



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

I am delighted to bring you up to date with progress on our NHMRC 1+1 grant. This is the last year of funding and we have until December to wind up the study. This year focuses on evaluation. We have been talking with colleagues in Darwin about how we can tailor this evaluation to meet their needs as well as our needs. This is not difficult but does mean we will attempt to capture as much data as we can to demonstrate how changes in service delivery over the last year or two may or may not have influenced outcomes for mothers and infants. We are constrained by time and resources so are likely to sample baseline data collected three years ago rather than use the population based sample Sarah Bar-Zeev investigated so thoroughly. Cath Josif will be undertaking this evaluation and will be working with PCIS data rather than the paper-based files that we worked with originally. She is visiting communities to talk with leaders, health service staff and Local Reference Groups currently and will collect the data in June and July.

We will have a smaller than usual meeting in a few months to share interim findings about this year's data collection with a full meeting planned for February 2013. By then we should have analysed all of the field data collected by Cath and be able to present you with something substantive. In the meantime I will continue to maintain links with staff members in the Northern Territory and ensure that this last phase of the study meets your needs as well as ours for completion. Sarah and Malinda's theses are close to submission and we hope Cath's thesis similarly will be submitted by the end of the year. There are numerous publications coming out of the work we have all done and we would like to draw your attention to the recent publication led by Prof Sue Kruske on Aboriginal parenting. This work was supported not only by the NHMRC grant but also an AIC partnership grant we held with the Department. I am hearing great praise for this publication from a variety of sources and would you encourage you to read this if you are interested in Aboriginal parenting styles. An abstract and their citation follows with other publications either out or accepted so you can follow in more detail some of our findings. I look forward to meeting you, if not later this year, at our windup meeting early next.

Best wishes,

Lesley Barclay AO PhD

Director and Professor; University Centre for Rural Health North Coast, Chief Investigator on behalf of the project



Sue Kruske

Sue recently published paper 'Growing Up Our Way: The First Year of Life in Remote Aboriginal Australia'. The citation and the abstract is as follows:

Kruske, S., Belton, S., Wardaguga, M., & Narjic, C. (2012). Growing Up Our Way: The First Year of Life in Remote Aboriginal Australia. *Qualitative Health Research*, 22(6): 777-87.

In this study, we attempted to explore the experiences and beliefs of Aboriginal families as they cared for their children in the first year of life. We collected family stories concerning child rearing, development, behaviour, health, and wellbeing between each infant's birth and first birthday. We found significant differences in parenting behaviours and childrearing practices between Aboriginal groups and mainstream Australians. Aboriginal parents perceived their children to be autonomous individuals with responsibilities toward a large family group. The children were active agents in determining their own needs, highly prized, and included in all aspects of community life. Concurrent with poverty, neocolonialism, and medical hegemony, child-led parenting styles hamper the effectiveness of health services. Hence, until the planners of Australia's health systems better understand Aboriginal knowledge systems and incorporate them into their planning, we can continue to expect the failure of government and health services among Aboriginal communities.

Malinda Steenkamp

Malinda Steenkamp is in the final stages of writing up her PhD. Her aim was to increase understanding of and ability to use the Northern Territory's routinely collected perinatal data to investigate inequalities in Indigenous maternal and neonatal health outcomes to better inform policy, practice and monitoring. To this end she has examined data issues that impact the NT Midwives Collection (NTMC) for 2003-2005 (coverage, clustering, completeness, content validity); investigated maternal and neonatal outcomes using NTMC data; and established indicators to evaluate and monitor improvements in maternal and infant health care delivery to remote-dwelling Indigenous mothers and infants in the NT. To date, she has five papers published or accepted for publication and another one in draft:

