

INTERVIEW: OTHER HEALTH CARE PROFESSIONALS

Date: 20 October 2004

Venue: Consultation rooms of therapist

Duration: 30 minutes

Interviewer = R

Participant = P

R Many stakeholders in different environments are involved in the evaluation or assessment of babies' development. The degree to which they focus on this development is inconsequential and it is the experience of therapists such as you, concerned with rehabilitation, that the diagnosis of handicaps and disabilities is made too late for effective intervention. What is your opinion and experience thereof?

P I think in the first place is that uhm that my feeling is that early intervention and early identification is an entirely new playing field and that we, there is so much new information thereof, so many things available, but most people uhm will say never mind, but you know what it is, the child is normal uhm a bit late in developing, wait until your child is three years old and this is actually a pity, because one can do all the therapy before he is three years old and that is too late as they turn three years and older. So, I think my feeling is that the information on what one can do in such an intervention is too limited. I do not think people always know what each type of therapist does and that one can work with children who are four weeks old, eight weeks old. Everybody always waits until children start talking before you can really do something uhm there is simply not enough information on everything concerning communication development.

R Have you had various such cases here in your own practice that you felt if only I could have had this child earlier, I could have done so much more for him?

P Yes, I think it is a regular a reasonably regular phenomenon it appears reasonably regular.

R That's it. What is, according to you, the responsibility of a nurse who works in a primary healthcare clinic regarding assessment of the development of babies? It is stated very widely, but if you can think how you would like to see her role with regard to the development, the assessment, the identification?

P I think it will be good if the nurse has a proper uhm almost a checklist, for the different developmental milestones. At this stage I feel as if the milestones are too wide. They look for example at uhm what a baby must be able to do at

three months and six months and eight months and 12, while weekly milestones occur within the first six months. The other thing is that most of the time one only looks at the motor development and chat about whether your child babbles and maybe you ask about the child's hearing, but there are no proper uhm questionnaires or checklists in use that looks at all these things such as parent-child bonding, parent-child interaction uhm communication development. Those things are left completely behind. There are also things that the parents do not always remember, because nobody ever asks them, but everyone asks when does your child begin to sit, when does your child start to walk and never ever are you about communication development.

R Do you think the nurse has the necessary knowledge and skills to identify early developmental handicaps and disabilities in babies uhm and if not, what do you think is the solution to put it right?

P I think in the first place people has too little information on which development milestones are important at which stage, and as I have said, I think the information that a person has is incomplete. I think that they are in a very good position to identify such children very early and that they have regular contact with the parents as result of inoculation uhm they rapidly build a relationship with mothers with young babies. So, the task with regard to this position is actually to pick up these children early.

R So, how do you think we can correct uhm this knowledge, information that is incomplete? What do you think we can do about it?

P I think one must look at what uhm nurses use to evaluate uhm in the first place there must be a proper instrument, there must be a good questionnaire or checklist for uhm more ages, I can say it must be complete. Even if it is a short questionnaire that parents complete, I know time is limited and one cannot expect that the nurse must have a whole diagnostic session on it, because well placed basic questions can give you enough information to say which referral is necessary and I also think that uhm training sessions to say exactly what each therapist type do to make the correct referral is very, very important because I feel that the information in that regard is not always sufficient; people do not ask what different disciplines do.

R In following up on your question or your answer regarding the measuring instrument: currently there is not a 'gold standard' as the saying goes, for assessment of babies uhm you referred just now to a checklist. Do you think this is the most effective way for the nurse in the clinic to assess the various areas of development?

- P My personal opinion is that a checklist will be a good thing because, in the first place the time aspect in a clinic is a big problem uhm because the nurse does not have in-depth knowledge of what the therapist is looking for regarding planning of the intervention. It is also necessary that one have basic information for referral, so I think a well-compiled checklist can address the problem of time. It is also something that can be given to parents in the form of an information brochure. Mothers can quietly think about it and it makes it more effective for me because to fire a lot of questions to parents and to get a rapid answer without giving the mother time to think about it, sometimes you are given wrong information, while if you can give it to the parents in the form of an information brochure and they can quietly read through it at their own time and maybe watch their baby for a while and then decide there are things that my baby is not doing quite right; discuss it with the nurse and then they can decide together to refer the child so that it is not just a question of diagnosis and treatment and not a participative decision making process.
- R How do you think they will it in the event where the parent does not have the necessary uhm development and education to, for example to read, to then take such an information pamphlet home to make her own?
- P I do not think it is so difficult to present behaviour that children should have uhm in picture form and uhm motor behaviour is of course easy and a mother, a person, can easily see whether a baby can adopt all these different positions, play in those positions uhm I think that the things with which children play and things such as parent-child interaction and bonding are things that one can represent to a certain extent by means of pictures, but it is also where the nurse's background information must be good enough to draw a fast conclusion to what the parent-child interaction and bonding is when they themselves are in the consulting rooms for inoculation. Even so it is a stressful situation, a good interaction occurs between a baby and a parent in such a uhm situation and it should give one good clues, again not to make a diagnosis and to treat, but only to decide a referral is necessary.
- R Uhm you have now also answered the next question.
- P Laughs.
- R It was about the opinion for giving practical guidelines for the nurse, so you have also answered that. Thank you very much. Eh intervention for shortfalls in development usually takes place outside the clinic and maybe liaison, interaction between the nurse and the therapist is inadequate. How important is this liaison, interaction for you in the continuing care of the high-risk baby?

- P I think it is of cardinal importance but I think it does not happen even for us who know that it must happen, it does not happen as well as it should uhm I think not always to the advantage of the patient. I think there should be much closer and much better cooperation between therapist doing the intervention and the nurse who uhm who does the tracing thereof. And I also think the more a person knows of each other's field, the more we can properly inform the parents uhm repeat information to parents because they hear one thing from one person and a next thing, but sometimes the information is half amiss and wrong, and one sometimes wonder what the parents had been told by other disciplines. I think if there is regular contact, shared training sessions uhm and shared uhm information inputs with one another, one may possibly have a good reference framework to again and again repeat information to parents uhm and to make cooperation and decision-making so much more effective.
- R Do you think it is really workable, because when you are in a busy practice and then also to focus on these shared information sessions, or do you think one should spare time for it?
- P I think practically it is very difficult because we all think about how much time you must spend and everyone has extra administrative work for which you cannot always ask a fee, so it makes it difficult, but I think we all have a responsibility towards the patient with whom we work and the responsibility makes that we actually make time for this type of information session, coming together to share information. The other important thing that I feel is a plus point for us, is that we all are exposed to CPD points, we can be acknowledged for it and we can organize small group activities and for one or other reason we simply do not do it because we can all find advantage in such a gathering, sharing information uhm by an organized uhm small group activity for the sake of CPD so, actually we all get something from it and uhm patients and our own professional uhm skills can definitely benefit from it.
- R Concerning the therapists in the provincial hospitals and in the clinics uh from my previous interviews it came out very strongly you know, that they do not even know who the therapist in the hospital is to whom they refer. The result is they get, they send a letter with the mother, make an appointment and then this person literally disappears from the horizon so they don't get feedback. So, it is not only in the private practice but also in the uhm provincial setup it also is a real problem. There they again say that it is the result of the patient load, work pressure, a staff shortage and all those types of things, but I think uhm at the end of the day when your concerns are patient care and

development, then we must really think about it. As result of a scarcity in trained therapists particularly in rural areas, the nurse is often the first contact with health care. In the literature it is referred to as role release and role extension with the therapist who then acts in a consultative capacity. What is your opinion concerning this? Do you think it can really contribute towards helping a little with these problems that have been identified with regard to interaction, early identification and early referral?

P I think it is something important if a person sits in the country and there is not enough knowledge and enough people, trained persons to do therapy and so on. So it is very important, I mean every bit of knowledge can help this patient so uhm it can be done successfully and everywhere in research it is told to a person that we must follow this trans-disciplinary approach and I think for our country it is our only option uhm the problem only is all our little professional selfishness I think (laughs) and we do not want to share because maybe we feel a bit threatened uhm but it is also because we do not have contact with one another, because we do not know each other's skills and we will never change it before we do not begin to share information and uhm to put this whole situation to the test and one can only test it and you can only iron out the problems if you have done it once. It does not help to sit with these negative thoughts every time and then to hope that something else is going to work because the ideal health model, as we all want it to work, is not a workable option. We cannot do it so uhm one must be prepared to limit oneself to those things perhaps circumscribed by your role. One must also know your limitations, it is also important and a person must learn to seek help, a person must learn to communicate with other disciplines without this professional jealousy, professional uhm (laughs) now I have stated it a bit strongly, but it is right, maybe one should not say it but that is really how I feel. One puts up walls and barriers that are not to the advantage of our patients or certainly not to the advantage of our own uhm own professional skills and uhm yes, and for us and for our country's health care it definitely is the best thing to do.

R Do you have any additional comments that you think will make a contribution?

P Can I tell you what I think of your clinic set-up? (laughs)

R You are most welcome.

P I am very grateful for uhm clinic personnel who are open to conversation, who are prepared to listen to what a person says and who uhm is prepared to give of their time to parents. Because some parents complain that they were strung like sausages good morning missus let us quickly do the immunization and

then you are out whilst it is actually very important for patients that someone spends 5 to 10 minutes with them, to chat a little with them and I think therein lies the key for the correct referral and the uhm showing the right way to patients for intervention and uhm and from my experience I really find that where one works together with people who are open as long as one is prepared to share information that one gets appreciation and good results from intervention, but where one also not always do your share to uhm make contact with other disciplines and in particular to make contact with the nurse, there are many things that fall through, so for me this is a passionate issue, that I must be able to work with something like that.

R Yes, no it is also very important for me that there must be cooperation and uhm if I think back to when I have done my M, I received this hiding by saying that you as a nurse is the problem why children arrive late at uhm early or at intervention or early diagnosis and action. You know, but I think there is two sides to an issue and can only tell you.

P It is very harsh to say something like that, because as a therapist I know that we do not make enough time and also not uhm take enough care to use you as nurse, to chat we don't even do that, actually expect and I think there even is an attitude in therapists that the nurse must contact in stead of the therapist seeking the nurse's knowledge for a change, the nurse contact, so yes, it again brings us back to the, our own (laughs) professional jealousy and things. This is for me, it is a very harsh thing to say, there definitely are two sides to an issue and I think, I think that therapists make life difficult for the nurse. We have not really talked to each other, the disciplines have never worked together, so it is an absolutely barren field that lies here and somewhere someone must start to scratch, begin to plough and plant and do something, so yes I think it is a bit harsh to say it is only the nurse's fault, it is not.

R But thank you very much for your time, I appreciate it. If I go now, assimilate it and realize that I still left out a few things, may I contact you telephonically just to get further information?

P You are most welcome.

R Thank you very much.

INTERVIEW: PARENT - CHILD WITH TYPICAL DEVELOPMENT

Interview date: 11 December 2004

Interview duration: 45 minutes

Venue: Interviewer's office

I = Interviewer

P = Participant

- I Tell me do you think every baby has the right to develop to his or her full potential?
- P Yes I think so because it's important for the baby to develop to its full potential and I think it gives him or her a chance
- R Uhm
- P So that maybe during because of the time it's much easier for the parents to see the development of a child
- I Uhm
- P So that they can recognize if there's anything wrong
- R Ok good. So uhm how do you think you as a parent can help your baby eh to reach this full potential? What can you do?
- P I think it's wise for every parent to read more meaningful material get some information anywhere
- I Uhm
- P from someone
- I Uhm
- P And make sure that he takes the child to the clinic for check-ups
- I Uhm
- P And identify if there's any problem
- I Uhm
- P Pertaining to the development of the child
- I Ok that's wonderful. Tell me uhm your knowledge about growth and development do you think it is sufficient?
- P I think it is sufficient for now because normally we take our kids to primary health care
- I Uhm
- P We normally take them for injections immunizations and it is then there that they can detect if there is any wrong with the child
- I Ok but, but with the knowledge that you have do you think you will be able to detect on your own that there is something wrong with your baby?

