menzies
school of health research

PO Box 41096, Casuarina NT 0811, Australia
John Mathews Building (Bldg 58),
Royal Darwin Hospital Campus, Rocklands Dve, Casuarina NT 0810
Ph: 08 8922 8196 | Fax: 08 8927 5187 | Web: www.menzies.edu.au
ABN: 70 413 542 847

discovery for a healthy tomorrow

Parental perspectives on what is needed, from pregnancy through to age 5 years, for children to grow strong and healthy

Amended Report 9 December 2009

prepared by

Ms Thérèse Kearns,[1] Assoc Prof Ross Andrews,[1] Dr Kate Senior,[1] and Dr Barbara Paterson[2]

1. Menzies School of Health Research, Charles Darwin University
2. Northern Territory Department of Health and Family Services

Acknowledgments

We gratefully acknowledge the involvement of Milingimbi and Oenpelli communities and thank the study participants, their families, health clinics and local researchers for their participation in the project.

Report: Parental perspectives on what is needed, from pregnancy through to age 5 years, for children to grow strong and healthy

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1 BACKGROUND

In 2006, the "Healthy for Life" (H4L) project funded by the federal government was implemented in two Top End communities, Oenpelli and Milingimbi. One of the aims of the project was to improve the health of Aboriginal and Torres Strait Islander mothers, babies and children by improving service quality and health outcomes through increased resources and focus on quality systems, community collaboration, early intervention and preventive approaches.[1]

During Phase 1 of the H4L program, chart audits were conducted to identify key areas of concern for maternal and child health. In the Top End communities priority areas identified included: smoking, injury prevention and identification of children at risk from social, financial, housing and food security issues. This report relates to a community consultation process, undertaken in later months of 2008 by Menzies School of Health Research, in which parents were asked about what they believe was needed in their community for children to grow strong and healthy – hereafter referred to as the "parental perspective study".

2 Aims and Objectives

The aim of the consultation process was to provide information to the H4L program from a community perspective, of what is needed from pregnancy through to age 5 years for children to grow strong and healthy by:

- identifying what the priorities are for parents in ensuring that their children have a healthy start to life; and,
- identifying what the community perceives are important health needs from pregnancy through to age 5 years.

3 METHODS

3.1 Community consent

The parental perspective study was part of the community consultation process required for the existing Healthy for Life (H4L) Program. The study was discussed with the Healthy for Life coordinators, Nurse Managers and community council representatives at Milingimbi and Oenpelli who supported the project being implemented in their communities as part of the H4L program.

3.2 Questionnaire

A questionnaire was developed by the Menzies School of Health Research investigators (TK, KS RA) and the Department of Health and Families (Barbara Paterson) to discuss with the local community workers at the training workshop. The questionnaire contained key themes with prompt questions that were refined after feedback was received from the local workers. The 2 questionnaires developed that were used by the local workers included 1 for

key stakeholders and 1 for the family interviews (Attachment A and B). The four questions that were asked included:

1. *What are the good things that help kids grow strong and healthy?*
2. *What does the community need to make sure mothers have a healthy pregnancy and baby?*
3. *What do family groups need to make sure mothers have a healthy pregnancy and baby?*
4. *What makes it difficult to bring up kids that are strong and healthy?*

3.3 Recruitment and Training

Local community workers were employed and trained to conduct the interviews and translate the questionnaires with the assistance of a Darwin based team, which consisted of a male Indigenous researcher and a female project coordinator. There was 1 male and 1 female community worker employed in Milingimbi and 2 male and 2 female community workers employed in Oenpelli.

An initial training workshop was held in Darwin on May 2008. All team members attended except for the 2 male community workers from Oenpelli who were involved with a men's ceremony. The topics covered at the training workshop included:

- project outline
- roles and responsibilities of research staff
- obtaining informed consent
- interview techniques
- practice session with consent forms and questionaires
- review of themes for key stakeholder and family interviews
- identification of possible interviewees

The training was then also provided on-site for the 2 male community workers from Oenpelli before the interviews were conducted in their community.

