NORTHERN RIVERS
University Department of Rural Health

Graduate School for Health Practice

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 improve 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

As Sue Kildea and I have both moved employer and residence over recent months I wanted to bring you up to date with where I am located but also how I am continuing to actively lead the project and ensure continued progress. I visit each month and spend at least 2-3 days meeting with the research team members and colleagues in policy and practice. This time also enables me to work with PhD students who remain in Darwin. We have two weekly teleconferences where we all get together to supplement the times in Darwin and I speak to researchers on the phone weekly or two weekly as individuals and through email on most days.

We have 4 staff pretty fully occupied on the projects I lead or related activities. They are based at Charles Darwin University. The NHMRC grant has been transferred to University of Sydney and the ARC grant remains at Charles Darwin and is being led by Sue Kruske. I assist with this. We have another 2 students who are also employed on the project, Sarah Bar-Zeev and Malinda Steenkamp who have moved from the NT for family reasons working on data generated from the project in other states. They are now enrolling at Sydney University.

I must admit to some anxiety when I left about getting this system up and running in ways that did not short change the project, students or staff, but now feel confident that we are managing well. Certainly the progress we report here is exciting as is the achievements of our clinical and policy colleagues in making change happen.

On the 28th May 2009 we held a one day Advisory Committee meeting at Charles Darwin University (CDU). Twenty-four people attended, nine from NT Health Government, 10 from CDU and Menzies, two remote outreach midwives from the study areas and one aboriginal researcher from one of our field sites. In the morning we reviewed, reported and discussed our research findings with those present.

In the afternoon, we hosted a 'Costing Maternity Care' workshop. We invited Professor Gweneth Norris who is a specialist in management accounting from CDU and a 'Health Gains' staff economist to help us to establish credible, feasible costing models that could be used for innovative models of care in the NT and nationally. We are working to cost quality as well as expenditure on services. This is challenging for non economists so we are very grateful for their guidance as Yu Gao begins to work on transforming some of Sarah Bar-Zeev's and other data into items for this costing work.

We are delighted to have this opportunity to report to you. Please contact myself or any of the researchers mentioned here if you want more information or have any queries about the content of this Newsletter.

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

Advisory Committee Workshop – what happened?

Lesley Barclay overviewed the study findings produced by the baseline data over the last two years. This included fragmented care, health service structure and organisation, PATS data, records and communication, culturally insensitive care, inconsistency of medical advice and support. She also reviewed how the baseline data is being used to improve the system, an example of which was provided in the morning as work on the discharge summary process.

Women bypassing the system for birth

Sarah Ireland and **Concepta Narjic** presented their work on women who chose to only partially use the maternity health system. The title of the study is ***'Niiyith Niyith Watman- The Quiet Story'.*** The study had quantitative and qualitative findings. The major themes were:

- women, through their previous experiences of standard care, appeared to make conscious decisions and choices about managing their subsequent pregnancies and births;
- women took into account their health, the baby's health, their access to a skilled birth attendant (modern or traditional) and designated men into a helping role;
- there is a breakdown of traditional birthing practices.

Quantitative findings showed that during 2003-2007: 32 women gave birth in the community; 8 women had no antenatal care; 33 women attended less than 5 antenatal care visits; and 36 women presented in the last three months of pregnancy. Aboriginal women have a higher rate of birth outside of hospital compared to the rest of Australia (9.35% versus 0.7%) despite no access to health system sanctioned community based birth services.

Conclusion and implications

The majority of babies born in the community are healthy. The audit showed that women were more likely to encounter complications during their pregnancy or immediately after birth, rather than during labour. By offering the choice of place of birth Aboriginal Women's Business and cultural obligations may be invigorated.

Suzanne Belton, Sarah Ireland and Concepta Narjic will continue working on the ARC work with those women who are using the maternal health system.

Epidemiological investigations

Malinda Steenkamp is one of two PhD students on the Healthy Start Project. For her PhD she is interested in three questions: (1) What databases exist now that shed light on the health of remote-dwelling Aboriginal mothers and infants?; (2) How accurately do these data reflect health status at community level?; and (3) How can the utility of the data be enhanced, e.g., through linking data or for monitoring of indicators? She is focussing on three data sets: the NT Midwives Collection, the hospital separations data set and the patient travel scheme data.

At the May 2008 meeting of the Healthy Start Advisory Group, she reported on her progress on data analysis. She has received and analysed unidentified midwives data; and submitted data requests for the other two data sources. However, these data cannot be analysed in a meaningful way without identifiable data elements and she is now in the process of requesting ethics approval for access to identifiable data. Malinda also plans to link the midwives and hospital separations data as this is likely to enhance the usefulness of both sources.

At the May 2009 meeting, Malinda presented preliminary results of her analysis of data from the NT Midwives Data Collection. She analysed the data at community level and identified important areas for further investigation. In particular, the two Healthy Start field sites had higher proportions of emergency caesarean sections than other remote Aboriginal women or urban Aboriginal women and very high proportions of babies from the two communities (39.8% and 36.8% respectively) were admitted to special care after birth. Malinda also reported on her progress towards establishing pragmatic indicators for the remote Aboriginal context.

The participatory component of the study

Sue Kildea gave an overview of the action research side of the study reminding everyone of the recommendations of the original 2004 workshop and looking at our progress in these areas. The recommendations included those from the Maningrida women: two-way learning, choice – where to birth, hostels – not safe, escorts; the Wadeye women: aboriginal women's leadership – working side by side, need ante and postnatal education centre, need birthing room for those women who are choosing to birth in their community, escort / hostels / children / midwife to visit; and the Policy Representatives and Service

Providers, communication, coordination, collaboration, continuity, education pathways for AHW – child health and midwifery, AHW role not well utilised in town, current system unsafe, hostels. The overarching aim of the 1+1 project resulted from this and is: To use a participatory action research (PAR) process to strengthen maternal and infant health services. This would be accomplished

through service redesign interventions developed using PAR and evidence based health care where we prioritise continuity of care during pregnancy, birth and infancy by multidisciplinary teams and improved efficiency, communication, health outcomes, and satisfaction (consumers, health service staff and policy makers).