- P Some, some of the things you can detect on your own but others you can't.
- I Ok so you will need help and more knowledge to do so. Do you think it would be nice for the nurse at the clinic to to inform you more about your baby's growth and development?
- P I think it's wise because sometimes there are people even in rural areas were they can't get more information maybe they travel to clinics once a month or twice so if that person has got the knowledge then sometimes if she doesn't get the time she can see or identify some of the problems on her own and the maybe take some initiative to see what she can do about the problem.
- I Ok good. Uhm How do you think they could help to to elaborate on your knowledge?
- P I think by having workshops by work shopping the mothers' uhm making information available like having some kind of pamphlets
- I Uhm
- P Mostly for development of the child
- I Uhm
- P Then that people can get more information
- I Ok excellent uhm tell me the nurse at the clinic you attended with your baby has she ever given you any information on growth and development of the child?
- P She never said a thing so that I kept asking her about some of the questions like my child is having yellow eyes
- I Uhm
- P At birth and then I took her for some tests took her for some tests and then they said I should come back
- I Uhm
- P And when I went back they said she was fine so when I took him to the clinic I told them about that the
- I The eyes, ja (yes)
- P The eyes and he told me it was nothing he'll see during growth whether it was something serious
- I Ok but she never gave pamphlets on growth and development she never offered any information on eh you bring the baby for 6 weeks, 10 weeks, 14 weeks so for instance in the next month you can expect the following to happen with your baby's development and growth
- P Eh uh (no) the only thing
- I That type of information?

- P The only thing that she gave me was a pamphlet were they they talked about
uhm immunization because I took him for immunization so it was stated the
after effects what I should expect after the
- I The immunization
- P The immunization how I should treat the after effects
- I Ok so she never offered you any additional information on growth and
development. Ok so right The service at the clinic were you satisfied with that
service or were there times that you felt frustrated with regards to I expected
more, I expected more information things like that?
- P The service was ok, anyway the nurse was fine
- I Uhm
- P He, he made us, she made us feel at ease you know
- I Ok that is great
- P And and the child also she she she she tried to make him calm because
normally when you take the child for injection it start to cry and everything
- I Mmm mmm
- P So she was nice anyway
- I Ok that's good so so you felt at ease with, so uhm uhm Besides the clinical
competence of the nurse what other characteristics would you expect from a
nurse? How would you like her to treat you and your baby?
- P Mmm I think every nurse should should give you a chance to ask questions
- I Mmm
- P To say how you feel what you experience
- I Mmm
- P Then your actual needs your fears
- I Mmm
- P For the future about the child maybe you can tell her what you think could
happen when sometimes your child is sick and then you fear about the
sickness
- I Mmm
- P And give you some more information or maybe pamphlets what to date or
even if there are no pamphlets at least tell her where to get the information
- I Ok the environment of the clinic as such is that important to you that it should
be neat, warm and friendly and comfortable those type of things or doesn't
- P No no it should be like that because
- I Mmm
- P Normally the the small kids they have this thing some of them can even it's like
they can feel they are going for injections or whatever

- I Mmm
- P So that fear so I think if the environment is good then maybe that thing will just come out
- I They will be more relaxed
- P Relaxed
- I Ok so you want the nurse to be friendly towards you eh she must respect you as a person and eh your opinions
- P Yes
- I That type of thing
- P Ja (yes)
- I Friendliness, ok good. So you would say you had a nice relaxed uhm relationship with the nurse when you went for the baby's vaccination? Ok, right with your last visit to the clinic can you tell me from the minute you walked into the door till you left what happened in that time? Just briefly
- P Mmm we went there and then normally you make an appointment
- I Mmm
- P So there was somebody in the consulting rooms we had to wait for some few minutes
- I Mmm
- P And then she called us in
- I Mmm
- P We sat there she just talked to us while she was busy preparing the dosage for the kid and then
- I What did you talk about? Can you remember?
- P Eh she asked us about the baby's weight
- I Mmm
- P Because the other time we were there she told us the baby was eating too much
- I Mmm
- P It was so I told her we no longer give him too much food so ok she prepared the dose and then asked me to take off the clothes and she talked to the to the kid
- I Mmm
- P While she was preparing that thing you know
- I Mmm
- P The baby kept smiling, and it was giggling
- I Mmm
- P And she she brought cotton wool and I don't know

- I The wipes, ok ja (yes)
- P So she gave the baby the injection
- I Ok
- P And then
- I Eh
- P She rubbed the Vicks
- I Eh, ok tell me did she weigh the baby?
- P Yes she took the baby's weight
- I Ok did she measure the baby's height?
- P Uhm yes somewhere on the
- I On the couch
- P Yes on the couch
- I Ok can you remember whether she measured the head circumference?
- P Yes, there was a measuring tape where she measured the circumference and then the length yes
- I Ok so that was done. Did she explain in any way to you why she was doing that and what did it mean with regards to your baby?
- P The only thing she said was that at least the baby is growing. The height she no longer was the same the length
- I Ok she mentioned some things but she didn't explain why. Would you like that she explains to you so that you can understand better why she was measuring and weighing and things like that?
- P Ja (yes) I think it is important because I know with the the weight they normally weigh the child to see if there is any weight loss or weight gain during that period
- I Mmm
- P To see if the baby is over weight or not because if the baby is over weight then eh she might have the heart problem
- I Ok
- P So eh she told me is measuring the length to see if there is any change
- I Mmm
- P And and she also ok she tried to see if the baby can is able to balance
- I Mmm
- P On the floor and to see if there's any development
- I So she she did some examinations with regard to the development
- P Mmm

- I To see whether the baby is lying on on the stomach if he lifts his head up nicely and if there is any head lag when she pulls him up from lying on his back
- P And then there was he make the toy
- I So she dangled
- P She rattled it to see if there's are any ear conditions
- I Ok so you were satisfied with with the examination
- P Yes
- I Ok right eh so it's just basically that you would like her to explain more
- P Explain more
- I Why she was doing anything specifically say for instance the head circumference and did she explain to you on the on the eh baby's chart the height and weight chart
- P Ok this chart she showed me uhm the way that the that the baby's weight and then she told me if this line is going beyond this one it means the baby is over weight
- I Ok she took the chart and she explained to you
- P Yes
- I Ok that's nice
- P And I should now monitor the baby's weight
- I Ok
- P Not to give him too much milk or food so that at least the weight would go down because maybe he was having a problem of phlegm
- I Mmm
- P He would normally get flu every now and then
- I Mmm
- P The nose would be blocked
- I Mmm
- P So she told me to monitor the weight
- I Ok right excellent. So you were satisfied in total with what you experienced at the clinic?
- P Yes
- I There was nothing in your point of view that hampered the services?
- P No
- I Ok excellent, uhm right tell me did the nurse ask you whether you had any concerns personally concerns for your family any worries things like that?
- P No she never asked me any thing like that all she wanted to know was whether there was suitable care with my boyfriend

- I Mmm mmm
- P Were we having things together?
- I Mmm mmm
- P Were we doing things together?
- I So she tried to concentrate on your family right but you felt that she could have asked a little bit more regarding your concerns your worries fears things like that
- P I think it is important
- I Ok right uhm pertaining to to the visit did she only focus when she was examining the baby did she only focus on the baby or did she tried to incorporate you, the family, the extended family? Did she ask questions pertaining to the family how, what, where? She asked about your boyfriend that's nice, but did she ask about any other family members?
- P No the thing what she asked me if there was any one in the family with with TB or any other disease
- I Mmm
- P So in my case there was no one with that it's only my grandmother who is having high blood pressure
- I Ok she asked medical history about the family right uhm did she ask you at any stage if you have an informal support system to help you look after the baby?
- P No she didn't
- I Do you think that is important to know for a nurse to handle or manage you and your child pertaining to his or her development?
- P I think it is important because some of us have no knowledge at all
- I Uhm
- P So it is important for a nurse to coordinate to at least give some information try and find out if there is any kind of support that you are getting as a mother on home or rent or whatever and try and see what she can do to help
- I Because that support is important
- P It is important
- I Because if you are all on your own and there is no one to assist you that's that's difficult for a mother
- P Yes it is very difficult because normally you find out that some of the mothers are still young they don't even have a clue they don't know anything
- I Mmm
- P So at least if there is some one out there maybe a mother aunt or whoever it is easier

- I Mmm
- P It's easier to grow a child in that way than when you are just on your own and you don't get any support
- I Ja because when you are on your own problems might occur and you don't know how to handle it
- P How to handle it
- I Or how to cope with that
- P Especially with this young kids sometimes you just will be sleeping at night and then the child getting the fever and you don't even know how to handle the fever what are you supposed to do or maybe something can just happen and you don't know how to handle that at least if you have someone you can go to or maybe ask for advice
- I Ok excellent. Ja (yes) so and you do have people like that in your
- P Yes
- I That's great, that's great and it is important to make use of them because then they at least feel involved ja (yes). Tell me did the nurse at any stage tell you about sources in the community that you can make use of with regard to your child's development growth and things like that? How she assist you in
- P She never mentioned anything
- I Do you think you would like to know more about the resources that is available for instance to just make eh eh like your library tell you have you ever been to the library uhm there's lots of books that you can know maybe read about how a child is growing up there is things like uhm what we call kindermusik you know with music how to stimulate a baby's growth and development mothers and miracles so there are several things like that eh Do you think uhm you would like to know about things like that and then at least if you know there are things like that available you can make an informed choice whether I would like to take my child or not
- P Yes I think it is important to get information like I said sometimes it is not easy to go to the clinic or to nurse now and then every now and then but at least if you know there's information out there available you can just go and read or maybe buy a certain book because you know that the book is going to help it's gonna (going to) guide you on how to help the child grow and develop
- I Ok did you did you breastfeed your baby at any stage?
- P Yes
- I Did she refer you to any support group like eh eh a breast feeding support group where other mothers who are breast feeding come together and you you support each other and you get some one from outside to come and and give

you talks and more information, share your anxieties and fears and worries and things like that

P No she never mentioned anything like that

I Ok once again you would have liked to know about groups like that

P To know more

I Because a new mother as you've mentioned earlier, you know you don't know everything and that support

P And even if you are like a new mother sometimes maybe you had a child 10 years ago some of the things are out of your mind and you would like to know more maybe there are some new things you might like to know

I Mmm

P So at least if you come together as groups if you share your ideas your angers your fears what you've experienced during the process

I Do you think that such a support group would work in in your eh situation in your where you live in your community do you think young mothers would be interested in a support group like that?

P I think it might work it might work if if you as mothers are willing to do it

I Mmm mmm

P And you can you can you know discuss the the importance of such a support group

I Mmm mmm

P Maybe try to sit down and discuss your problems your fears what you experienced

I Mmm mmm

P Even if someone is not interested I think that person would feel maybe this would help why especially because maybe sometimes I've experienced this and this but I didn't know how to handle this so if somebody experienced the same problem that I had and managed to overcome hat problem then it might be easier if that person explains to me how she overcome the problem where she went you know who helped her

I Mmm mmm

P Or whatever it is what she did

I Ok no thank you that's interesting. Were you in any way involved in planning the interaction or was it the just the nurse as the so called expert and you sat on the other side of the table as the mother with the baby and she sort of told you what to do and she never allowed any discussion. How, how was that interaction, if I can use the word power, the power between you as a mother and the nurse. Was the power just with the nurse or was it a shared power

were you at any stage allowed to be part and parcel of the decisions and the intervention as such?

