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

On 19th May 2010, we held a half-day Advisory Committee meeting at the NT Department of Health and Families' (DHF) facilities. Eighteen people attended with a number of last minute apologies. Attendance included representatives from the NT DHF, Royal Darwin Hospital (RDH) and Menzies School of Health Research.

It was our seventh Advisory Committee meeting. We are in the process of supporting the implementation of interventions and starting to evaluate some of these. At the meeting, we presented the preliminary findings from Sarah Bar-Zeev's study evaluating the quality of maternal and infant care provided in two remote health centres compared with both CARPA and the Women's Business Manual. Our concurrent work has identified barriers to the provision of effective care of pregnant women and infants. Sarah's work is identifying what we do well and where we need to improve. We also presented preliminary findings from Malinda's work and the early results from the evaluation of Midwifery Group Practice (MGP) at the meeting.

On the 23rd of April I presented our work in Alice Springs at a Remote Health Management workshop. John Wakerman worked with the managers in the afternoon. It was fantastic to see the energy and innovation reached at the end of the day as remote health leaders worked out how they could provide leadership for improvement. Alongside this, is work led through Health Development and Jill Davis around parenting support that we hope to be involved with in the future.

We are pleased that our research results are informative and accepted by academic peers, as well as by policy makers. We have now published one book chapter and two peer-reviewed articles with more in train. An Honours student has graduated and two PhD students are progressing well and are on track to complete around the end of the year. We have shared our results with colleagues at five national and international conferences.

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

Baseline audit data

Sarah Bar-Zeev presented the preliminary findings from her study evaluating the quality of maternal and infant care provided in two remote health centres. Data was derived from interviews with health care providers, participant observation and audit data from maternal and infant records in both health centres (2004-2006). One component of the study was the comparison of the care that was provided to pregnant women and their infants with the care that is recommended in the CARPA and Women's Business Manual protocols.

The results showed that antenatal services were highly utilised in both health centres. Women had a median of 7 antenatal visits (min 0 - max 19) though these visits often commenced later in pregnancy than optimal to be effective in maximising outcomes.

There was generally good adherence by health care providers to protocols for routine antenatal investigations and the initial detection of complications. However, documentation of follow up treatment for identified complications including sexually transmitted infections (STI's), anaemia and urinary tract infections (UTI's), all of which had prevalence rates consistent with or higher than those previously reported for Aboriginal women in other Australian studies, was poor.

The most poorly documented aspects of antenatal care were those related to smoking use and cessation advice, alcohol use and fetal anomaly screening.

Remote health services were also highly utilised by infants, with a median of 35 (min 0 - max 80) presentations during the first year of life. High rates of anaemia and growth faltering were detected but similar to the maternal cohort, there was poor implementation of timely treatment for these vastly prevalent problems in both communities.

Multiple reasons were identified by health care providers as barriers to provision of effective care of pregnant women and infants. This included lack of time available to provide clinical care and health promotion compounded by a high administrative burden; limited opportunities to work alongside Aboriginal Health Workers (AHWs); high staff turn over, discontinuities in care which exist within the current models of health service delivery, inadequate staff knowledge and experience providing health education to Aboriginal families, limited access to resources and ineffective recall systems. This data forms part of the baseline study for the 1+1= A Healthy Start to Life project. A comparative analysis of the quality of care will be conducted by Cath Farrington as part of the MGP evaluation.

Use of population data

Malinda Steenkamp presented an update on three aspects of her PhD work. The first concerned the development of practical indicators for use by policy makers, service managers and researchers involved in the care of remote-dwelling Aboriginal women and their infants. A final set of 45 indicators was selected through a Delphi process. The final framework combined life stages from conception to first birthday with *Health Status/Outcomes*, *Determinants of Health*, and *Health Systems Performance*; as well as with *Patient Assessed Value*, *Provider Performance*, and *Health System Efficiency*. The proposed indicators measure important issues re remote maternal and infant health in a practical way and they incorporate many existing indicators. It is important to remember that "You manage what you measure!". What is measured is based on one's underlying view of a system. **We need to think about what we value and, therefore, measure.** We also need to think about whether we are going about this in the right way. The challenge is to balance a health services perspective with an Aboriginal one. The two are not mutually exclusive.