3.4 Identification of key stakeholders and family groups

At the training workshop the community workers identified potential key stake holders who could be approached for interviewing. If the key stakeholders were not present in the community at the time of the interviews others were then identified by the community workers. Informed consent for participation was obtained and the key stakeholder was interviewed. Responses were either voice recorded on a MP3 player or handwritten on the questionnaire form. The key stakeholder was then asked to identify a family group that they felt might be willing to be part of the family interviews.

The family groups were then approached by the research team and, if willing, a time was organized to conduct the voice recorded interviews of family members present. Informed consent was obtained from family members

before commencing the interviews. A hand written summary of the family group interview was also recorded during these sessions.

3.5 Data analysis

The voice recordings were later reviewed by the Darwin based team (Indigenous researcher and the project co-ordinator) and the responses transcribed. The responses were then put into common theme categories for reporting.

3.6 Ethics approval

The project was approved by the Human Research Ethics Committee of Northern Territory Department of Health and Families, number 08/16.

4 RESULTS

4.1 Key stakeholder interviews

Milingimbi

The Indigenous male researcher from Darwin attended this community to work with the male and female community workers for a 2 week time period. The male and female community workers identified 15 key members to be interviewed of which 13 consented. Of the 13 interviews performed, 11 recorded either voice or written responses about the 4 questions to be asked of the family groups. The 2 key members whose responses were not recorded were voice recordings that could not be found on the MP 3 player.

The majority of interviews (8/11) were conducted in the morning with the remaining 3 in the afternoon. The interviews were performed in various locations: around the local community supermarket (3); on the beach (3); under a tree (1); at home (3); and at the local arts and crafts centre (1).

Most key stakeholder interviews in Milingimbi (8/11) were with male participants (Table 1). The persons interviewed were: community elders (4); other local community members (3); a shire worker (1); a worker at the school (1); a land owner (1); and 1 was not specified. Each was asked about the appropriateness of the questions to be asked and what responses they would give to each of the four questions.

Table 1. Key stakeholders interviewed by age and gender

Milingimbi	20-30	40-50	60+	Unknown	Total
Male	4	2	1	1	**8**
Female	1	2	0	0	**3**
Total	**5**	**4**	**1**	**1**	**11**

* The 2 excluded in Milingimbi were elderly 1 male, 1 unknown gender

Oenpelli

The Indigenous male researcher and the project co-ordinator from Darwin attended this community to work with the 2 male and 2 female community

workers for a 2 week time period. The male and female community workers identified 5 key members that were present in the community at the time and all were interviewed (Table 2). Of the 5 interviews performed all responses were hand written by the researcher staff. The key stakeholders included 1 teacher's assistant, 1 Aboriginal Health Worker and 3 community members. Two of the interviews were conducted in the morning and the other 3 in the afternoon. Three interviews were conducted at home on the verandah and the other 2 in the community under a tree.

Table 2. Key stakeholders interviewed by age and gender

Oenpelli	20-30	40-50	Unknown	Total
Male	2	1	0	**3**
Female	0	1	1	**2**
Total	**2**	**2**	**1**	**5**

The key stakeholders were asked to review the four research questions to confirm that they would be appropriate to ask in family groups. None of the 16 key stakeholders suggested any changes, and most responded to the questions so their answers have been included with those of the family group interviews.

4.2 Family group interviews

There were nine family groups interviewed in Milingimbi. Family group interviews were conducted with families from each of the five camps in Milingimbi that included: bush, garden, army, top and bottom camp. Six interviews were taped and hand written and three interviews were hand written only. Males and females were almost equally represented in the family groups (Table 3).

In Oenpelli, four family groups were interviewed from two of the four town camps, three from Arrguluk and one from Banyan. Three other families had given verbal consent to be interviewed but were unable to be located at the time of interview. All family group interviews were voice recorded. More females than males were interviewed.

Table 3. Family members interviewed by age and gender

-	Male	Female	Total
Milingimbi	25	27	**52**
Oenpelli	2	6	**8**
Total	**27**	**33**	**60**

4.3 Interview responses

The responses from Milingimbi and Oenpelli have been combined as the information provided could be categorized into similar themes. Family groups in Milingimbi were much larger than those in Oenpelli and were more easily organized. Eliciting responses about who was responsible for implementing each of the categories was more easily identified in some categories than others.