- P It it was some kind of discussion I asked her questions and she told me you should expect this and that during the development of your child
- I Mmm mmm
- P And I asked her questions that I felt that I needed clarity on
- I Mmm mmm
- P And then she explained everything to me
- I Ok but you never once felt that that she was the one who felt that she had the knowledge and you should listen to her and you should uhm do what she tells you and things like that?
- P No
- I Ok well that's great. Uhm do you think she regarded you as a person who is competent and able to look well after your baby?
- P I think she regarded me as a competent person because uhm normally the child goes for this immunization after some weeks I think if if there was anything she thought was wrong with the baby she would have explained to me maybe I am not doing this correctly maybe you should do it like this so she was pleased
- I Oh that's excellent
- P With how I was taking care of my baby
- I Ja (yes) that's great. Tell me do you think your contact with the nurse gave you entrance to more knowledge, more competence and skills and resources
- P In a way I might say so, because it is not each and every nurse who would make you feel at ease when you are with her, but I thought the one that I was interacting with was really helping
- I Ok, but regarding to information she could give more information
- P I think she could give more information
- I Ok and and and ways ways of empowering you with competencies, you think she could do a little bit more?
- P A little bit more
- I Ok and with regard to resources she never referred to resources in any way
- P No
- I So besides the fact that she made you feel at ease and it was a warm encouraging relationship she could do more with information competency building and and resources
- P Yes

- I Ok right. Do you think it would be nice for a nurse to come and visit you at home with your baby? How do you feel about home visits?
- P I think they are important at least in in making home visits the nurse is able to see how you interact with your baby how you relate to your baby
- I Mmm mmm
- P Maybe in that way she is able to monitor the progress because every time you go to the clinic you bring along your babies card and if there is anything she thinks you should improve on maybe relating to how you take care of your baby
- I Mmm
- P At least she knows uhm she has an idea how you relate your child
- I Ok and she can see the environment and
- P Where you live how you, the impact that it has on your child, where you have to improve, maybe you know the the the effects of the environment where you live in how it have can effect your child's development and growth
- I Ok do you think it is possible for nurses in the current eh scenario of rendering services for health care to do home visits? Not just the private clinics I'm talking about the government clinics and things like that. Do you think their work load allow them to do uhm home visits? Or is it a nice to have?
- P I don't think it allow them to do it they have too much to handle
- I Mmm mmm
- P And then the hours that they are working it's it's like they are working long hours so I don't think it's going to be easy for them to have home visits
- I Ok so one must be realistic about things like that it's a nice to have and it would be excellent for them to visit you at home
- P But the hours that they are working won't allow them to do that
- I Ok do you think in your mind that nurse or nurses working in a primary health care clinic have got the necessary knowledge and skills with regards specifically to the management of the development developmental needs of your baby?
- P No I don't think they really have the necessary knowledge and skills unless otherwise if they are neglecting some of the things because some of them really don't don't treat don't treat eh eh these mothers they don't handle them well and some times even after you give birth they they they they really won't how should I say. Sometimes you'll have a child and then they say you know when you gave birth they didn't remove all the phlegm from from the child then at least there are some skills lacking from the nurses
- I Mmm mmm

- P They should really get enough training on on on the child's development
- I Ok right can I ask you why did you choose to visit a private clinic and not your local clinic in in your township?
- P Uhm local clinics eh they there queues are normally long
- I Mmm mmm
- P And then if the queues are long somewhere along the way these nurses get tired and they don't really give the kids a thorough
- I Attention
- P Yes they don't give the kids thorough attention that's why I said I'll go to a private clinic because I know with the private clinic you have an appointment you know that at that period the nurse will be ready and she would really give your child all the attention and she'll go through it thoroughly
- I So there are a difference or differences eh regarding you between a private clinic and a government clinic?
- P Yes
- I Your first child did you take him to the government clinic?
- P Yes
- I So you have first hand experience of of of the services rendered there at the clinic ja so you can compare nicely now the private clinic with regards to the local government clinic
- P Yes
- I If you think back at the time when you attended the government clinic eh what barriers besides you mentioned long queues now what other barriers are there with regards to rendering a proper quality service to the client
- P Uhm we also had a problem of lack of resources
- I Mmm mmm
- P Sometimes you take a child there and then they find out a child is having a certain illness
- I Mmm
- P And if they check they don't have proper medicine for that type of illness so you just have to go home with that child and then it's it's really sad if it won't have money to take the child to a private doctor so you just have to stay home with that child having some kind of an illness
- I Mmm
- P Until such a stage that you can take him back to the clinic and then she can get eh proper medicine and sometimes there is a lack of staff
- I Mmm
- P Eh a shortage of staff in that maybe there will only be 2 nurses there

- I Mmm mmm
- P And there are a lot of people there waiting for those 2 nurses to take care of them so it's really not it's not good
- I Ok if you think back eh with the first baby when they examined your baby compared to the nurse you took your youngest baby to how do that weigh up with the visit at the private clinic?
- P You know what normally the nurses at the the government hospitals and clinics sometime they look at you they see if you got knowledge
- I Mmm
- P So they're able to undermine if they see this one doesn't know a thing I can just do this and tell them to take the baby home but if they realize that at least you've got some knowledge know how you should be treated you know what to expect from them it is then that they are able to give a child a thorough checking
- I Mmm mmm
- P So eh really it is not that easy why especially for those people who don't eh access to information you know it is not that good
- I Mmm mmm
- P But with people with knowledge who knows what they should expect
- I Mmm
- P At least they are trying to give what that person expect
- I Mmm Ok have you got any other comments you would like to add? That you feel could be important to me with regard to clinics the services the nurses anything regarding that?
- P I think they should improve their situations at clinics why especially government clinics you know the the the treatment that are giving people there some some nurses really are not giving people proper treatment so if they could improve on the the kind of treatment
- I Is that now the personal treatment relationship wise or
- P No relationship relationship
- I Or competencies or skills and knowledge how would you explain that?
- P Uhm some of them really lack uhm ex the skills the experience and I think when it comes to eh giving birth they didn't give uhm this student nurses the chance to when when coming to giving birth because really sometimes these people don't have the necessary skills they are still on training and I think that that the process of giving birth it's it's very dangerous there might be some complications so it's wise if it is handled by somebody who really knows what she is supposed to do

I Uhm that's a valid point, any thing else?

P No

I Then I would just like to say thank you for your time I really appreciate it

INTERVIEW: PARENT - CHILD WITH DEVELOPMENTAL DISABILITY

Interview date: 20 December 2004

Interview duration: 60 minutes

Interviewer = R

Participant = P

R In general do you think each baby has the right to develop to his full potential?

P Yes, yes definitely.

R Why do you think so?

P Uhm, I think everybody is capable to more and uhm in the end it counts against the child if he not uhm when he is an adult he is not going to to how can I in English have the skills and those things in other words he cannot live the life that he could have lived if his potential is not developed.

R Yes.

P And in the end it depends on the parents and and all the people that he encounters or to when he himself cannot decide whether he will do it, to do it for him.

R Yes.

P To take that decision on his behalf, yes.

R No well. How do you think can parents assist that their baby whether a normally developed baby or a baby with a handicap help to achieve this particular individual baby's potential?

P Uhm, I rather believe in things like uhm, uhm this Mothers and Miracles and music and so forth and I think at the end to spend time with children and to see uhm who looks after your child when you work and ah, there are people who for instance do not believe in routine examinations done by pediatricians and so uhm while I think it is important.

R No well.

P I think it is very important.

R Your knowledge regarding growth and development, do you think it is sufficient?

P Yes, no ah, I think so. I, uhm rather read a lot and I myself 'swot' education and even 'swot' psychology, so I have at least

R A good background with regard to that.

P Yes, yes.

R That your tertiary training supplied you with. So do you think you you will, the knowledge will assist you to identify problems?

- P Yes, well it has uhm it has helped me, me in my case, although uhm the moment when you are personally involved then
- R You are not objective.
- P It is but partly, I think it is partly a denial type of thing and uhm one, maybe it is because it is my fourth child, one becomes know, not so uptight with the first best little thing, you begin to think no what, everything comes with time and so on and uhm but yes, if it had not been that I uhm eventually insisted that I want to make sure whether there is a problem with my child, then I don't know by this time we should surely have found out, but uhm I, I have reasonably early thought there is something.
- R Something is not right for you.
- P Yes, yes.
- R Tell me do you think the average mother in the community, has the, has the right knowledge and background to be able to help eh with with early identification?
- P Uh eh no, no.
- R Do you think it is responsibility of the nurse in the clinic, one of her responsibilities to sharpen up this mother's eh knowledge with regard to the growth and development of babies?
- P Yes, yes very definitely.
- R Good uhm the clinic that you visit, has the nurse ever given you any know background knowledge or information regarding growth and development?
- P They have, they have yes.
- R The format of the content of this information was it very basic information, was it only in broad outline?
- P Yes very basic.
- R Very basic, so you think there could be a bit more in depth.
- P Yes, yes.
- R Information given?
- P Yes, yes.
- R Which, which domains, which areas of a baby, development have they touched?
- P To a great extent partly uhm motor development and so forth, but uhm but really also in broad outline things like sit and uhm taking things from the one hand to the other, there was never really looked in very fine detail.
- R So the other areas for example speech and language and, and mental development.
- P Yes.

- R All those types of things were touched nowhere.
- P Did not get much attention.
- R Good uhm at what age have you realized with with little baby that there or when have you started to feel there is, something is not right?
- P He began to sit at uhm six months, began to sit.
- R Uhm.
- P But uhm I (interrupt interview, children require attention).
- R You were busy telling.
- P Yes eh at six months he began to sit, but he wanted, he did not want to stay in a sitting position. He only sat for a few seconds and the he shoots himself backwards.
- R Mmm.
- P And when I, we have been away when he became six months on, on leave and my other children had chicken-pox, so I waited before I took him for his six month's immunization and then it was at seven. Actually it was for his six-month follow-up and not immunizations. Took him for his follow-up examination at the pediatrician and I said to him that it bothers me, because it is not that he falls topples over due to, to flaccidity. It is almost as if it is an act of will.
- R Mmm.
- P And uhm now that I have now done. So I have here uhm but it was the first uhm open. Wait, wait it is as if I want to speak in English.
- R Use English.
- P The first obvious.
- R Sign.
- P Awfully obvious sign that something is not right. When he, I mean by eight months still not wanted to, I cannot just put him down and leave him. He could sit, but I could not him at all, I could not put him down and just turn around, because the next moment he simply shoots backwards, no matter how much he his head hurts.
- R Mmm mmm.
- P In ten minutes he does it again and uhm now yes then unfortunately, I don't know whether I must tell the rest of the old sad story.
- R You can by all means.
- P Because you know, it had then, at eight months I then began taking him for occupational therapy and then unfortunately for three months took him to an occupational therapist, who never told me uhm listen here you must go to a

more specialized specialist I almost want to say not only an ordinary pediatrician.

R Yes, yes.

P And she has uhm really seems to me acted unprofessionally in the sense that she uhm only saw him once in three weeks and uhm just continued for three months. There had been no progress, but she has, she just carried on and on and uhm I have so after two and a half months then I said to her should I not maybe just take this child to a neurologist or someone. Must I not do something else.

R Further.

