with health staff in remote identified inadequate time and resources for effective health promotion and education, recall and follow up. Recommendations by staff have been made to increase the number of community based workers to provide education and preventive care alongside health staff - outside of the Health Centre setting.

Family of infants: experience of care

Sue Kruske reported on the ethnographic work being done by herself and **Suzanne Belton** in the two communities. Women were recruited into the study during pregnancy and visited every 2-3 months throughout their pregnancy, whilst in town waiting to have their babies and then again in their communities up until their baby was one year old.

Major findings included:

- High use of health services
- High rates of morbidity
- Poor quality of health care
- General satisfaction with the services
- Identity of remote staff was nurse/midwives
- General perceptions that their infants were healthy.

A case study was presented on one of the mother-infant dyads. This mother was articulate, confident, had good family support and was providing a good environment for her child. A review of the baby's notes at 12 months showed the infant to have suffered some growth faltering, recurrent left ear disease resulting in perforations from 9 months, recurrent infected scabies and persisting mild anaemia since 6 months of age.

The chart audit demonstrated the consistent problems in health services that included

- Episodic care (where only the presenting problem is treated)
- Growth not being plotted
- Ears not being checked
- No dental checks/education
- No work documents as being done outside the clinic
- No public health strategies being implemented
- Anaemia/ear disease, skin not properly treated

When the mother was asked about her perceptions of her child's growth, ears, skin, anaemic ('thin blood') the mother largely reported no problems. Her baby was growing well, had no problem with thin blood or ear disease. These perceptions were consistently reported across the two study sites and indicate a significant disconnect between the women's stories and the documented health concerns.

Other data collected was around Aboriginal child rearing practices. Main findings were around the differences between Aboriginal and mainstream beliefs where the child is the 'active agent' and it is the families responsibility to respond to the child's needs. So if a

child turns his head away from food indicating he is not hungry it would be considered cruel to force him. Similarly children should never be alone, including to sleep. It is not desirable to cause a child to cry or not respond to a child crying. These beliefs have significant consequences for the uptake of health care messages that rely on families doing things to children (like administering medicine), sometimes against their will.

Recommendations from this part of the research include:

- Learn more about Aboriginal understanding of common childhood conditions
- Explore Aboriginal child rearing beliefs and practices
- Explore the disconnect and how we can bridge it
- Address common morbidities from a public health perspective
- More Aboriginal workers so that information can be provided to Aboriginal families that fits in with their worldviews and staff can get a better understanding of how to be effective
- Work more effectively with support staff (outreach and community based)
- Support to work outside health centre
- Work proactively to identify and work with families early.

Costing studies

A costing subcommittee has been convened and has been working on the costing protocol in the 1+1 project for nearly a year. We (researchers and Health Gains staff) are working closely with both a Melbourne and Sydney team who are currently performing economic evaluations of maternity models of care. We will be undertaking three components of economic evaluation across the 1+1 and MGP work. One is using the Standard Working Unit (SWU), which was used by the Health Gains Unit of DHF, to compare the current antenatal and infant care patterns (in remote) and their associated costs with the 'Standard Care' recommended by CARPA. With the Health Gain's support, the SWU figures have been updated to 2008 figures. The second component is to conduct an economic evaluation for MGP (urban component). We are in the process of exploring methodologies that would be optimal for this with our DHF colleagues and experts in the field. The third component will be costing quality, employing the Total Quality Management (TQM) framework. The economic evaluation studies are still in early stages and **Yu Gao** is leading some of these sub-studies.

Use of population data

Malinda Steenkamp presented findings for remote-dwelling Aboriginal women and infants based on population level data. Malinda's project is about increasing understanding of the utility of population-level health data for better informing health care policy and service delivery to mothers and babies in remote Aboriginal communities in the NT. She is addressing three questions (1) what data sets are available for getting information on mothers and infants; (2) what are the data issues that impact on the utility of the data (e.g., mobility); and (3) how can we improve the utility, e.g., through linking data sets?

