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. It is designed to improve maternal and infant health for remote dwelling Aboriginal families in two large remote Aboriginal communities in the NT. 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 24 November, we held a half-day Advisory Committee meeting at the NT Department of Health and Families' (DHF) facilities. We are missing our Project manager, Gao Yu, who has given birth to David. This means we are late with this newsletter. I apologise. We are nearly four years into a five-year project. As an oversimplification we have found thus far:

- Avoidance of some services, e.g., about 10% of women giving birth outside of the tertiary setting;
- Massive utilisation of other services such as infant health care;
- Poor follow through, e.g., the treatment of anaemia in infants and mothers;
- An alarming 'normalising' of illness by mothers where excessive levels of illness are considered normal;
- High levels of neonatal nursery admission, i.e., 30% or more; and
- No psychosocial assessment, parenting support and limited opportunities for Aboriginal leaders to support families or provide psychosocial support.

On the plus side major change is occurring:

- Discharge processes have improved.
- The Midwifery Group Practice has begun and we are assisting to evaluate the outcomes of this major investment.
- There are designated midwife and child health positions being established in some remote communities. We can see some risks that need to be managed in relation to clinical governance and education.
- We have produced Indicators that are specific for the remote mothers and infants and could measure improvement to maternity and infant health services for the NT.
- The *Healthy Under 5s* program is being implemented with a large number of practitioners enrolled in an on-line training program to improve their child and family health skills.
- We are ready to analyse the '*Dealing with Difference*' program that hopefully has helped increase cultural safety.

We are about to start another small study to explore the very high rates of neonatal nursery admission in association with Charles Kilburn. This will involve a detailed retrospective clinical audit of the indication for admission to the nursery and care received during the nursery stay, some interviews and other work.

Next year our work is around evaluation and continuing to report. We will also revisit a sample of remote clinic data to see if there is a difference from 2007/8 when the baseline data was collected. We will also undertake a comparison of current care (practice) with protocols to see if this has improved and continue reporting data through publications.

Lesley Barclay AO PhD

Director and Professor; University Centre of Rural Health; University of Sydney and Chief Investigator on behalf of the project team

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This project is led through the University of Sydney and the Graduate School for Health Practice, Charles Darwin University

Midwifery Group Practice evaluation

At the Advisory Group meeting, Sue Kildea spoke about the evaluation of the Midwifery Group Practice (MGP). Sue and Cath Farrington are investigating if the establishment of the MGP for remote dwelling mothers and babies, when compared to baseline data, results in improved quality of care, maternal and neonatal outcomes and is cost effective. The evaluation employs a mixed methods participatory approach and uses a prospective cohort and retrospective control.

Ninety-nine interviews have been conducted over a 12-month period with 64 stakeholders, including women from two remote communities and the strong woman workers attached to the practice. The MGP midwives, Aboriginal Health Worker / Student Midwives and a comparison group of core midwives from the hospital have completed five rounds of questionnaires – The MBI: Human Service Survey and Attitudes to Professional Role questionnaire. The MGP midwives have also recently completed an Industrial questionnaire (IQ). The IQ explored the midwives patterns of work and the effect of working flexibly on their lives. Chart audits have been completed for (147 / 186) women and (167 /187) infants. All data collected is in the preliminary stages of analysis.

The first data analysis of 111 women showed that the MGP cohort has a smaller proportion of women aged less than 20 years compared to a comparison group from the NT Midwives Collection (all women from Darwin remote 2003-2005) and baseline data (women from the 1+1 study). We are not sure if this is due to small numbers but have been granted an extension of the evaluation to investigate further.

The evaluation team raised a number of issues for consideration and discussion, which included:

- How the designated midwife positions could work together with the MGP
- The possibility of a designated obstetrician and paediatrician attached to the practice
- Consideration of a Case Review meeting for all women at 34-36 weeks gestation between remote and MGP staff and involving DMO/LMO and obstetrician for women with identified risk factors.
- Data management particularly in relation to multiple recording and data entry.
- Role of AHW/SMW and how they work with others clinical / advocacy / partnership.
- The role of a senior Aboriginal woman and how this position is best supported and works with others work.

In summary, the evaluation team has observed that progress to date suggests that the MGP is a highly valued model of care by both women and stakeholders.

Use of population data

Malinda Steenkamp presented an update on two aspects of her PhD work.

Firstly, she presented the comparison of live birth counts for the two field sites from three sources: the local birth records for the two 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.

Malinda also presented findings on her investigation into special care (SC) admissions. More than 35% of infants from the two field sites for the *1+1 A Healthy Start to Life* project were admitted to special care after birth. These proportions were significantly higher than for other comparison groups. However, the NTMC data presented below did not allow for length of stay to be taken into account. When special care nursery admission is defined as a stay of longer than four hours, the proportion declines to around 30% (Bar-Zeev, Unpublished PhD Thesis, in preparation). Even so, this proportion is still higher than the national average and higher than the corresponding figure for non-Aboriginal women living in remote areas.

Ethnographic work

Sue Kruske presented findings of two years of ethnographic work following a group of women through pregnancy and their child's first year of life. Key findings included:

- Children are considered to be autonomous individuals from birth but need to fit into the wider group collective (interdependence with autonomy VS Independence).
- Families believe that their babies are born with the ability to communicate their needs and families must respond.
- Giving the infant what he/she wants reflects a deep respect for individual autonomy – the infant is learning how to cooperate by having their wishes respected.
- All people, including children have a right to make their own decisions about their own actions. It is inappropriate to force others to do something against their will.
- To say 'no' or 'don't' 'squashes the child's curiosity' and damages their autonomy.
- Distraction, teasing and fear are used to modify unwanted behaviour.
- To leave a baby to cry is cruel.
- To separate a baby from family is cruel.

All of these findings have implications for health service delivery where we often expect the mother and family to make decisions on the child's behalf or make the child do something against his or her will.

For more information about the 1+1 A Healthy Start to Life Project please contact:

Prof Lesley Barclay on (02) 6620 7266 or ***lesley.barclay@usyd.edu.au***

Prof Sue Kildea on (07) 3163 6388 or ***sue.kildea@acu.edu.au***

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.*

Please make a note - the date for the next Advisory Group meeting is 26 May 2011.

Season's greetings and our best wishes for the New Year!