P Then she said well maybe I think about it .Uhm she then told me the name of a specialist in Pretoria, but in the same breath told me that he is very fully booked so I will ten to one wait at least three months before I can get in there and uhm he can be very obstreperous and and half blunt, but I must not pay attention to it and in the end a uhm friend of mine who wanted to know how this thing bothers my child not that something must be at fault, because I mean he now was almost eleven months at that stage and he could still not sit and uhm otherwise he seems cognitively it appears as though it is all right, but this obvious thing you see now golly it just is not right. And she then told me of another occupational therapist who does not have an uhm official practice, but who is a wonderful, wonderful occupational therapist and human being. We have literally begged the woman to please just look at our little one.

R Mmm.

P And when she the morning, it was a Wednesday morning, eight o'clock came here and nine o'clock she phoned me and told me that she is going to arrange an appointment for me that eh eh a in Potch, but then it was prof S... who was the locum in place of E... S...and eh actually he is an oncology pediatrician. But then she knew him and she arranged that he talk to the neurology pediatrician in in Bloemfontein and that same day we took him for a brain scan. So for this woman it was absolutely obvious that something must be at fault. That a person cannot just plod along. Well sure at the end he was diagnosed.

R Tell me uhm so he was more or less firstly diagnosed at eleven months?

P Firstly diagnosed.

R Tell me this nurse at the clinic have they to some degree suspected something with earlier investigations?

P Uh eh, no.

R Has there been anything visible with previous investigations according to you?

P Do you know what uhm except.

- R That he could not sit there must have been.
- P Other things you know the sit was the first uhm very obvious thing.
- R Mmm.
- P When A... now worked the first time with him, A... F... the wife of doctor
S... F... when she now the first time uhm worked with him she fixed my
attention on things that I have just oh I unfortunately I think it was a
coincidence of circumstances. I have four children and I was a teacher and I
was awfully busy and uhm then she now fixed my attention on other smaller
things like for example that he uhm not behind him or do not turn to the side to
take things.
- R Mmm.
- P He plays just in front of him, he takes things in front of him he does not turn to
the side and then it became clear that control of his trunk and things
completely uhm yes is off standard. It was definitely not what it should have
been and there are other things like muscle tone that she also for me uhm.
- R Pointed out. Showed that I, it is something that I not enough uhm have known
about and I have not uhm realized.
- R Do you think the nurses if they have the necessary knowledge and background
and skills could it perhaps earlier have been picked it up for you?
- P Yes.
- R Because look at birth an examination is done, plus minus at six weeks then
again at three months.
- P Three months and at six months.
- R And by only handling a child you must realize that he reacts or his reaction is
not right.
- P Yes.
- R And that pick-up you know the head remains behind and all those types of
things.
- P Yes, I rather feel, I really feel where someone must uhm.
- R Somewhere picked up something.
- P Somewhere damn.
- R Because you really came a very long way.
- P Look the very obvious things have here at six months where you now expected
a child must begin to sit now it begins to show uhm but it feels to me someone
who has more knowledge and when I eventually got him to H... D... the uhm
speech therapist then she showed me everything, the inside of his little
cheeks, his tongue, his lips everything's muscle tone is low. It's not it is

absolutely it is rather uhm reasonable I do not want to say now deadly serious, a layperson will look at him and not.

R And think nothing is at fault.

P Yes and think nothing is at fault with him, but uhm people who are trained are like she like A... with F... B... with doctor F... B... I have I have all the time taken him here to doctor V... brought him here uhm when I then took him for the first time uhm since he was diagnosed uhm to doctor B... because we struggled so with his reflux that I now also found out is ten to one as result of the muscle tone.

R Mmm.

P Uhm when I took him to doctor B... and I say uhm you know he has a very low muscle tone his first words were sure so I see and that is before he touched him examined anything to do with him just this child on my lap.

R Just his attitude.

P Yes just with it for him and I cannot understand that no-one else uhm maybe they saw it, but did not tell me.

R Many have a wait and see attitude you know.

P Yes.

R While we are involved with early childhood intervention only a question of we look and we rather refer.

P Yes, yes, yes.

R And manage when necessary, because the earlier you intervene the better are the outcomes.

P But that is what I now see with uhm S... if I now and I I everything must be applicable. What what C... has done for my child is actually, actually I should report her, because it is actually unbelievable that an occupational therapist did what she has done.

R Uhm.

P And this is a woman who is world-renowned, it is a woman with a very good reputation that deprived my child of three month's therapy, three months that my child could have progressed. Then I don't even speak of all the other people who have worked with him and saw uhm must must at least have seen the signs.

R Picked it up yes.

P She has now worked very intensively with him. My child could not sit, my child could not turn to the side, my child could not even pick up things alongside him. He did not when he fell, he did not try to stop himself with his hands.

R Uhm.

- P If he fell forwards, he did not try to stop with his hands. She has tried to teach my child to crawl. She had him on his hands and knees and tried to teach him to crawl while he could not even sit.
- R Uhm.
- P And uhm so yes we feel we have been uhm left in the lurch.
- R Mmm mmm.
- P Through and I have all my children, all four of my children for routine examinations, not to GPs, I took them to pediatricians. They have not been injected at the Klerksdorp clinic with their immunizations I have them uhm yes I have him here to B... and I do not want them, they were very nice, they have not rushed and gabbled.
- R Uhm.
- P They were very nice they have not rushed and gabbled and nobody, nobody realized it, not even someone like C... who who.
- R Neuro development.
- P Well only once very three weeks, but then for uhm half-an-hour to an hour worked very intensively with him. She told me that his muscle tone is low, but she has done things with my child that he should not have done for time to come. She deprived him of uhm well no good but in three months what I now take what he has accomplished in three months since A... has worked with him. A... saw him for an hour and immediately did something about it and uhm oh he progressed so much it's unbelievable. Uhm I could erect monuments for her, A... and H... D... I would have done it. These really are the most wonderful two women and you know they, they work together. They they absolutely talk weekly to each other concerning S... specifically eh and the one says what she sees and what she needs and the progress.
- R Wonderful approach.
- P Absolutely wonderful.
- R Sure it is.
- P I only have the greatest praise for them, but we uhm we really feel we were left in the lurch in general not only by the nurses by.
- R By various members of the health team.
- P Yes people who should.
- R It is a reasonable common occurrence.
- P Oh no it feels for me.
- R You are not the first and the only and that why I say that is about what the focus of my study is.
- P Yes.

R To see if we can sort out the problem, because uhm it seems as if it is anyhow not a priority in the South African health system.

P Not a priority.

R You know development of babies, they rather focus on on diseases and HIV.

P Yes.

R That at the end of the game can anyhow be carried forward to your child's development.

P Yes.

R They see development as as a healthy baby uhm clinic you know separate whereas I feel every handling where where you or contact that that you have development of a baby must be part of that visit.

P Yes.

R You must be impressed by absolute ah only a few little questions that you to the parents, because I feel that a mother's instinct is highly valuable.

P Yes, yes.

R You know, because a mother is not going to say listen here I think there is a problem with my child and then she is now just neurotic.

P Yes.

R She experiences that child on a daily basis.

P Eh, eh.

R And and that information that she has is very valuable.

P Valuable yes.

R And you must react to it this is simply my point of view you know.

P It is very bad for me as to how I for example uhm struggled that someone must actually do something about his about about the problem that we had with his reflux.

R Yes.

P I only want to know how it has impeded his development, because he permanently has heartburn. I mean any any adult with heartburn.

R He certainly has limited his movements.

P Yes he did not want to be manipulated on his stomach and and nobody around here was willing to for him eh oh Losec, because things like this uhm Ulsanic uhm has not done the trick and it often makes his milk, or his feed thicker in his stomach. But the moment that you press on his stomach it still comes out and it is still sour and uhm at the end it cost us to phone the uhm pediatrician in Bloemfontein so that he can phone somebody here and say but prescribe this and that for this child and since since he started using Losec

R He is a different child

- P Oh man, I wish I could for you... A will be able to testify how that child, A... and H... how he within a short period of time that his uhm uhm specifically his progress to get him to crawl.
- R Uhm
- P How it went forward only since he can can be manipulated on his stomach
- R Oh it's wonderful
- P Sure so
- R Tell me R... how have you initially felt when you realized but there is now this real problem with him and the he was diagnosed eh how did you feel about that news?
- P You know very, very upset and uhm angry. Angry with the people who never noticed it and uhm who worked with him and did not uhm fixed our attention on it. Uhm ah I don't know everything I don't want to sound as if I let everything go back to C... but to an extent we, we had very angry. Look doctor V... perhaps at a stage I should have gone back to him out of my own perhaps I should have done it. Ah and it does not help to blame yourself in the end and I have decided I will not do it I have done what certainly would have been expected from a standard person. I to Ok my child to a pediatrician and said to him it worries me that he has said to an occupational therapist and that I to Ok and not to any 'palooka' this is a woman with a very good reputation. Uhm so very, very upset and we were angry so we felt as if we. Uhm.
- R Had been wronged
- P Had been wronged, yes
- R Your child in particular.
- P Yes, yes.
- R Tell me has any form of support been given to you after you had been given this news
- P Except by A... mmm and no
- R It's damn not nice
- P (Laughs) No look it was oh no it was very bad uhm our family doctor felt extremely bad that he had not realized it.
- R Mmm.
- P Ah I know everybody have much well good let me say damn so he said he felt very bad that he had not picked it up although he had been a very healthy baby and uhm I had never with him specifically gone and sat there with him and said to him 'ma' please know let he now really examined him and but I arrived there with him in my arms with other children and he did not notice. He

felt very bad about it. Someone like C... had until today not even said golly sorry or...

R Mmm

P Uhm not anything

R What type of support do you think will be of value to you?

P You know information at that stage I cannot tell you uhm that it was what I thought the most traumatic story of everything was uhm the fact that so many people had something to do with him who said no man it cannot be major ah it cannot be something major ah no he's just slow or so. Uhm so it was a tremendous shock and since we had discovered what the problem is. Beginning with a radiologist who sat behind a table and peered at us over his glasses and told us no uhm his brain had or is busy to shrink there are some of his brain cells so as to say the sun shines in the day and the moon in the evening or night. Uhm hence it was you get this terrible shock and nobody can tell you well he had not explained uhm what atrophy is uhm he could not have given an idea what it could have caused it. He could not have given us an idea as since when I Ok not that I say it is his job, but beginning with him nobody could have given you information. Nobody knows you hear this terrible word uhm of this terrible thing that happened to your child and you do not have an idea of what it is all about. Is it going to continue, is it going to happen again, what has caused it, what does it mean? What oh no information was uhm A... was has has uhm has rather done for us at the end ah tried to explain what uhm the thing of atrophy now means. What it now and and she arranged for us for a pediatric neurologist to us ah a neurological pediatrician to uhm see us within two weeks in Bloemfontein and uhm arranged that we can phone him so that he can give us more information though not that he much over the phone but at least can give an idea what these things what these things that we have heard means and so on uhm/

R So it was a terrible shortcoming for you?

P Yes

R That there had never any information been given to you. Was there any form of emotional support?

P Ah well A...(laughs) A... and and just the family that's just yes yes.

R Good so tell me are there times that you still feel depressed or worried over you child's future?

P Do you know uhm ah at times then I am so I feel I feel so half sorry for him I feel this potential that he has had that half from him away. Wait let me first explain the whole story. It now seems at the end what it could have caused it is

that uhm doctor P... says according to my file with him is that I had uhm flu at weeks pregnancy. Now I am allergic to paracetamol so I could not drink Panado or so uhm for fever and.

R Uhm.