Sue described some of the challenges the team were facing and the strategies used to address these. In particular, communication across such a large study and ensuring stakeholders are aware of the actions is a challenge addressed by Reference Groups and Subcommittees.

The rapidly changing environment in the NT has at times has led to opportunities not previously available. The funding for the ***Midwifery Group Practice (MGP)*** to provide continuity of care for the women from Maningrida and Wadeye when they are in town and the designated midwifery positions in these communities, which will link directly to these teams, are examples of this. The evaluation of the MGP will be an extension of the 1+1 project and Cath Farrington has been employed to do this work. The evaluation will also use PAR to identify emerging issues and make recommendations as the team develops. To date we have agreed terms of reference, ethics approval, an evaluation subcommittee and the evaluation tools are almost developed.

Information Systems and Discharge Summaries

Cath Farrington gave a presentation on ***Information Systems and Discharge Summaries***. She provided a recap of research conducted by PhD candidate **Sarah Bar-Zeev** and findings presented by researchers from 1+1= A Healthy Start to Life project at the Advisory Group meeting last October. Discharge process and information systems were identified as key areas for improvement in that research and the vignettes and case studies in Cath's presentation highlighted fragmentation and discontinuities in care throughout the discharge process. This discharge process has changed considerably since Sarah's data was collected and Cath described progress made and opportunities for improvement as well as raising some issues that require more thought. Electronic Discharge Summaries (EDS) were introduced early in 2007. Changes to the EDS process have been informed by the work of 1+1 and feedback from both remote and urban communities.

The defaults mechanism in the EDS has been revised and removed so that the user must select the type of birth from a drop down box. This should prevent the wrong information going into the summary. With the introduction of the Domiciliary Midwifery Service the midwife and RMO complete their sections of the summary but do not dispatch it.

The final discharge summary is dispatched when the woman is discharged from the domiciliary program and this is considered timelier. The Maternity Services Manager acknowledges that there are still issues if a woman is discharged straight from the Hospital to the community the main reason being a backlog of EDS for the RMOs. CARESYS Training is now offered weekly for midwives RMOs and RNs and as part of induction. Business Rules are being developed and there are guidelines for completing the EDS beside each computer in the ward area.

A domiciliary support person has been appointed to address queries regarding EDS. She ensures that these have been completed correctly and are ready for input from the domiciliary midwives prior to discharge. She also ensures that EDS are sent to designated contact at the community.

The Antenatal Clinic (ANC) is in the process of gaining access to PCIS with some staff undergoing training. It is anticipated that this could reduce the administrative burden for remote health centre staff and free them up to provide antenatal and postnatal care. Cath highlighted the importance of training for staff to feel confident using PCIS and maximise its potential. A Length of Stay and Discharge Policy which will have as its focus streamlining information systems is being developed. Case conferencing and discharge planning has been identified as a priority for those women who have children discharged from the Special Care Nursery (SCN). The Lactation consultant, SCN staff, Social Worker and 6A staff meet to plan discharge and follow up requirements and then liaise with the community re a documented plan. Delivery suite and Ward managers are chasing up access to the ehealth application for their areas. This may alleviate issues identified by Sarah Bar-Zeev in relation to those women who present after hours with no records where tests are being duplicated because delivery suite staff has difficulty accessing information. In her presentation Cath suggested that it might be a priority to promote the ehealth program to remote dwelling women through the health centres / ANC and maternity ward.

Cultural Insensitivity

Sue Kruske and Lorna Murakami-Gold: Sue Kruske gave an overview of the ***Dealing with Difference Program***. This program involves a two day workshop and monthly teleconferences for 3 months. It aims to increase the effectiveness of the interaction between health providers and clients where the client does not share the same cultural background. This is achieved through assisting health providers reflect on their own culturally informed values, beliefs and attitudes and how we

easily pass judgment on others when these values and beliefs are not shared. Literature on evaluation of prejudice reduction programs are limited and this project intends to rigorously evaluate the program before, during and three months after the workshop. The evaluation component will be undertaken by Lorna Murakami Gold.

To date there has been one workshop delivered with further workshops planned for June and July. Participants will be invited from a range of settings and include:

- Managers
- Remote staff
- Outreach Maternal and Child Health staff
- Midwifery Group Practice staff
- Hospital staff

Sue Kruske acknowledged the senior DHF support of the program and the cooperation of a number of individuals who assisted in identifying participants and releasing them to attend.

'Costing Maternity Care' workshop
After lunch, Lesley Barclay, Gweneth Norris, Yuejen Zhao, Sue Kildea, Sue Kruske, Yu Gao, Malinda Steenkamp, Sarah Bar-Zeev, Desley Williams and Cath Farrington remained and worked as a group to workshop Total Quality Management (TQM) framework.

The group listed all the antecedents for low birth weight and classified these into six categories: social demographic environment, maternal health, health service, health professional, cultural and health

service delivery model. The TQM process we used to work on 'quality' includes 4 cost categories: prevention, inspection, internal failure and external failure. To apply the TQM framework in health system, the group renamed its 4 cost categories to: prevention, monitor, intervention and adverse outcome. We are tying these in the first instance to preventing low birth weight and how this could occur.

After the TQM workshop, Dr Yuejen Zhao reviewed the costing project plan drafted by Yu Gao and provided some constructive suggestions.

We look forward to reporting further on other aspects of the project in October this year.

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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