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Guidelines for contributors

AAIMHI aims to publish quarterly editions in March, June, September and December. Contributions to the newsletter are invited on any matter of interest to the members of AAIMHI.

Referenced works should follow the guidelines provided by the APA Publication Manual 4th Edition.

All submissions are sub-edited to newsletter standards.

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Experiences with Médecins Sans Frontières

Uganda: The Jewel in the Crown

Judy Coram

Médecins Sans Frontières is an independent humanitarian organisation committed to two objectives: providing medical assistance wherever needed, regardless of race, religion, politics or sex and raising awareness of the plight of the people they help.

The decision for me to leave the security of my job as a Maternal and Child Health Nurse in Melbourne and join Médecins Sans Frontières was not an easy one but one I have no regrets about. With the completion of the Masters in Infant Mental Health and my own children flying the nest to find their own way in the world, it was an opportune time for me to take on this new challenge. I feel very fortunate that this work has enabled me to have many enriching experiences and given me the opportunity to work with different cultural groups.

I have spent two years now working with Médecins Sans Frontières. My first mission, in 2007, was in Thailand with an HIV and tuberculosis (TB) project. This project was working in a TB clinic with the cross border Burmese and the second project was working with the Hmong refugees based in a detention camp from Laos. I was working here as a nurse and counsellor for 12 months and my work related to setting up children's activities including an early intervention group.

My third mission was from March 2008 until March 2009 in Uganda, working

with counsellors in an HIV program and setting up children's counselling for those with HIV. I was also able to work closely with the midwives in our prevention of mother-to-child transmission program (PMTCT). This program can reduce the risk of transmission of HIV from a mother to her child, with the use of antiretroviral drugs (ARV). My role also required me to travel into the rural areas of the West Nile region, providing support to counsellors in remote health centres.

Uganda is a landlocked country, situated on the equator just north of Lake Victoria in eastern central Africa. Its neighbouring countries are Kenya, Tanzania, Rwanda, Democratic Republic of Congo and Sudan. Uganda has a total area of approximately 236,000 square km. The current population is estimated at 30 million, of which more than half are below age 15. The average life expectancy at birth is estimated at 42 years. The annual population growth rate is about 3.1%. Approximately 85% of the population lives in rural areas, with the majority working in the agricultural sector at subsistence livelihoods dependent on seasonal rainfall. The industrialised sector remains poorly developed, particularly outside the capital Kampala.

HIV/AIDS

The World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) esti-

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mate that there are more than one million adults and children living with HIV/AIDS in Uganda. Since the epidemic was recognised in 1988, the prevalence rate among adults has decreased from 30% to 6% in 2004/2005. Uganda is one of the countries internationally recognised to have controlled the HIV/AIDS epidemic through its 'Abstinence, Be Faithful' condom strategy. However, the reality remains that 70% of Ugandans do not know their HIV status and the infection rate increased from 70,000 in 2004 to 135,000 in 2006. Approximately 220,000 individuals are estimated to clinically require antiretroviral therapy (ART). By 2007, 120,000 people had initiated the highly active anti-retroviral therapy (HAART).

The following diary entry is from the first week that I arrived in Arua and gives some indication of the work ahead.

The next day I went to the hospital to visit the AHAP HIV/AIDS clinic and was met by a sea of faces all waiting to see the doctor, counsellor or waiting for their drugs. There are the same faceless blank unanimated faces as I saw in Thailand. This is a busy clinic with over 7,000 enrolled and over 600 children. There is a small waiting area for the children with a few broken toys and the remnants of some drawing materials where the children are left to play on their own. The children just sit quietly with dejected faces in this area, not taking much notice of anything in particular. There is a peer support worker who supervises them but with little input or structure. There are no children's groups at present or adolescent groups. The children are difficult to engage and draw into conversation and appear to lack interest and curiosity and will sit for hours without moving or talking to anyone. When given pen and paper they will sit and copy letters by rote rather than try to express themselves by free drawings.