P So no and the neurologist says it is almost 100% sure that it that it what had caused it because he says I mean at that stage it is particularly the brain that develops and uhm apparently the temperature in the uterus is 2 degrees higher than the rest of your body so that when the mother's uhm temperature rises say to 40 39, 40 degrees it is very bad (children cry terribly) it is very bad news for for the those brain cells that and it but is only something uhm it is something that has happened what it is not something that has been there since the beginning ah ah uhm with development problem so it is just externally that it that it has been an influence yes. So sometimes but, I uhm I have really made up my mind not to sit on a heap and feel sorry for myself and for him. Uhm I have decided I will rather try to do for him.

R As much as you can.

P As much as I can possibly do yes.

R This is wonderful, tell me if you feel down, to whom do you turn for support?

P A... (laughs embarrassingly).

R It is wonderful to have someone like that.

P I do not know whether you know her.

R I do not know her, I think I should go and meet this woman.

P Oh it's the most wonderful, wonderful person.

R I know H... very well.

P Oh yes, and she's also

R I have never heard heard about the woman.

P And I will not actually uhm uhm leave out H... What now, what now for A... it is an unbelievable special person that you know uhm she is no longer working officially. But she also has an M in occupational therapy and she was a tutor in occupational therapy at Kovsies and she also has done that NDP the eh eh neuro development that course.

R Uhm

P And uhm yes unbelievable (terrible thunder and rain that suddenly started to fall). Now what eh eh makes it so special is that she now comes here on a Monday and a Wednesday morning and than we now had for him from the roof a hammock and balls and everything. She absolutely adapts to him if he does not feel well the day, even if she sits, sometimes she sits here from half-past seven to nine o'clock (son calls).

- R There he is it's so fantastic that she comes here to your house.
- P Yes and she really is an unbelievably special person. She loves him very, very much and she is very supportive so uhm.
- R It's wonderful.
- P and uhm doesn't ask a cent for the therapy that she gives him she does
- R She does it as an act of love
- P She does it absolutely as an act of love.
- R Ah it's fantastic. Tell me what type of strategies have you employed for yourself to be able to manage this situation?
- P Uhm well I stopped working, that I certainly feel bad about (very heavy thunder, disrupts interview to call in other children who are outside).
- R You say you have stopped working, yes.
- P Oh, I stopped working and this is the one thing that I feel bad about uhm, ah I was simply too busy to after him eh things like children's music and where I took all my other children, I was I simply did not have time and uhm then I felt bad about it, because it was extra stimulation that he could have received that he didn't have and that could perhaps have helped that he that his problem earlier uhm that his problem earlier by other people uhm
- R Was picked up.
- P Was picked up yes and since I now stopped working I see to it that he gets to music and Mothers and Miracles. Initially H... has seen him once every two weeks and then I asked A... to convince her to see him each week. Because she really does very, very good work and uhm she and A... complimented one another well uhm because she saw the importance of motor development for speech development that if he doesn't have control over his trunk if his tone and so on is not right his speech can and so on and then uhm I see to it that I in the mornings all his therapy and things classes (children interrupt again) do everything in the morning so that it does not unsettle the lives of the rest of the children, because the neurologist said to us that we must be very careful thereof, uhm because you give all your attention to him this lets the rest of your family derail completely.
- R Yes.
- P In due course leaves a completely dysfunctional
- R So you found a golden midway
- P Yes.
- R So when the children return from school then everything is finished (not quite clear, because baby's crying dominates voices)
- P Yes.

- R This is wonderful tell me uhm you spoke just now of of the information that is terrible shortcoming, what would you suggest regarding this information to improve this shortcoming in information?
- P Yes, well this is certainly now out of this type of thing is after all now the sort of information that a standard person needs so I do not believe. Do you know I would really things like a clinic and investigations or visits I think recommend say for instance at a monthly basis
- R Uhm
- P So that a person can enlarge the opportunities that it can be picked up and then automatic (end of tape last few words not recorded).
- R The service that the nurse at the clinic offered you were you satisfied with the service or has there anyhow been times that you felt frustrated that, that you have not found that that you were looking for with regard to their management.
- P Do you know I was really satisfied with them, they were very, very nice and relaxed and could chat and ask questions and so on, but the times that I was there, uhm because I can now, I can now not remember the specific times for immunization.
- R Six weeks, ten weeks, fourteen weeks.
- P Fourteen weeks.
- R And the again at nine months. At six months you go for a general examination.
- P Yes so by the time that I him at nine months. The early things I know here at fourteen weeks they have said that his neck must begin to be firm he begin to have better control but maybe (Baby sounds interrupt, cannot hear clearly)
- R So it had already been clear.
- P Yes, yes.
- R If they had referred you at that time to someone early intervention could have been applied
- P And at nine months it was that I have said to them never mind he is with an occupational therapist. She says
- R So and so.
- P All right yes
- R Tell me how will you describe the relationship with the nurse?
- P Uhm no very good uhm no yes on a and and so that I could ask questions and its not that I intimidated or
- R Or felt uncomfortable
- P Yes quite comfortable.
- R Apart from clinical competency what other qualities must a nurse working at a clinic have? What is important to you?

- P She must definitely have interpersonal skills and I think a nurse must be careful to be rigid when it comes to babies, because it also is so that not everyone begins to sit at exactly six months or so it does not help that they upset everyone for each little event. I would rather say, say to a person, say come back in a month's time that we can again see is it right, but interpersonal skills definitely. And they must also eh eh counseling uhm counseling uhm
- R Yes.
- P I should also think have skills to support one when you uhm find out something like that.
- R Do you think concern, consideration for you and your opinion
- P Yes, yes.
- R And your wishes that they should always treat you with respect
- P O very definitely yes, yes I
- R Do you want a warm, friendly environment?
- P Yes, yes definitely. No not a cold clinical, uhm sit in a row and uhm scold a little one who cries if he is injected that type of thing uhm not at all, not at all uhm patronizing.
- R Mmm
- P So if you for example give baby a bottle and she thinks breastfeeding
- R ? (Cannot hear what is being said).
- P Yes, that type of thing, because I have now accidentally, mercifully for him breastfed till nine month, but uhm I know I know that there is people that for example will say to pregnant women uhm they must breastfeed, because your child will be more intelligent if you breastfeed him. That type of thing I absolutely abhor. After four children of which I two, well one a year and nine months and two only breastfed for six weeks I can now with reasonable certainty. Well it can perhaps the nearness perhaps makes a difference if the bottle baby is put down there every time with a bottle, but it's surely you cannot as a rule say this child is going to be stupid and that type of thing I cannot go with it.
- R Your last visit to the clinic, can you briefly describe what happened during your visit?
- P When I was there last with him, it was for his MMR (measles, mumps and rubella)
- R Mmm
- P And uhm what then, then, then I now told her told the sister told at the very end with what he had been diagnosed and so on. She was very sympathetic and she uhm has then uhm well had a similar experience with her own child and

she has for me she could partly comfort me and eh eh and positively inspire and so she was very sympathetic and and has also uhm felt guilty that she herself has not earlier considered it seriously.

R With your previous visits what all have they done. Have they only focused on the immunization for example? What have they done when they examined him physically for example?

P They have well uhm for example in front of a mirror and held toys for him and so forth, but uhm if he did not respond to those things as how they perhaps expected him to respond the uhm accept that it is perhaps the strange situation and so on that makes him not to react as is expected.

R Good have they weighed him?

P Yes, yes, yes.

R And all those basic things had been done so uhm.

P Yes, yes.

R Has the nurses to some degree explained to you why she is doing what she is doing?

P Eh uh (indicates no)

R Do you think this is a shortcoming?

P Yes

R Are you eager to know why they do certain things with your child?

P I am eager to know yes. As far as immunization goes they have very, very well explained to me how the things have changed and uhm and so on and gave me pamphlets and information, but uhm I mean they always had at the pediatrician and at the clinic measured his the circumference of his head. When I now at a stage here at ten and a half months said to Christa I really feel we must get to another doctor or does she not think one must now do something I have also said to her what does she think it can be then she said well all that she can think it could perhaps be that he is busy developing a hydrocephalus uhm and then I did not know his head has always been

R Bigger.

P Bigger than they feel it should be is it about, is there something abnormal. Everybody always measure his head but nobody say

R Why they do it

P Why they measure it or say or tell me listen here no it's right or but then uhm a person sits and looks at his head, then you see now his forehead bulges a little here and then you also think just now it is maybe this, this and then now you don't have an idea.

R Then you have received information without it being really explained to you.

- P Yes, yes.
- R And this let loose a maze of emotions.
- P Yes, yes.
- R And what had been necessary oh my
- P And uhm I mean when we when she now for me now when I get home now I measure his head now I have a size, but now I don't have an idea
- R Why they measure the heads and wherefore is it measured?
- P Yes does that size means something too big certainly damn now not too small, because what is it now exactly.
- R Tell me has the nurse during your visits at any time enquired whether you experience concerns or stressful situations?
- P Eh uh no
- R And do you also see it as a shortcoming, because you want to see it is a place where I can go to share
- P Yes, yes
- R I feel open enough and be comfortable to be able to share, but she doesn't give you space to be able to do it.
- P Not space yes.
- R Yes well uhm during your visit has the nurse focused only on the baby or has she gathered any information with regard to your family your relatives, even the extended family as we are now talking?
- P No only that the
- R Only the baby.
- P Sure the first time you know the basic information how many children you have and how many pregnancies I have had and what type of births, but not a thing further, not again.
- R Has she in some way enquired whether you have informal support networks?
- P No, eh uh.
- R Because it is, it's important because I mean if you sit in this situation and you have this great need to, to, to that someone can keep an eye on him, must keep. Where do you go, what do you do?
- P Yes
- R Those type of things.
- P Yes, yes
- R So it is important that a person must look at the available resources that are available.
- P That is there.
- R What is available and encourages you to extend these resources

- P Extend
- R And to make use of them
- P And I think people are rather inclined to accept that because it is one's fourth child
- R You know
- P You go, but especially with a fourth child you are busier you have less time uhm and you have physically too little time to where with your first child you could have sat for hours and look at him how he plays you simply no more that you put the toys in front of him and you go on with whatever the hundred and ten things.
- R Yes.
- P That you must do
- R Yes and each baby is a unique being
- P Yes, yes, yes
- R Tell me has the nurse in any way referred you to because you spoke of mothers and miracles and child music, has she in any way referred you to something like that
- P No
- R To stimulate your child's development?
- P To stimulate no, no and I think it is very necessary, because when I well something like this mothers and miracles is unbelievable it really is and child music too.
- R Tell me were you in any way actively involved in the physical planning and decision-making regarding your child's continuous uhm intervention?
- P When A... uhm came into the picture, since she came into the picture uhm we became more involved since we realized what is wrong with him and since she came into the picture uhm we became much more involved. Yes uhm while he has been with C... was uhm we ourselves felt she should be the one who knows
- R The expert
- P Yes the expert so you accept absolutely uhm
- R That what is being said
- P That what she does that what she does and that what she says uhm
- R So there was never with you, you never sat with her around a table and the options for you were put on the table and all the proposals and has she
- P No.
- R Asked for inputs by other therapists, never?
- P No.