Malinda has continued to analyse unidentified data from the NT Midwives Collection for 2003-2005. Overall, the profiles for the two field sites of the *1+1 A Healthy Start Project* are very similar to other remote areas and to the profile of NT Aboriginal women as reported elsewhere. There are notable differences for a number of variables. At this stage, it is not clear how recording practices are influencing this or how important these variations are for policy and planning. One notable difference between the communities and other comparison groups is special care admissions of infants. The admission rate was 39.9% and 36.8% in Community 1 and Community 2, respectively, which was significantly higher (p=0.000) than the overall admission rate for all Aboriginal infants in remote areas (24.9%).

For Community 2 about 57% of the infants admitted to special care were preterm. For Community 1 this figure was 41%, which is in line with what was found for other comparison groups. Other than preterm birth, no clear patterns for reasons for admissions could be discerned at this point. It is likely that linking data from NT Midwives Collection with data from the NT Hospital Separations data for the two field sites will provide more insight.

Malinda provided an update about her work on pragmatic indicators for remote dwelling Aboriginal mothers and infants. She identified and reviewed 42 sets of indicators/audit tools related to Aboriginal health; reproductive/maternal health; /obstetrics; child/infant health; and remote health. From these, she identified 1,082 individual measures, of which 652 (60%) were specifically relevant to areas listed above. She developed a framework, organised the 652 measures into lists dealing with different stages of the patient journey (antenatal, birth & postpartum, first year of life). These evolving lists were reviewed five times by a growing group of 14+ experts. The fifth review was completed

recently and the list of indicators and findings are being finalised.

The indicators suggested by Malinda address the remote context and the challenges with providing care to mothers and infants in these areas more explicitly. It also adds measures that focus on issues where there are few practical existing ones, such as patient perspectives or continuity of care. **For further information or for a copy of the indicators, please contact Malinda at msteenkamp@usyd.edu.au**

Midwifery Group Practice

Cath Farrington provided an update on the progress of the evaluation of the Midwifery Group Practice (MGP) in Darwin. The evaluation will use a participatory action research process and a mixed methods design to evaluate the clinical effectiveness, sustainability and satisfaction with MGP. Cath described the methodology of the evaluation in some depth.

Cath explained that quantitative data collection includes chart audits of all women in MGP and questionnaires administered to MGP midwives and a comparison group of core midwives. These questionnaires administered at three monthly intervals will inform findings on the sustainability and satisfaction of midwives with the MGP. An industrial questionnaire administered at twelve months will also provide information on the sustainability of the MGP and its ability to recruit and retain staff and the effectiveness of salary arrangements. The first round of questionnaires has been sent with 10 /14 being returned. A time and motion study is being planned to collect detailed data to contribute to the planning of the appropriate caseload for midwives working in this type of model. Australian benchmarks need to be modified for this context.

Qualitative data collection includes interviews with MGP staff (8/8 completed), Core midwives (7/9), DHF staff (5) and other key stakeholders (1). Cath explained that interviews would be conducted at the commencement of the MGP and in twelve months time with the exception of the Aboriginal Health Worker and senior Aboriginal woman who accompanies women to town who will be interviewed every 3 months.

Cath observed that the challenges and limitations she had met so far included a reluctance of some staff to be involved in "surveys", staff turnover and the delay in commencement of the MGP which will only allow for data collection over a one year period.

The next Advisory Group meeting will be in May 2010. An agenda for this workshop will be sent to all Advisory Group members closer to the date.

Investigators on the study are: Professor Lesley Barclay, *Project leader*; Professor Jonathan R Carapetis, *child health, infectious disease prevention*; Prof Sue Kildea, *PAR, service intervention, evidence based care*; Assoc. Professor Sue Kruske, *child health, parenting practices, nurse workforce reform*; Professor Gweneth Norris, *management accounting, costing, economic analysis*; Dr Carolyn McGregor, *patient journey modeling, health informatics*; Dr Joanne Curry, *patient journey modeling analyses*; Prof Sally Tracy, *innovative service delivery, cost, evaluation, risk management*; Dr Suzanne Belton, *ethnographic studies*, Dr Jacqui Boyle, *Obstetrics, service design*, Dr Ngiare Brown, *Indigenous child health*, Dr Steve Guthridge, *epidemiology, statistical advice*, Noelene Swanson, *remote health service reform*.

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Research Update No 7 Nov 2009

Happy Christmas!