About half of the 600 children in the program were orphaned and many of

them had arrived at the clinic without caretakers. Initially it was very difficult to engage them and to work with them on many levels. Firstly of course the most obvious was not being able to communicate with them as most of them spoke Lubarra only, and many of the younger ones were terrified by my white *msungi* face! Trying to bring Western style 'therapy' into this setting was not always so helpful and initially it felt very overwhelming, trying to meet the needs of the hundreds of children attending the clinic often on their own. It is not unusual to have 8-year-olds arriving by themselves and managing their own treatment. Many of them were completely unaware of their positive HIV status and why they had to swallow tablets everyday. One 8-year-old boy, when I suggested to him that he may have lots of questions as to why he comes to the clinic, responded with "yes and they won't tell me!"

The biggest issue for most attending was the lack of secondary education as many of the children could not afford the school fees. There is a mentality here however that the *msungi* has everything and that we should always give to them. There is a sense of powerlessness about them that they have no way of changing their situation. With no government assistance and incredible poverty, just getting enough food for their survival is their overall driving force. This does not often leave them open to allow themselves other emotions and I always go back to Maslow's hierarchy of needs when I feel challenged by introducing relationship-based counselling and looking at their psychosocial needs. The greatest challenge in the counselling role for me personally was to place clear boundaries on the therapy when there is so much need for survival and no other referral agencies! The other is not having the support and supervision of other mental health practitioners in the field and although there is a supportive team the focus is more medically oriented.

The work in the nutrition ward was the

most challenging but rewarding during my time in the program. This was additional to my work but it was so clear that the majority of infants in the nutrition ward were requiring more than just frequent milk feeds. They all presented with being shut down, disassociated and severely depressed. Many of the caretakers had sacrificed this baby for the next one.

There is a lack of awareness of the psychological impact for the mothers and infants of weaning their babies from their breasts so abruptly at 6 months. The very act of breast feeding which is the fundamental drive of being able to keep their babies alive and nurtured is removed from them. This has far more overriding psychological consequences not only on their nutritional requirements but also on the mother/infant relationship. Many of the infants admitted in the nutrition ward were there in response to this, or for some other impairment in the relationship, most requiring an infant mental health intervention, not only adequate nutritional supplements.

The following two clinical interventions indicate some of the clinical work implemented in this program. Pseudonyms have been used. The accounts include feedback from Frances Salo Thomson.

Intervention 1

The power of a relation: an infant mental health clinician's approach to work with infants and children in a resource poor setting within an HIV program in Arua, Uganda

The sacrificial lamb: Fariha's experience of forced weaning and absent maternal presence

On entering the nutrition ward for malnourished infants and children in Arua in the HIV Program in Uganda my eyes were drawn to a tiny baby lying motionlessly, between sheets pulled tightly on a large bed. There was a frantic look about this baby's eyes, which were

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darting in all directions but not looking at anyone, totally disconnected from all around her. She was clenching and wringing her hands together almost in a desperate way but she just lay there oblivious to her mother's absence and to others present around her. She appeared to want to 'push away' any attempts to touch or stroke her. I learnt that she weighed 6kg and was 7 months old and had been forcibly weaned at 4 months old when her HIV positive mother became pregnant again. She had been admitted into the nutrition program with severe malnutrition and oedema. As she lay on the bed I talked to her about how sad she must have been about her experience of being forced so prematurely from her mother's breast with no available substitute milk as the family was very poor. She was being given 3-hourly supplementary feeds but there was something in her frantic, sad eyes which made me think that her poor malnourished state was more than just lack of milk. Before I left that day she caught my eye and blinked at me. Despite the nutritional supplements she continues to lose weight.

The following day I felt compelled to visit Fariha again and found her mother Bernice sitting on the bed in a bright red dress and headscarf. Fariha was lying against her mother like a new born baby intermittently weeping and crying sadly. I asked her mother about the experience for both of them at the time of weaning. When I suggested that it must have been a sad time for them both, Bernice laughed and seemed unable to think about what the experience had been like for Fariha. I observed that Fariha was unable to tolerate her mother's laughter and cried each time she laughed. It was as if she was starving from the lack of her mother's understanding and attunement to her feelings of sadness and unavailability now that she was going to be displaced. However following this Bernice was able to acknowledge that they were both sad at this time when

she had to stop feeding her and she cried a lot and she did not know what to feed her. Bernice then brought out a photo of a baby but I could not recognize her as Fariha. She was strong and sitting up and happily smiling. I could sense Bernice's sadness and grief for her strong healthy baby. I showed Fariha the picture of herself and talked to her about when she felt nourished and safe with her mother. I was amazed at how long Fariha stared at her photo following this, and it also surprised her mother.