- R It is important for you
- P Very important, very important yes, yes.
- R Yes good
- P A... really goes out of her way to uhm she brought me a thing they speak that of a wall that is like eh eh ah he's now packed it looks like small bricks it's literally the wall like
- R Building blocks.
- P Building blocks that she has now explained to me. Before you can get to these bricks and first master these things be and uhm you must be able to master everything to get there that's why we work on this and work on that and that is why she cannot uhm teach him to crawl, because he must also this and that
- R He must first be taken back to find those building blocks before he
- P Before he yes, yes
- R It is important yes. Tell me uhm do you feel that the nurse in the clinic see you as a person who is competent to look after you baby?
- P Yes.
- R You never got that thought that feels, ah but shame
- P (laughs) No I think at this stage maybe but it now the maturity of age and or the wisdom of age and (laughs) and after four children that I will sort of not allow it anymore, because that is not how I have experienced in the past particularly with my eldest child uhm uhm but at this time I am not easily intimidated. Earlier on I very definitely accepted it like that, but
- R Do you think the nurse at the clinic does not yet have the, the, the realization of eh the power of a parent-nurse relationship still remains with me as a nurse. I am the expert and she must do as I say or is it a participative where where power and decision-making must be shared?
- P No I think there is unfortunately still uhm nurses who to a great extent fall back on their book knowledge and simply just say what the book says and so it must be and uhm
- R And not see the broader picture.
- P Not see no yes, yes
- R Tell me do you think the contact that you have had with the nurse has it given you entry to knowledge, skills and resources regarding your child's setup to can manage better?
- P Uhm eh no, no not from the nurse's side. I really have the, the one thing on which I received the most information from them, has been immunization further, further there had been not really
- R Sufficient information.

- P The first time they had given me some pamphlet I think it was only one folio with very, very basic uhm indications of
- R Of development
- P Of development, yet
- R And not even all the areas
- P Yes, sure, no.
- R Basically motor orientated
- P Yes, yes
- R Uhm do you think the nurse possesses the necessary knowledge and skills to be able to identify developmental handicaps and disabilities or to be able to realize but here is a problem let us rather refer to a knowledgeable person like an occupational therapist or a speech therapist
- P Uhm I am not sure. I almost do not think so and I have in the meanwhile since we have now found out about his thing become aware of the fact that there is terrible jealousy amongst the different uhm professions. That uhm occupational therapists look down on speech therapists that this group look down on those that they feel threatened by one another that they do not like that uhm
- R Cross reference
- P That there is cross reference and
- R And this is so absolutely important for your child
- P It is the most stupid thing for me it is the most stupid thing for me
- R And one actually wants a one-stop shopping experience.
- P Yes.
- R Because you just want to walk in and you will basically can eh currently in America they have. H... they have perhaps told you of the arena assessment where the occupational therapist, the speech therapist, the pediatrician the
- P Yes
- R Everybody, who is involved with your child, sits in a team setup
- P Yes
- R And and work with the child and they see what is going on and the you as parent is involved
- P Yes, yes
- R The whole situation, discuss his progress. The focus is on the strengths of the child and not only on the disabilities.
- P Not disabilities
- R For example focus together on it and the family is terrible involved

- P I would absolutely will give my all to have that and that to me is very, very sad I cannot understand do you know C... has for example basically I have now found out about uhm independent sources that C... apparently cannot stand H...uhm and that is apparently an absolute issue of she feels threatened by H... and she feels that H... interfere in her field. That H... interferes in the field of H... and that is, I now see how the things uhm overlap
- R It is interwoven and I mean if I do not have a little of your knowledge I cannot do identification to refer to you and you know
- P Yes and the thing is.
- R (baby cries loudly). But I must be able to see there is a problem
- P Yes
- R So that I can refer to that person
- P And it is for me and at the moment it is absolutely wonderful for me that Hanlie and A... can work together in such a manner
- R Can work together.
- P Work together. What is very interesting to me is I mean they are two two different people so each one has her own personality and each one has her way of of doing and sometimes they will
(Interrupt interview to give baby the servant)
- P What I wanted to say they complement each other, because S... would for example at a stage not in a side-sit he will definitely definitely not. The moment when they get him into a side-sit he yells blue murder and forces himself out of it and uhm it is also important for H... that he in a side-sit because he must it means his control of his torso is food which means his speech can progress so it is also important for her that he can be in a side-sit or comfortable is in a side-sit that he can stretch out his hand and so forth (talk to dog) and uhm when H... got the idea to him in a big basin to a big basin with sand play sand with play sand and him then first with one leg folded in and then later quietly the other one while he sits and plays he then stretches automatically
- R Then his attention has been diverted.
- P Yes so their personalities complement one another.
- R It's wonderful
- P And they work together, their personalities complement one another and it is clear for me that they work towards the same goal and that is to develop him. So and, and if, if a person can get it because A... now knows the neurologist personally uhm per and then also has worked with him for a long time she liaises anyhow with through the internet and she often speaks to him by

telephone but it would have been wonderful for me if if the doctor here and a nurse together sat with the two of them and talk and plan for uhm for the

R His future

P His future yes.

R How to manage it further ahead you know.

P Yes

R No this is extremely important. Tell me has the nurse ever visited you at home?

P No eh uh

R Not even when you have told them of of your your child's diagnosis?

P No, no

R Do you think it is a shortcoming?

P Yes

R Do you think it is necessary that the nurse pays home visits even if is only to hear how it is with you and S...?

P Do you know I think so. Something like that is wonderful I think that uhm even not only with children who have problems. I think a system where after one had a baby say those first three months after one had a baby. I think something like that will be wonderful and I think the moment they become involved with a child in that way then problems will, will

R More easier is identified.

P Definitely, definitely

R Do you have any other comments? Anything that you are willing to share with me that you think could be of value to my insight in, in a parent-nurse child with problems

P Uhm ah it seems to me at the very end only really as if when someone's heart is really in something that it is not only a job uhm it makes a big difference because since people absolutely work with S... and it is for them an issue of their hearts uhm my child develops and he progresses and he is just budding and for me it feels as if other people earlier on had such a passion his problem would have been picked up earlier and all that can with him and even though not all those brain cells can be replaced or you can't do anything that can make them grow he does not have such major damage to his brain that he uhm is lost that he is lost

R He is still going to can function.

P He has so MUCH potential, yes and uhm and this is and it feels to me uhm that potential there there all the time it feels to me there are eleven months in which we could have worked on it what we not what one has now not

done much about. If I now take since he had been for his first brain scan in May uhm they already can uhm the week before last when was it now when he has been for his second brain scan uhm they could uhm already see a difference on the brain scan that his white white matter had already increased

R Fantastic.

P And the small space between his skull and brain is already smaller uhm and this is a question of, you can really say six months and and I am not, apparently there are people that believe that you can now at two years make a forecast of where he would eventually end, but that I also do not want, because it is not for me

R It is day-to-day for you

P Well yes and

R You will build on that.

P Yes and immediately it is a limit to you if somebody tells you, but that is how far he will go in life then then they limit him

R Who are they anyway

P Even if they limit only my my eh eh uhm my thinking it already is a limit it is already a limit uhm and oh yes I want to go back to the story yes in in the very end a passion and love for what you do in the very end it makes a big difference

R Do you think the training of the nurse can also make a difference and or or additional courses that must specifically be introduced in particular for the nurse

P Oh yes

R Who works in the community?

P In the community

R That the focus is not only on immunization, but that should be directed at a wider area.

P Yes I definitely think so and I would rather say uhm that they must have a type of specialization that if a nurse wants to practice something like that if she wants to go into practice for a baby clinic or a clinic where she works uhm specifically with babies then they must specialize must they do extra courses in which they eh eh are sharpened up concerning development and all all the skills that a child must have and that they are then better equipped and are disposed towards more knowledge that they can share with the parent. I definitely think so. Yes I think uhm you know like a theatre sister specializes at the end and specializes like a maternity sister a sister must like that, because it

is not only about injections. That immunization is actually, it certainly is not a side-issue, but it is not the the uhm main

R Yes it is part of of protecting a child

P Yes, yes.

R That can handicap his development, but I mean.

P But it does not help a child never gets polio and he never gets diphtheria, but he is lost, he becomes four or five years old before he is diagnosed uhm the neurologist told us there are many children with similar type problem as my child who are only diagnosed at two or three years, because uhm the whole time it is wait and see, wait and see and and then a terribly tedious way that is followed before this child can eventually be properly diagnosed and by that time very precious time has been lost, because I mean a child's brain is at this stage you can uhm do much much more with him than what you can achieve when he is six or seven years old.

R No thank you very much (end of tape- appreciation expressed regarding participation and time).

ANNEXURE F

FIELD NOTES

Management

(Researcher included one example)

FIELD NOTES INTERVIEW 2

Participant: Head: Department of Health, City Council of Klerksdorp

Management Function: Head of Department

6 October 2004

Had an initial meeting with the participant to establish contact and to get consent from the council to conduct my research at Park Street clinic.

To establish contact with the clinic staff he arranged a meeting with the clinic nurses for me. Unfortunately this meeting did not take place due to an urgent union meeting.

Our meeting took place in his office (his office used to be at Park Street clinic, but due to problems with floor space he had to move to a building situated in another part of the city centre). I explained the purpose and possible benefits of the study to the participant and after reaffirming that participation is voluntary, I asked him to sign the informed consent. I also asked if he had any problems with the fact that the interview will be taped. The participant had no problems or questions and consent was signed.

I felt more in control of this interview although I had a problem with my notebook that kept going into “hibernation”. The environment was more conducive to a quality interview – quiet and no disturbances. The participant was relaxed and eager to participate, over eager I might add – he wanted to focus on his own agenda and concerns. Eye contact was maintained and the participant frequently used hand gestures to emphasize his replies. However, English is not the participant's first language and that could have stifled more comprehensive replies. Several times during the interview the participant used Afrikaans words to assist him to bring across his meaning.

After listening to the recorded version of the interview and verifying with my notes, I identified the following as important aspects:

- Agreed with statement that development of children is important, however he would rather focus on other aspects of care e.g. immunisation, due to work pleasure
- Know that there are policies but unsure about content “can’t quote them”
- Feel that it is easy for authorities to articulate policies, but not so easy for them to execute it due to time constraint when it comes to training off staff with regard to that policy. Feel that they do try to build consensus by making information available through the ranks. However, the maintenance of the policies is a problem – due to workload no one is currently checking to see if it is maintained
- See prevention and early detection as a responsibility of the community nurse as she has first contact with the mother and she can refer if there’s a problem
- Not sure how to define the scope of practice of the community nurse but he is “comfortable that the majority of them work within their scope of practice” Do detect a note of uncertainty about what the scope of practice really mean and how to apply it to the real work context - it should be all of them and not just the majority
- Very concerned about the stress, due to workload and type of work, that nurses are exposed to
- Resources – Moratorium on filling of posts since 1995 and province is currently filling the vacant posts not the city council. Province, however, contribute to the budget but has a policy “no nice to haves so it’s only the bare essentials that they are providing”
- Training - Grateful towards province as training of staff is funded by province
- Interagency collaboration - According to him there is good interagency collaboration, especially with hospitals and NGO’s. On management level there is also a good relationship
- Barriers – funds, workload, floor space (facility), shortage of personnel, absence of other health care professionals were identified
- In-service training – think it needs more attention
- Quality of care – do look at stats, get feedback from area and facility managers as well as from parents. Good hands-on relationship important. However, ratio of complaints very high – 80 %
- Development of infants not getting the necessary attention due to an aim that is more curative

My impression:

- Development of infants doesn’t get the necessary attention. Not high on his priority list due to own priorities and work pleasure – immunisation and HIV/AIDS
- Their aim is more curative than preventative and promotive

- Responsibility for rendering of services is not clear cut - council versus province and that could have a negative impact on services

Shortcomings of interview

- I tried to follow up on clues but am still unsure as to what will be guiding commentary
- Did not follow up sufficiently on clues to elicit further information
- Did not address what management is currently doing to support staff or to enhance their knowledge and skills

Follow-up interview will be arranged at a later stage.