1. What are the good things that help kids grow strong and healthy?

The most common repetitive themes for this question were responses about family, education and nutrition. Other themes that were not discussed in as much detail were culture, health promotion, sporting activities, employment and economics. Responses to the three most common themes were:

- *Family*

  Having good role models which meant having healthy parents who could teach children about nutrition and good health practices was a common response. It was also important that the children were loved, respected and cared for so that they would grow up to look after themselves and could make healthy choices in life.

- *Education*

  Two way learning was discussed in many of the interviews. It was important that the children learned both cultural ways and "Balanda" ways as both were considered important for the children to grow up strong and healthy. Further encouragement for children to attend school from parents and family was considered important if the children were to get better jobs as "supervisors and coordinators." School was also considered an important environment to learn about traditional and western food practices to improve nutritional intake.

- *Nutrition*

  Traditional food, hunting and gathering was considered essential for a healthy diet in Aboriginal communities. The old ways were considered more healthy as "you had to exercise and drink water" and "that going to the shop was the lazy way" to feed the family. More healthy options from the community store and takeaways were needed with less unhealthy options being offered.

2. What does the community need to make sure mothers have a healthy pregnancy and baby?

There were three repetitive themes that had very strong support from the community. These included: no alcohol/smoking/gambling, educational programs for antenatal care and play groups and support services for domestic violence. The other 4 themes mentioned were: strong cultural practices, healthy food, child care centre and to a lesser extent employment.

- *No alcohol/smoking/gambling*

  There was great concern that pregnant mothers and family members spent too much time and money on alcohol and/or gambling and/or smoking (including gunja). Money used for these activities was not being spent on

food and there was concern that the children were staying up all night and not getting enough sleep or being sent to school.

- *Educational programs for antenatal care and child play groups*

These programs were considered important for educating community people about health, but they needed to be conducted in a place/centre that was culturally appropriate for the community. It was felt that young mothers needed to care and look after themselves better with a healthy diet and regular check ups and be given strategies to do this from the educational classes. It was also mentioned that it was a family responsibility to help the mothers attend these classes.

- *Support services for domestic violence*

There was a need to "stop fighting and violence" and that a service provided by the clinic or council was necessary to ensure mothers have a healthy and happy pregnancy and child. It was also identified in Oenpelli that there were no safe houses for mothers to go if worried about their safety.

3. What do family groups need to make sure mothers have a healthy pregnancy and baby?

The three most common themes that were discussed in the interviews included: clinic visits during pregnancy, no smoking/gambling/alcohol and other drugs and having a clean house. Other themes that were discussed included: strong culture and support from family, nutrition and education.

- *Clinic visits during pregnancy*

It was considered important that family groups should encourage clinic visits during pregnancy for "check ups" and "medication" and to discuss issues of concern and receive advice. Home visits by health staff were not suggested by participants as an important way of improving antenatal care but culturally appropriate centres were. A family in Oenpelli who felt that it would be OK for home visiting stated that they would be embarrassed to bring someone into their home because it was not new and clean.

- *No smoking / gambling / alcohol and other drugs*

Discussion around this topic did not change and included the themes that it was present, it was wrong and that something needed to be done about it.

- *Clean house*

A clean house, clean environment with no rubbish was considered very important for family groups to provide a safe environment for pregnancy and the new baby.

- *Strong culture and support from family*

The family groups were seen to be responsible for ensuring a strong culture and it was felt that difficulties arose when there was no guidance from family members. Families should support one another and talk with the mothers offering advice and encouragement. Family groups were to take responsibility for ensuring that the environment was safe, that pregnant women went to the clinic for check ups, took their medications and ate good food.

- *Nutrition*

Providing healthy food from the bush and store to complement clinic check ups and health promotion activities was discussed in terms of good nutrition and outcomes for pregnant women. It was important that pregnant women ate the correct bush foods to make them strong and the baby healthy and that the family could inform them of these foods.

- *Education*

The education discussed was always two way, both Yonlngu and Balanda and was needed to teach mothers and children. It was stated that "education is the key to everything."

4. What makes it difficult to bring up kids that are strong and healthy?

Money was the common theme discussed though-out this question that was implicated with gambling and grog. The other key areas that created discussion included: families, culturally appropriate services and lack of knowledge.

- *Money, gambling and grog*

> "The lack of employment and money makes it difficult to bring up kids that are strong and healthy."