Fariha and I then began a series of communications through blinking which lasted for several minutes. I felt that the blinking was some sort of acknowledgement from her that I understood how sad she felt that she was slowly starving to death. I felt it was important for them both to have a photo of this moment and took a photo of them both, ready to return the next day.

On beginning to leave Fariha and Bernice I noticed a bed next to Fariha's which had a sheet draped over it and on lifting back the sheet I expected to find a dead baby. There I found the saddest sick little baby called Johnny dying of HIV all alone, gasping for breath. I felt what an injustice that this little baby has to die hidden under a sheet with no-one next to him. He was very weak but when I put my finger into his hand he squeezed my finger. I was sorry that I was not able to stay with him any longer and I hope that someone was with him at the end. How different his future would have been if he had been born into a different country and different circumstances. On a personal note I am still trying to come to terms with some of the tragedies of living in Africa for some of the 2.7 million children affected by HIV/AIDS.

Visit one to Fariha

Fariha was again lying motionless by herself in her big bed so vacant and absent staring with glassy eyes into nowhere. She appears to have given up any hope of living or finding some-

one who cares for her. I don't think I can find the energy for this intervention and it feels like it is too late for her. I stayed with her as she lay on her side staring into nothing and began talking to her. Occasionally she wrings her hands in dismay but mainly she is just absent from everything, constantly staring into nothingness. She suddenly turned into my face and blinked at me. I have never seen such sadness and dismay in a baby before and it is difficult to observe the pain she is in. I feel so unable to continue with this as the mother has reported to the midwife that she does not think about her now but only about the next baby growing inside of her. I feel she has become a sacrificial lamb to this mother who is looking to the next stronger baby. She is now 5kg and slowly starving to death in front of our eyes despite the nutritional feeds given every 3 hours.

There is an overwhelming suffering here in this hospital and it is not easy to walk through the filthy, understaffed wards where you are met with a sea of misery and death. A young woman from the Congo whom I had counselled yesterday and who had looked so toxic, had died that evening. Everyone is struggling to keep up with this inhumanity and suffering. The National staff appear to be oblivious to what is happening around them or maybe they have just become sensitized to it. I am worried that this may happen to me as well. Johnny had died that morning by himself.

Visit two to Fariha

On the next day's visit to Fariha I was expecting her to be lying alone in her bed but was surprised to see her sitting on the knee of the mother in the next bed and sucking on a mango. Her mother was sitting opposite her on the bed and she was pleased to report that she had put on half a kilogram. It was a surprise to see the first weight gain for a week. There was a different look to Fariha today and she stared long and hard at me and no longer seemed so

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far away. I commented to Bernice how alike they looked except for the large smile that her mother wore. When I left them I did not have the same overwhelming feelings of hopelessness and dismay I felt the day before. Was Fariha given the opportunity to put some of her feelings onto me I wondered today? I do not always understand this work and how it works but even though her weight gain could be explained by her loss of oedema, her change in affect and expression cannot be. I felt perhaps she had decided to live today! I hope I am right.

Response from Frances Salo Thomson

It is heartbreaking stuff to read about - the effect of actually doing the work and being surrounded with so much pain and suffering is almost unimaginable. I think it's understandable one would feel like giving up, not only the patients but also the staff, again and again and again, and perhaps sometimes the staff do cut themselves off as the best way they have of managing and presumably some also burn out before they actually leave the service.

While Fariha would be helped physically if her oedema got better there is no way that alone would give her the will to live if she hadn't felt it was worth it - that she mattered to someone, that someone had had a meaningful connection with her - infants still die even if physically there is nothing wrong with them if they have no reason to live - as Spitz found in institutions in the 40s.

I think this child felt you realised both messages in her eyes - the franticness that she felt she was dying because there was nothing connecting her to her mother, and her sadness at the lost love between them.