ANNEXURE G
WORKING DOCUMENT: ANALYSIS OF DATA
&
FEEDBACK FROM INDEPENDENT ANALYSIS OF DATA

Initial draft

TABLE 3.1 SCHEMATIC EXPLANATION OF CATEGORIES AND SUB-CATEGORIES

MANAGEMENT	
Category	Sub-category
1 Framework for managers to support developmental care of infants by community nurses	<p>1.1 Clinical Governance</p> <ul style="list-style-type: none"> • Clinical supervision • Training • Spot checks and on-the-spot training <p>1.2 Support System</p> <ul style="list-style-type: none"> • Investment in staff • Empathy • Information and helping behaviour • Feedback and communication • Recognition and trust • Time • Referral for professional support <p>1.3 Interagency Collaboration</p> <ul style="list-style-type: none"> • Meetings • Referral systems • Knowledge about other health care professionals <p>1.4 Training and Development</p> <ul style="list-style-type: none"> • Orientation • Existing knowledge and skills of community nurses • Intellectual stimulation • In-service training • Formal training • Interdisciplinary training • Funds for training <p>1.5 Resources</p> <ul style="list-style-type: none"> • Budget/finances • Equipment • Personnel

	<p>1.6 Administrative tasks</p> <ul style="list-style-type: none"> • Reports • Statistics
<p>2 Developmental care of infants by community nurses</p>	<p>2.1 Human rights to develop to full potential</p> <ul style="list-style-type: none"> • Can't speak for themselves • Parent/community nurse responsibility • Burden on community <p>2.2 Focus on development of infants in clinic</p> <ul style="list-style-type: none"> • Manager's perception of degree of focus • Domains of development <p>2.3 Professional accountability with regard to scope of practice</p> <ul style="list-style-type: none"> • Manager's perception of scope of practice
<p>3 Barriers to developmental care of infants by community nurses</p>	<p>3.1 Lack of resources</p> <ul style="list-style-type: none"> • Funds • Personnel • Equipment <p>3.2 Knowledge and skills of community nurses</p> <p>3.3 Workload</p> <p>3.4 Referral system</p> <p>3.5 Physical environment – space</p> <p>3.6 Lack of guidelines</p>
<p>4 Government support with regard to developmental care of infants by community nurses</p>	<p>4.1 Policies and guidelines</p> <p>4.2 Identification of priorities</p> <p>4.3 Consensus building</p> <p>4.4 Management of change</p>
PERSONNEL CONCERNED WITH CPD	
<p>1 Training programmes</p>	<p>1.1 Reasons for training programmes/sessions</p>

	<ul style="list-style-type: none"> 1.2 Format of training 1.3 Content of programmes/sessions 1.4 Time-limit for programmes/sessions 1.5 Shortcomings 1.6 Resources for programmes/sessions 1.7 Focus on infant development 1.8 Interdisciplinary training 1.9 Knowledge of trainer 1.10 Evaluation of efficacy of programmes/sessions
2 Needs analysis	<ul style="list-style-type: none"> 2.1 Assessment of community nurses' needs 2.2 Format of assessment 2.3 How often are needs assessed
3 Knowledge, skills and competencies of the community nurse	<ul style="list-style-type: none"> 3.1 Sufficient knowledge 3.2 Perception of community nurse with regard to shortcomings in knowledge and skills 3.3 Evidence-based practice
4 Provincial support with regard to developmental care of infants by community nurses	<ul style="list-style-type: none"> 4.1 Existing policies, guidelines 4.2 Identification of priorities 4.3 Focus on infant development
5 Management of infant developmental needs by community nurses	<ul style="list-style-type: none"> 5.1 Infant development included in community nurses daily tasks 5.2 Consensus on management of infant developmental needs by community nurses 5.3 Guidelines on management of infant developmental needs 5.4 Gap between reality and the ideal with regard to infant developmental needs 5.5 Anticipatory guidance offered by community nurses

OTHER HEALTH CARE PROFESSIONALS	
<p>1 Late identification of developmental delays and disabilities by community nurses</p>	<p>1.1 Perceived reasons for late identification</p> <ul style="list-style-type: none"> • Insufficient knowledge and skills about infant developmental surveillance • Work load • Wait and see attitude • Parents bring children late for assessment due to insufficient knowledge on infant development • Impact of HIV <p>1.2 Regular phenomenon in practice</p> <p>1.3 Value of guidelines for community nurses</p> <p>1.4 Most effective way of assessment for community nurses</p> <ul style="list-style-type: none"> • Checklist • Physical assessment according to evaluation form
<p>2 Perception of the community nurse's knowledge and responsibility with regard to infant development</p>	<p>2.1 Insufficient knowledge</p> <p>2.2 Adaptation to changing roles in health care</p> <p>2.3 Focus on infant developmental delays during pre-service training</p> <p>2.4 Important responsibility</p> <ul style="list-style-type: none"> • First point of contact for health care • Relationship with parents • Anticipatory guidance
<p>3 Interaction between community nurses and other health care professionals</p>	<p>3.1 Insufficient interaction</p> <p>3.2 Professional jealousy</p> <p>3.3 Sharing of knowledge/CPD sessions</p> <p>3.4 Importance of communication/feedback</p>

	<ul style="list-style-type: none"> • Ensure continuity of therapy • Comprehension and knowledge about the role and function of other health care professionals
4 Interdisciplinary training	4.1 Attitude towards interdisciplinary training
COMMUNITY NURSES	
1 Developmental care of infants by community nurses	<p>1.1 Professional accountability of community nurses</p> <ul style="list-style-type: none"> • Scope of practice • Responsibility of community nurses <p>1.2 Human rights to develop to full potential</p> <p>1.3 Focus on prevention and early identification of developmental delays and disabilities</p> <ul style="list-style-type: none"> • Ideal setting for identification of developmental delays and disabilities • Late identification of developmental delays and disabilities • Identification of developmental needs of infants technique, domains/indicators, consensus among community nurses • Inclusion of family • Anticipatory guidance to optimize infant development <p>1.4 Policies and guidelines</p> <p>1.5 Cultural competence</p> <p>1.6 Documentation</p> <p>1.7 Support to parents</p> <p>1.8 Resources in the community</p>

	<p>1.9 Referral system</p> <p>1.10 Home visits</p> <p>1.11 Reflection on personal interaction style</p>
<p>2 Impact of existing infrastructure and possible barriers to developmental care of infants by community nurses</p>	<p>2.1 Infrastructure</p> <ul style="list-style-type: none"> • Resources • Environment • Telecommunication <p>2.2 Barriers</p> <ul style="list-style-type: none"> • Knowledge of nurses • Rendering of comprehensive service • Support by and communication with management • Telecommunication • Specific guidelines • Work load • Poor work performance of colleagues • Resources • Funds • Access to information e.g. pamphlets for clients/patients
<p>3 Management framework to support developmental care of infants by community nurses</p>	<p>3.1 Lack of understanding of needs</p> <p>3.2 Resources</p> <p>3.3 Training opportunities</p> <p>3.4 Lack of feedback</p> <p>3.5 Negative attitude</p> <p>3.6 Insufficient contact</p>
<p>4 Training and professional development of community nurses to support developmental care of infants</p>	<p>4.1 Pre-service training</p> <p>4.2 Orientation of new personnel</p> <p>4.3 Existing knowledge about developmental care</p> <p>4.4 In-service training</p>

	<p>4.5 Provincial training programme</p> <p>4.6 Interdisciplinary training</p>
FAMILIES: INFANTS WITH TYPICAL DEVELOPMENT	
<p>1 Perception of infant developmental care by community nurses</p>	<p>1.1 Identification of infant developmental needs</p> <ul style="list-style-type: none"> • Information obtained from parents and inclusion of family • Assessment of infant development • Identification of delay/disability <p>1.2 Provision of information on infant development by community nurse</p> <p>1.3 Provision of information on resources in the community</p> <p>1.4 Recognition of cultural traditions</p> <p>1.5 Satisfaction with services</p>
FAMILIES: INFANTS WITH DEVELOPMENTAL DELAYS/DISABILITIES	
<p>1 Perception of infant developmental care by community nurses</p>	<p>1.1 Identification of infant developmental needs</p> <ul style="list-style-type: none"> • Information obtained from parents and inclusion of family • Assessment of infant development • Identification of delay/disability <p>1.2 Provision of information on infant development by community nurse</p> <p>1.3 Support for families by community nurses</p> <p>1.4 Provision of information on resources in the community</p> <p>1.5 Recognition of cultural traditions</p> <p>1.6 Interaction of community nurses with other health care professionals</p> <p>1.7 Satisfaction with services</p>

Second draft:

Table 3.1 Categories, sub-categories and themes

Categories	Sub-categories	Themes
Support by management for developmental care of infants	<ul style="list-style-type: none"> • Clinical governance • Mentoring of staff • Resources and infrastructure • Interagency collaboration 	<ul style="list-style-type: none"> • Orientation of staff • Up-dated policies and guidelines • Recordkeeping • Clinical supervision • Training and development • Patient complaints • Acknowledgement of input and achievements • Investment in staff • Communication and feedback • Role expectations • Finances/funds • Adequate staffing • Adequate equipment • Appropriate facilities • Liaison and meetings
Developmental care of infants by community nurses	<ul style="list-style-type: none"> • Rights of the infant to develop to full potential • Focus on developmental needs 	<ul style="list-style-type: none"> • Infants can't speak for themselves • Aim of life to develop into independent adult • Burden on community • Parents' responsibility • Government priorities • Perception of management • Perception of other health care professionals • Perception of nurses • Elements of assessments

	<ul style="list-style-type: none"> • Professional accountability • Training and development • Family care • Parents' view and expectations of community nurses 	<ul style="list-style-type: none"> • Enhancing development • Barriers that nurses experience • Perception of scope of practice of the nurse • Knowledge, skills and competencies • Evidence-based practice • Ethical standards • Preservation of human dignity • Pre-service training • In-service training • Formal training programme • Continuous professional development • Relationship with parents • Addressing concerns of parents • Information on resources • Social and formal support • Recognition of cultural traditions and practices • Reflection on personal interaction style • Accessibility • Approachability/interpersonal skills • Knowledge and competence • Information and advice
<p>Management of the infant with delays and disabilities</p>	<ul style="list-style-type: none"> • Identification of delays and disabilities 	<ul style="list-style-type: none"> • Changes in health care • Anticipatory guidance • Intervention • Follow-up services

	<ul style="list-style-type: none">• Views on late identification of developmental delays and disabilities• Collaboration and co-operation with other health care professionals	<ul style="list-style-type: none">• Insufficient knowledge and skills of community nurse• Insufficient knowledge about typical infant development• Workload• Wait and see attitude• Impact of HIV and poverty• Logistics• Traditional healer• Referral and feedback• Interaction/communication with other health care professionals• Ensuring continuity of therapy• Interdisciplinary training and skills development
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Final draft