Malinda also presented the comparison of live birth counts from three sources: the local birth records for two remote Aboriginal communities, the Registrar of Births, Deaths and Marriages' collection (BDMC), and the NT Midwives Collection (NTMC) for 2004-2006. The birth counts were not consistent among these three sources. Counts from local birth records were about 10% higher than BDMC counts and 18% higher than NTMC numbers. Interviews conducted by Sarah Bar-Zeev

identified that about 10% of infants born were considered to be 'visitors' to the community. A large part of the differences in livebirth counts appear to be due to short-term mobility which is an integral part of Aboriginal life and has an impact at the local level. Service populations of community health centres may be underestimated if based on BDMC and NTMC data.

Lastly, Malinda presented findings on her investigation into special care (SC) admissions. Results presented in November 2009 showed that 39.8% of infants from Community 1 and 36.8% of infants from Community 2 were admitted to special care after birth in RDH. These proportions were significantly higher than for other comparison groups. She investigated this further to identify possible reasons. Malinda found that for infants admitted to special care, their remote-dwelling mothers were more often aged < 20 years, had more than four antenatal visits, more often have labour complications and more often had emergency caesarean sections. The infants admitted to special care were more often born preterm and received resuscitation. These findings are similar to the profiles for all NT Aboriginal infants. This investigation did not find any clear profiles or reasons to explain the higher SC admission for the two communities. We hope that looking at hospital data and linked data in the future might provide clearer answers.

Midwifery Group Practice evaluation

We are currently conducting the evaluation of the pilot continuity of care service model for remote dwelling women coming in to Darwin to give birth. The evaluation of the MGP uses a participatory evaluation process and a mixed methods approach whereby quantitative and qualitative data collected from a range of sources will be integrated into the final report. On behalf of Cath Farrington, Professor Sue Kildea presented some preliminary findings from the evaluation. Fifty-seven stakeholders, core midwives and MGP team members have been interviewed. Three rounds of questionnaires have been distributed to the MGP team and Core midwives. The first measures Attitudes to Professional Role and the midwives and AHW have returned scores ranging from positive to very positive. The 2nd questionnaire the Maslach Burnout Inventory (MBI) Human Service Survey contributes to understanding of the sustainability of the MGP as it provides information about the psychological wellbeing of AHWs and midwives working in the model. A Time and Motion Study (TMS) was conducted over two weeks. The participatory nature of the evaluation is assisting the team and their manager to establish benchmarks for this new model of care.

Health Economic Evaluation

On behalf of the costing team Yu Gao, Sue Kildea, Lesley Barclay, Sarah Bar-Zeev, Cath Farrington, Yuejen Zhao, Sally Tracy and Lisa Gold, Sue presented the health economic evaluation framework. The economic evaluation will take the perspective of the health system and compare the direct costs of antenatal care, birth, postnatal care (up to six weeks) and neonatal care (up to 28 days) pre and post establishment of the MGP. Women included in the economic evaluation analysis will come from the two studied Aboriginal communities. The study will employ Standard Working Units (SWU), which was developed by the DHF Health Gains Team, to estimate the unit cost for antenatal care visits. The hospital cost will be based on Australian Revised Diagnosis Related Group (AR-DRG). The pathology cost will use the standard Medicare fee. Pre and post MGP quantitative and qualitative data will be presented to conduct a cost-consequences analysis. It is believed that this approach will provide decision makers with a more informed basis to resource allocation than cost-effectiveness analysis alone.

The next Advisory Committee meeting will be in November 2010. An agenda will be sent to 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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