You were direct, going straight to what you intuitively know is the heart of the matter - the sadness about the weaning (not the physiological side)

- and you are persistent which says to them both that you haven't given up even though they somewhere know that you, too, like them, feel like doing that and in response the mother responds to you by finding the photo - it reminds me of the case of Brigid Jordan's in 'Free to be playful' paper with a very worrying baby where after an intervention by Brigid the mother finds the teddy bear in her bag.

I think, in response to your wondering if Fariha put her feelings onto you, that she knew that you knew that - which always sustains people, giving them hope - you'd also joined up her and her mother (you join with and you join up) and you communicated to the child in her language (blinking) which suddenly made the world much more intelligible - think of the power of imitation - babies can do it from birth to 'join with' the other and also to get a response from them - and Meltzoff talks about imitation as a two-way bridge that bears traffic from birth and also helps build the sense of self. So you gave the child back a sense of self - even if she does die, she will not have felt so frantic because she will have felt accompanied.

Visit to Fariha

It is two weeks since I last wrote about little Fariha and there have been some difficult visits in between; one day walking in to the ward and finding her still losing weight, skin and bone with a huge cannula in her scalp. Several times she was there by herself without her mother as she teetered between life and death. Another day I went to the ward and her bed was empty and I was certain she must have given up the will to live. I was very relieved that she had only changed beds.

Today's visit was unimaginably amazing as I observed this little girl and her mother together. Something has happened to Fariha: as she began to play with me, she turned and looked me

right in the eyes and managed the tiniest little smile! The session began with Bernice coming from outside into the ward but this time having brought Fariha with her. As she lay nestled into her mother I sat talking with them both on the bed and began to touch her toes and play 'this little piggy with her' When we had finished she pushed her foot toward me asking for another turn. This then led to 'round and round the garden' on her hand very slowly. She then reached out and lay her hand on mine and began to play with my ring and bracelet. I was reminded of Anne Morgan's work with the use of her bracelet. At this point I began to talk to Bernice about the change in Fariha and even if she was not putting weight on there was something very different in her today which Bernice was able to see. We talked then about Fariha's earlier absence and her loss of the will to live which led to Bernice acknowledging the same. As she talked about this tears welled into her eyes and I felt it was truly a giant step for them both. Fariha then started to pat the case history in my hand, making a noise and I imitated this action which went on for several minutes. All this time I felt a connection with her I have never felt before. She then reached out to my face and grasped my nose squeezing it gently and at 8 months this was the first sign of any sense of agency I had observed with Fariha since starting to work with her.

I have to say that this was the most powerful experience for me as I believe that Fariha rejoined the world and found a place in it today. Her life and death struggle has been a difficult journey to take, often leaving me feeling lost and hopeless with no energy to work with her. There were days I felt I could not go and see her in the ward and I felt frustrated at her mother's lack of physical and emotional presence. I think today it was also a very important step for her mother as the new baby growing inside her was not there to re-

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place Fariha as the stronger child, but more to join with them. I hope I am right!

Response from Frances Salo Thomson

I think the fact that you kept persisting by visiting even when things looked horrific and worst of all when the empty bed made you feel she'd given up, and you were looking at a dead person's space, gave both mother and child hope which must be the most potent therapeutic factor there is.

I wondered with what affect she patted the case file which she may have known represented her? — whether there was something warm and positive and excited, whether it was like a transitional object, whether she was patting something into life?

At any rate, it clearly functioned as a transitional type gesture as soon after she joined up with you, exploring your nose, which is what a five to eight month old baby does in differentiating self from object and which this infant was never able to do with her own mother.

I think these children really do know that you think about them – “I think about you.”



Fariha and her mother

Intervention 2

Mournful, solitary William – moving from the lost child, absent and forgotten to William's Fan Club

William first came to my attention when the Children's Activity worker mentioned to me about a little boy who had been dropped off by Joan, one of the PMTCT midwives to the group. She reported that William was a neighbour of hers and she was concerned about him as he just sat by himself all day without moving or speaking. After one day in the group, Paul, the man who worked with the children also reported that he was concerned about this little boy who just sat and stared with no attempt to engage or play. He sat silently and solitarily for the whole time he was in the group. The next day Joan dropped William off again and when I first met him I observed the same sad vacant hopeless expression seen on the faces of so many African orphans. I sat next to William during the group, starting slowly to touch him, saying his name, talking to him quietly about how sad he looked. He sat frozen in his solitude with these wide, scared, hopeless eyes. He made no attempt to reach out or move from his position. I then gently lifted him between my legs where he sat quietly while I stroked him and continued to talk to him.