1. Steenkamp M. Clustering in Northern Territory perinatal data for 2003-2005: implications for analysis and interpretation. *Health Information Management Journal* (in press, accepted 24 May 2012)
2. Steenkamp M, Rumbold A, Barclay L, Kildea S. A population-based investigation into inequalities amongst Indigenous mothers and newborns by place of residence in the Northern Territory, Australia. *BMC Pregnancy and Childbirth* (in press, accepted 23 May 2012)
3. Steenkamp M, Rumbold A, Kildea S, Bar-Zeev S, Kruske S, Dunbar T, Barclay L. Measuring what matters in delivering services to remote-dwelling Indigenous mothers and infants in the Northern Territory, Australia. *Australian Journal of Rural Health* (in press, accepted 20 May 2012)
4. Steenkamp M, Johnstone K and Bar-Zeev S. (2012) Can we count? Enumerating births in two remote Indigenous communities in the Northern Territory of Australia. *Australian and New Zealand Journal of Public Health*, 36(3): 281-4.
5. Steenkamp M, Bar-Zeev S, Rumbold A, Barclay L and Kildea S (2010). Pragmatic indicators for remote Indigenous maternal and infant health care – why it matters and where to start. *Australian and New Zealand Journal of Public Health*, 34(s1): S5 - S8.
6. Steenkamp M, Boyle J, Kildea S, Rumbold A. Adolescence is not the issue for Indigenous mothers: Birth outcomes in early and late teenage pregnancies in the Northern Territory, Australia (To be submitted to the *Journal of Adolescent Health* mid-June).

Sarah Bar-Zeev

Sarah is nearing completion of her PhD and plans to submit her thesis for examination by mid-year. Sarah currently has three papers in press, two under review and further publications from the baseline study are planned. These will include a paper examining the high prevalence of postpartum haemorrhage among remote dwelling Aboriginal women and the management of the third stage of labour and a paper reporting the consequences of fragmented health services for remote dwelling mothers and infants using patient journey modelling as a framework.



1. Bar-Zeev, S., Barclay, L., Kruske, S., Bar-Zeev, N., Gao, Y. & Kildea, S. (2012) Maternal health service use among remote dwelling Aboriginal women in northern Australia and their disease burden. *Birth* (accepted for publication)
2. Bar-Zeev, S., Kruske, S., Barclay, L & Bar-Zeev, N., Carapetis, J. & Kildea, S (2012). Use of health services by remote dwelling Aboriginal infants in tropical northern Australia: a retrospective cohort study. *BMC Pediatrics* 12:19 (online)
3. Bar-Zeev, S., Barclay, L., Farrington, C. & Kildea, S. (2011). From hospital to home: The quality and safety of a postnatal discharge system used by remote dwelling Aboriginal mothers and infants in the Top End of Australia. *Midwifery*, In press.

Cath Josif

Sue Kildea and Cath Josif reported findings from the evaluation of the MGP at the Health Advisory Group meeting held in December 2011. The final report was submitted to the Department of Health in February 2012. Cath has had one paper accepted for publication and another paper in draft.

1. Josif, C., Barclay, L., Bar-Zeev, S., Kildea, S., Brittin, M. (2012) How Participatory Action Research supported improvements to the postnatal discharge summary process used for remote dwelling Aboriginal mothers and infants in the Top End of Australia *Action Research Journal* (Accepted for publication).
2. Josif, C., Barclay, L., Kildea, S. 'No more strangers': a qualitative study of the experiences of women, midwives and stakeholders with a new model of care for remote dwelling Aboriginal women in northern Australia. *Midwifery*. For submission June 2012.

Cath is currently working on the final phase of the Healthy Start project. Research in the post intervention phase will explore the impact changes to service delivery have made on quality of care (as measured by diagnosis, treatment and follow up of key indicators during pregnancy, birth and postnatal), service utilisation and maternal and infant health outcomes and service providers in the maternal health care system.

Deborah Donoghue

Deborah Donoghue from the University of Sydney's Centre for Rural Health has been working with Dr Charles Kilburn and the team to investigate the finding that a third of the babies from the two communities were admitted to the Special Care Nursery. A retrospective audit of the records of all babies admitted to the nursery in 2010 was undertaken and analysis is underway.

Yu Gao

The costing study for the Midwifery Group Practice (MGP) is complete and the findings will be presented in a paper entitled 'An holistic economic evaluation of a Midwifery-Group-Practice for Aboriginal mothers and infants in the Northern Territory, Australia'. The paper will use an holistic approach to compare maternal and infant health outcomes, women's experiences and cost differences for pre and post MGP groups. The costing paper is in early draft.

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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