It was felt that funding was needed to create jobs with the government and community working together and "that people should not have kids just for the money, they should be thinking about their future." Concerns were also expressed about the humbug on payday and the money being spent on grog, gambling and other drugs. One lady stated that, "drug dealers are sick in the head, [we need to] stop gunga and kava." It was felt that because of these negative influences" mothers were doing bad things when pregnant."

- *Families*

Grandmothers stated that things were difficult as they were having to take more and more responsibility for their grandchildren if the parents were involved with grog or gambling or gunga. Families were not supporting

one another and the extended family was not helping out as much as they have in the past. It was felt that children were not being looked out for after school and were learning bad things as well as good. It was expressed that in some circumstances there was "no caring or loving" and that parents were doing other things instead of looking after their children. The lack of a clean environment was of great concern to one family who felt embarrassed for people to come into their home. It was felt that people should be working for the future and looking out for their children's future.

- *Culturally appropriate services*

The need for culturally appropriate services was mentioned frequently. It was suggested that a culturally appropriate centre for pregnant women would be a great place to make time to teach young mothers. It was felt that parents held back if the service was not culturally appropriate and did not have relevance to the country. It was also thought that the elders needed to be invited to the schools to tell stories about their culture and that open days should be held so the children could learn about spear making, dancing, painting and going out into the bush. For the culture to remain strong for the children it needed to include: "hunting, swimming and camping."

- *Lack of knowledge*

This theme was mentioned in relation to poor food choices from the local store that could be improved by putting up healthy signs in the shop. It was also related to the two way learning that was needed for the children to move ahead. The use of multi media that the children learned at school could be used to promote health messages as this was the way to move forward.

5 COMMUNITY FEED BACK

A return trip was made to Milingimbi 26-27 October 2009 to feed back the results of the study to the clinic, shire, school and community members. The community had responded to many of the concerns raised by the parents and following are initiatives that have been put in place.

Gunja/Kava//smoking/gambling

- Proposed controlled gambling and kava areas

Childcare

- Anglicare 3 hrs a day for 3 days a week *(MAF pilots wife)*
- Purpose built creche for 0-3year olds *(community midwifes to tap into for childcare and antenatal education)*
- Alpa store/clinic to be involved with preschool program and education for nutrition

Strong culture and support from family
- older men to tell stories to kids at school
- older ladies to tell stories to young women *(community midwives, strong women and Aboriginal community workers to be involved with education*)
- NT housing implementing lifestyle program

6 CONCLUSION

Smoking, gambling and alcohol were major issues raised for these two Top End communities and were identified as barriers to growing up children that are strong and healthy. Maintaining a strong culture and family relationships with culturally appropriate services and two-way learning appears to be crucial in engaging the communities to improve the health and welfare of their mothers, babies and children. These communities have identified key areas where changes could be made to service delivery of priority areas that are of greatest concern to them and their community.

This study has found that there was generally good public health knowledge among the people who were interviewed. This has also been found in other studies which have examined people's perceptions of health and the factors necessary for achieving good health in remote Indigenous communities.[2] However, what people say about health is not necessarily what they believe or do, and the reality may be much more complex.[2] Senior found that there were a range of barriers which affected people's abilities to put their public health knowledge into practice, ranging from the interactions with traditional beliefs of disease causation, the legacy of the Missionaries and the effect of this history on peoples desire to take responsibility for their own health through to a current distrust of health services. These sorts of barriers can only really be examined through a long term engagement with a particular community.

7 LESSONS FROM THE FIELD

7.1 Recruitment of research staff

The community workers recruited for the project were recommended by the community clinics and H4L coordinators. The position descriptions and role expectations were discussed with the community workers in Milingimbi over the phone before they attended the training workshop. This initial contact was considered important by the project coordinator in forming a relationship with the community workers. In Oenpelli, the opportunity did not arise to talk with the community workers before they attended the training workshop and so more time was spent developing a relationship with the workers in the community prior to conducting the interviews.

The community workers recruited in Milingimbi were a husband and wife team who were middle aged and well respected in the community. They both had senior positions in the community previously and were very literate in English. They were confident about the interviewing process and how it could be

managed in their community. In Oenpelli the community workers were much younger and required more time to build up a working relationship before they felt confident in assisting with the interviews. The younger workers were not confident in approaching key stakeholders or family groups if they were not closely related but were able to assist the Darwin based team to make the initial introductions to discuss the project.