Table 3.1 Themes, categories and subcategories

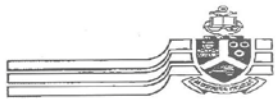
Themes	Categories	Subcategories
Support by management for developmental care of infants	<ul style="list-style-type: none"> • Health care governance • Organizational culture and climate • Resources and infrastructure • Interagency collaboration 	<ul style="list-style-type: none"> ▪ Policies and guidelines ▪ Induction of staff (orientation) ▪ Role expectations ▪ Documentation ▪ Professional performance management (supervision) ▪ Training ▪ Client feedback ▪ Acknowledgement of input and achievements ▪ Investment in staff ▪ Communication and feedback ▪ Finances/funds ▪ Adequate staffing ▪ Adequate equipment ▪ Appropriate facility ▪ Liaison and meetings
Developmental care of infants by community nurses	<ul style="list-style-type: none"> • Rights of the infant to develop to full potential • Focus on infant developmental needs 	<ul style="list-style-type: none"> ▪ Infants can't speak for themselves ▪ Aim of life to develop into independent adult ▪ Burden on community ▪ Parents' responsibility ▪ Government priorities ▪ Perception of management ▪ Perception of community nurses ▪ Perception of people involved in

	<ul style="list-style-type: none"> • Professional accountability • Personal professional development • Family care 	<p>training of nurses</p> <ul style="list-style-type: none"> ▪ Perception of other health care professionals ▪ Perception of parents ▪ Assessment of infant for developmental delays and disabilities ▪ Promoting development ▪ Barriers that nurses experience in infant developmental care ▪ Surveillance and home visiting ▪ Perception of scope of practice of the nurse ▪ Competence ▪ Evidence-based practice ▪ Ethical standards ▪ Preservation of human dignity ▪ Pre-service knowledge base ▪ Identification and acknowledgement of training needs ▪ In-service training ▪ Continuous professional development ▪ Formal training programme ▪ Focus on infant development ▪ Relationship with parents ▪ Addressing concerns of parents ▪ Information on resources ▪ Recognition of cultural traditions and practices ▪ Reflection on personal interaction style
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	<ul style="list-style-type: none"> • Parents' view and expectations of community nurses 	<ul style="list-style-type: none"> ▪ Perception of service delivery ▪ Accessibility ▪ Approachability/interpersonal skills ▪ Competence ▪ Information and advice ▪ Explanation of procedures
<p>Management of infants with developmental delays and disabilities</p>	<ul style="list-style-type: none"> • Identification of infant developmental delays and disabilities • Management of infant developmental delays and disabilities • Support to parents of infants with developmental delays and disabilities • Views on late identification of infant developmental delays and disabilities • Collaboration and co- 	<ul style="list-style-type: none"> ▪ Identification ▪ Intervention ▪ Anticipatory guidance ▪ Follow-up services ▪ Effects of developmental delays and disabilities on parents ▪ Social support ▪ Lack of focus on infant development by community nurse ▪ Changes in health care ▪ Workload ▪ Impact of HIV and poverty ▪ Logistics ▪ Traditional healer ▪ Insufficient knowledge about typical infant development ▪ Negligence/denial by parents ▪ Lengthy process of identification ▪ Wait and see attitude ▪ Referral and feedback

	operation with other health care professionals	<ul style="list-style-type: none">▪ Interaction/communication with other health care professionals▪ Ensuring continuity of therapy▪ Interdisciplinary training and skills development
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FWA Nr. 0000 2567
IRB Nr. 0000 2235



University of Pretoria
Faculty of Health Sciences Research Ethics Committee
University of Pretoria
Date: 20/11/2003

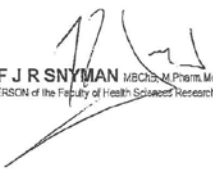
Soutpansberg Road
MRC-Building
Room 2 - 19

Private Bag x 385
Pretoria
0001

Number	: 278/2003
Title	: The management of developmental needs of infants by community health nurses
Investigator	: Prof N C van Wyk, Department of Nursing Science; University of Pretoria.
Sponsor	: None

This Protocol and Informed Consent have been considered by the Faculty of Health Sciences Research Ethics Committee, University of Pretoria on 19/11/2003 and found to be acceptable.

*Prof P Carstens	BLC LLB LLD (Pret) Faculty of Law
Prof S.V. Grey	(female) BSc (Hons); MSc; DSc; Deputy Dean
*Prof V.O.L. Karusseit	MBChB; MFGP (SA); M.Med (Chir); FCS (SA); Surgeon
Dr M E Kenoshi	MB,ChB; DTM & H (Wits); C.E.O. of the Pretoria Academic Hospital
Prof M Kruger	(female) MB.ChB.(Pret); Mmed.Paed.(Pret); PhD. (Leuven)
Dr N K Likibi	MB.BCh.; Med.Adviser (Gauteng Dept of Health)
*Miss B Mullins	(female) BscHons; Teachers Diploma;
Snr Sr J. Phaloli	(female) BCur (ELA) Senior Nursing-Sister
*Prof H.W. Pretorius	MBChB; M.Med (Psych) MD: Psychiatrist
Prof P. Rheeder	MBChB; M.Med (Int); LKI (SA); MSc (CLIN.EPI); Specialist Physician
Reverent P Richards	B.Th. (UNISA), M.Sc. (Applied Biology) (Knights), M.Sc (Med) (Wits), TechRMS, DipRMS
Dr L Schoeman	(female) Bpharm, BA Hons (Psy), PhD
Dr C F Slabber	BSc (Med) MB BCh, FCP (SA) Acting Head; Dept Medical Oncology
*Prof J.R. Snyman	MBChB, M.Pharm.Med: MD: Pharmacologist
*Dr R Sommers	(female) MBChB; M.Med (Int); MPhar.Med;
*Prof TJP Swart	BChD, MSc (Odont), MChD (Oral Path) Senior Specialist: Oral Pathology
*Dr S.J.C. v/d Walt	(female) D. Cur, MEd, Department of Nursing


PROF J R SNYMAN MBChB; M.Pharm.Med: MD: Pharmacologist
CHAIRPERSON of the Faculty of Health Sciences Research Ethics Committee - University of Pretoria

* = Members attended the meeting on 19/11/2003.

APPLICATION TO CONDUCT A STUDY

Faculty of Health Sciences Research Ethics Committee
University of Pretoria
Pretoria Academic Hospital
Tel: (012) 339 8612
Fax: (012) 339 8587
E Mail: manda@med.up.ac.za - Main Committee
E Mail: dbehan@med.up.ac.za - Student Committee

Sou'pansberg Road - MRC-Building - Level 2 - Room 19
Private Bag x 385 - Pretoria - 0001

GENERAL INFORMATION AND AGREEMENT BY APPLICANT

APPLICANT: Investigator - Ronéll Leech

DEPARTMENT OF NURSING SCIENCE, UNIVERSITY OF PRETORIA:

Telephone Number: (012) 354 2125 **Fax Number:** (012) 354 1490

E-Mail address: nursing@medic.up.ac.za

Postal address: PO BOX 687 Pretoria 0001

FULL TITLE OF STUDY:

The management of developmental needs of infants by community health nurses

OUTLINE DETAILS OF PREVIOUS STUDIES CONDUCTED IF ANY:

None

ARE ANY SPECIAL PRECAUTIONARY MEASURES TO BE TAKEN AND BY WHOM?

Over and above the agreement by the applicant, the applicant will ensure the following:

- Confidentiality of information
- Anonymity of participants
- No damage/harm to any property/staff of Klerksdorp Municipality

INDICATE EXPECTED DATE OF STUDY / EVALUATION REPORT:

DAY	MONTH	YEAR
	December	2004

INDICATE NUMBER OF CLIENTS INVOLVED:

SOURCE	ESTIMATION
RECORDS	? 50
STAFF	? 5
PARENTS	? 5 - 10
MANAGEMENT	? 4 - 5

THE NAME OF THE HEAD OF THE DEPARTMENT:

Professor NC van Wyk

WILL SUFFICIENT STUDY MATERIAL BE AVAILABLE?

Yes

INVESTIGATIONS (N/A)

AGREEMENT BY APPLICANT

The applicant agrees as follows:

- To conduct the study recorded in and under the conditions set out in this application form
- To conduct this study at no additional expense to the Klerksdorp Municipality whatsoever
- To exonerate the Klerksdorp Municipality from all liability of damages, legal, financial or otherwise
- To inform the Municipal Manager: Klerksdorp Municipality and other relevant authorities should it be deemed necessary to deviate from protocol or stop this study
- To make available without delay all the results of this study to the Municipal Manager: Klerksdorp Municipality
- I understand that the Municipal Manager: Klerksdorp Municipality having allowed this study to be conducted places himself or the Klerksdorp Municipality under no obligation whatsoever

THE APPLICANT MUST SIGN HERE:

APPLICANT- INVESTIGATOR			DATE		
Signature	Initial(s)	Surname	Day	Month	Year
<i>Leech</i>	R	LEECH	20	OCTOBER	2003

INITIAL CONSENT BY DEPARTMENTAL HEAD

I, Professor NC van Wyk, Head of Department of Nursing Science grant permission to submit an application to conduct a study to the Chairperson(s) of the relevant Ethics, Research and Therapeutic Committees of this Hospital.

The researcher conducting the study will be: Ronéll Leech

THE HEAD OF THE DEPARTMENT MUST SIGN HERE:

HEAD OF DEPARTMENT			DATE		
Signature	Initial(s)	Surname	Day	Month	Year
<i>Van Wyk</i>	NC	VAN WYK	20	OCTOBER	2003

THE APPLICANT MUST SIGN HERE:

RESEARCHER			DATE		
Signature	Initial(s)	Surname	Day	Month	Year
<i>Leech</i>	R	LEECH	20	OCTOBER	2003

THE APPLICANT THAT APPLY FOR THIS STUDY MUST SEE TO IT THAT THE MUNICIPAL MANAGER OF THE KLERKSDORP CITY COUNCIL WHERE THE STUDY WILL BE DONE – SIGN HERE BEFORE THE ETHICAL COMMITTEE RECEIVE THIS APPLICATION FORM

APPROVAL BY: MUNICIPAL MANAGER

I, TZ Mokhatla, Municipal Manager of Klerksdorp Municipality, hereby agree that this study be conducted in the Klerksdorp Community Health Centre, Park Street, Klerksdorp. The researcher conducting the study will be: Ronéll Leech

MUNICIPAL MANAGER			DATE		
Signature	Initials	Surname	Day	Month	Year
<i>TZ Mokhatla</i>	TZ	MOKHATLA	15	OCTOBER	2003



**REQUEST TO HAVE COUNCIL AS
PRIORITY INFORMATION CENTRE
IN OBTAINING Ph DEGREE IN
MANAGEMENT OF DEVELOPMENTAL
NEEDS OF INFANTS BY COMMUNITY
HEALTH NURSES**

PURPOSE OF REPORT

To inform Council that the Department of Health PHC has been elected to participate in a research project of a student obtaining her Ph degree in the management of developmental needs of infants by community health nurses.

BACKGROUND

Sr R Leech was in Councils service from 1984 to 1996 as Assistant Chief Community Health Nurse, more specifically training of PHC personnel and Management of Park Street Clinic.

She is busy doing her PhD in the management of developmental needs of infants by Community Health Nurses with the following in mind and will make use of clinic personnel politician and members of the community for information.

➤ To describe what the responsibility / function of the community health nurse is within her scope of practice, with regard to the management of developmental needs of infants at a primary health care level

- To determine the developmental and support needs of infants and their families
- To identify the issues / aspects of developmental care that a nurse can address within her scope of practice
- To determine what are the training needs of the community health nurse in the management of developmental needs
- To determine what support / infra structure is needed to enable the nurse in the practice to fulfil her responsibility.

GENERAL

- There will be no financial impact or time loss for Council or its employees
- Council will be indemnified against any losses and / or claims from Sr Leech
- Council will be prominently mentioned in the compiled document; which will be available for scrutinization.

RECOMMENDATION

That cognisance be taken of the PhD to be done by Sr R Leech on the management and developmental needs of infants by community health nurses and that information will be gathered from Council's clinics.