At the initial planning stages for the project it was considered important to recruit male and female researchers so that the key stakeholders or family groups had the option of speaking with a gender specific person. This was used more often when interviewing key stakeholders as the gender specific interviewer was more likely to approach a same gender key stakeholder.

For the family group interviews, the families were happy to talk together as one group. At most of the family group interviews there was a male and female interviewer present so that questions and responses could be directed towards the person that the family groups felt most comfortable with.

7.2 Interest in the project

In Milingimbi there was more participation in the project and a greater willingness to sit down and discuss the concepts than what was experienced in Oenpelli. The senior positions of the community workers may well have played a critical role here. Also in Milingimbi, a lot more people sat outside of their homes and were more willing to engage in discussing the project than residents in Oenpelli. In Oenpelli people were more likely to remain inside their homes and door knocking was not as successful in engaging people as seeing people sitting outside of their houses.

Community interest and researcher/community relationships were vastly different in both communities. The senior Milingimbi couple were able to engage readily with the key stakeholders and family groups whereas the younger researchers did not have the confidence in approaching key stakeholders and family groups that were unrelated.

Longer time periods in Oenpelli would have been beneficial in developing stronger relationships with the young researchers and for improving community engagement.

7.3 Interviews conducted

In the majority of family interviews conducted there was only one spokesperson that spoke for the family group. However discussion in language occurred among family members as the questions were being asked.

7.4 Questions and responses

There were 4 four questions that were asked of the key stakeholders and the family groups. Each question included a series of prompt questions to ask if

either the interview needed direction or responses to the questions were proving difficult to acquire. Many of these prompt questions were overlooked by the interviewers or were not responded to in any depth from the participants. Engaging in interviews of this depth requires extensive training and experience that could not be provided in a one day training workshop.

Ideally it would have been more effective to have a least a month in each community to sit and talk with each family member and gain some respect and trust in the community.

8 REFERENCE LIST

1. Healthy for Life. Commonwealth of Australia, 2006. (Accessed 29 May 2009, 2009, at http://www.health.gov.au/internet/h4l/publishing.nsf/Content/home-1.)

2. Senior, K. A, 2003, 'A gudbala liaf? health and well being in a remote Aboriginal community: what are the problems and where lies responsibility? unpublished PhD thesis, Australian National University, Canberra.

9 ATTACHMENT A

Interview Form – Key Stakeholders

Date & Community of Interview (eg. Monday 23 August 2008 in Milingimbi)
_____

Person's Position (eg. Works at school, community elder, health worker)
_____

Approximate Age & Gender (eg. Female - late 20's **or** none of your business)
_____

Place of Interview (eg. Under a tree by the beach **or** at home on the verandah)
_____

Time of Day (eg. Early morning **or** lunchtime **or** late afternoon **or** night time)
_____

Type of Day (eg. Hot **or** raining **or** cool **or** just nice **or** sunny)
_____

Questions to Ask Key Members
Do you think that it would be OK for us to ask parents the following questions to find out what they believe is needed in their communities for children to grow up strong and healthy?

1. What are the good things that help kids grow strong and healthy?

- Health
- Family
- Education
- Employment
- Culture
- Sports and Activities
- Nutrition
- Economics
- Health Promotion

Add on more if the key members have some suggestions or comments:
_____
_____
_____
_____
_____

2. What does the community need to make sure mothers have a healthy pregnancy and baby?

- Strong Cultural Practices
- Healthy Food
- Employment prospects
- No Smoking / Gambling / Alcohol
- Support Services from clinic and council for domestic violence
- Child care centre
- Education Programs including antenatal classes, play groups,

Add on more if the key members have some suggestions or comments:

_____
_____
_____
_____
_____

3. What do family groups need to make sure mothers have a healthy pregnancy and baby?

- Strong Cultural Practices around the role of males and females in the family
- Healthy food choices from bush and the store
- Good budgeting skills
- No Smoking / Gambling / Alcohol and other drugs
- Support from family
- Clean house
- Clinic visits during pregnancy
- Support person for delivery of baby

Add on more if the key members have some suggestions or comments:

_____
_____
_____
_____

4. What makes it difficult to bring up kids that are strong and healthy?

- Lack of employment and money
- Poor food choices at the store
- Money going on grog and gambling
- Humbug for money on pay day

Add on more if the key members have some suggestions or comments:

_____
_____
_____
_____

Does the key member know of any families that we could approach to ask about whether they would agree to participate in the family interviews?

_____
_____
_____

THIS SECTION IS FOR YOU TO FILL OUT ABOUT THE PERSON YOU HAVE JUST INTERVIEWED

Person's Behaviour (eg. Very interested **or** found it boring **or** talked lots)

_____
_____
_____

Other Comments (eg. Lots of people in the community for ceremony)

_____
_____
_____
_____

10 ATTACHMENT B

Interview Form – Family Groups

Date & Community of Interview (eg. Monday 23 August 2008 in Milingimbi)
_____

Which camp do you live in? (eg. Bush camp, top camp, garden camp, etc)
_____

Approximate Age & Gender of participants and Role
(eg. 1 Female - late 20's mother, 2 males early 30's uncles, etc.)
_____
_____
_____
_____
_____
_____

Place of Interview (eg. Under a tree by the beach **or** at home on the verandah)
_____
_____
_____

Time of Day (eg. Early morning **or** lunchtime **or** late afternoon **or** night time)
_____
_____

Type of Day (eg. Hot **or** raining **or** cool **or** just nice **or** sunny)
_____
_____

Questions to Ask Family Groups

1. **What are the good things that help kids grow strong and healthy? If people are shy to speak up then you can use the following prompts to get them talking**

    - Health (What are your thoughts on health workers visiting the home when you have a new baby?)
    - Family (What do they do that makes kids grow strong and healthy?)
    - Education (What would you change about the education to make it better?)
    - Employment (What sort of jobs would you like to see made available?)
    - Culture (Who would be responsible for teaching culture and where would it be done?)

- Sports and Activities (What do you have now that could be changed or made better?)
- Nutrition (What type of nutrition and where would it come from?)
- Economics
- Health Promotion (who would be responsible for promoting health and how would it be done?)

2. What does the community need to make sure mothers have a healthy pregnancy and baby? If people are shy to speak up then you can use the following prompts to get them talking

- Strong Cultural Practices (who would be responsible for teaching and supporting the cultural practices?)
- Healthy Food (Who would teach and take people out to get bush tucker, what would Alpa do to make the food choices better?)
- Employment prospects (Who would take responsibility for making more jobs, what jobs would you like to see?
- No Smoking / Gambling / Alcohol (Who would do the education and how would this be enforced in the community?)
- Support Services from clinic and council for domestic violence (when should this occur? Should we ask the new mums questions about these issues or when they are pregnant?)
- Child care centre
- Education Programs including antenatal classes, play groups, (Who would run the education programs? Where should they be, in the resource centre, clinic?)

3. What do family groups need to make sure mothers have a healthy pregnancy and baby?

- Strong Cultural Practices around the role of males and females in the family (Who is responsible for doing this? Does it happen? Do the young ones listen?)
- Healthy food choices from bush and the store (Who teaches about healthy bush tucker? Should this be part of the shires role to teach people about bush tucker or should it be the family? Does it happen? What could the store do to change things and educate people?)
- Good budgeting skills (Who should teach this, school, shire? Would people attend?)
- No Smoking / Gambling / Alcohol and other drugs (Who would do the education and how would this be enforced in the community?)
- Support from family (What sort of support, financial, spiritual)
- Clean house
- Clinic visits during pregnancy (What should they talk about eg. Smoking, cooking, violence, alcohol and gunga)
- Support person for delivery of baby

4. **What makes it difficult to bring up kids that are strong and healthy?**

- Lack of employment and money (What could be done about this?)
- Poor food choices at the store (What could be done about this?)
- Money going on grog and gambling (What could be done about this?)
- Humbug for money on pay day (What could be done about this?)

THIS SECTION IS FOR YOU TO FILL OUT ABOUT THE PERSON YOU HAVE JUST INTERVIEWED

Person's Behaviour (eg. Very interested **or** found it boring **or** talked lots)

_____
_____
_____

Other Comments (eg. Lots of people in the community for ceremony)

_____
_____
_____
_____