After the group I went to ask the midwife about his history and he compliantly allowed me to carry him in my arms and he felt limp in my arms, with no protest. Joan reported that his mother had died last year from HIV and that his uncle had picked him up from his village as there was no-one else to care for him. His uncle worked at the hospital and was responsible for his care but it appeared he had little time for him. It was thought that William was about 2-3 years old but no-one knew much about him other than he was HIV positive and under medical care at the AHAP clinic. I suggested to the midwife that she leave him at the group each morning.

The next day William was not at the group and Joan reported that she had gone to the house he was living at and was told by the young maid caring for him that he had no clean clothes to wear. As he was living in the hospital grounds we decided we would do a home visit. There were many children outside playing but no William. There was a young girl who was looking after him but he was alone and sitting inside the house. The house was dark and damp and there was mess everywhere. William had the same blank expression on his face and he had a strong odour from being unwashed and uncared for as we carried him from his home to the children's *tukul* area.

William sat next to me during the group time, again not interacting or being part of the group, in his own cocoon of silence, blankly staring at nothing or no-one. We began to talk about the parts of the body to the children as many of them have a very poor image of their 'sick' bodies and most of them in this group do not know why they come to the hospital and take drugs everyday. We began to name the head [*drɪ*] eyes [*mile*] ears [*sɪ*] mouth [*tile*] nose [*omvu*] hands [*wɪ*] shoulders [*opidrɪ*] and feet [*pə*] and toes [*pə anzɪ*]. After this we all sang 'heads and shoulders knees and toes, knees and toes' with the actions, and continued with 'this little piggy went to market' in the group and wiggling all their toes around the group. They then got into twos and tried to do the actions with each other. I was so preoccupied with all the other children in the group that I completely forgot about William at this point. The next thing William, who was sitting next to me, thrusts his foot out at me as if to say, "where's my 'this little piggy'?" I was surprised by this sudden initiation by William.

A few days later I went into the group and found William relaxed and stretched out between Paul's legs like a young baby being nursed. I felt that here in the group with Paul he was re-

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ceiving the closeness and contact he was so desperate for since the death of his mother.

I was not sure how to proceed with William over the loss of his mother but I felt that this little boy would not be able to move forward unless this painful part of his life was spoken about and acknowledged.

It has always been a challenge for me in this setting to be able to work therapeutically with the children because of the problems in communication and my inability to speak Lubarra. I have tried to use gesture and sign language and drawing as a way to communicate with them but I am often met with blank stony stares. It is often difficult using the staff as they are unable to bear the pain of the children and as soon as they cry they want it to stop, saying that it is upsetting them. They find it hard to understand that this is important for the child to move forward and they often become intrusive during the therapy.

I sat next to William with the mother [*miandri*] doll with the baby [*obekua*] on the back and asked him to hold her. I began to show him the baby on the back saying the mother's name and began to remove the baby tied onto the mother's back in the traditional way. I placed the baby away from the mother and said 'William, baby sad, baby alone [*odekua adule*] no *miandri* and began to talk to William, saying "*miandri* gone, William sad." At this point he began squirming and began talking for the first time, some words which unfortunately I could not understand. He held the doll to him tightly. The difference for me working therapeutically here in this setting is there is not the time to work at the child's pace it seems, because of the overwhelming numbers of disturbed children and the number of motherless children. It seems too rushed at times to go directly to the core of the problem without enabling them to do this themselves through their play, however it seems to be the only way for me to manage in this setting. Maybe



however I am responding to my own urgency and feelings of being overwhelmed at times.

Over the next few days William continued to attend the group seeking close contact either with Paul or myself. One morning Paul rang me to say that William's uncle was sending him back to his village today as he was unable to care for him. It was arranged that we would all meet together with William's uncle to discuss his future as there was great concern over this decision. William was in need of starting ARV treatment as his physical condition was deteriorating but the clinicians were reluctant to start treatment until a reliable caretaker was identified. William's village was a long way away from the hospital and there was no family member there to care for him.

Uncle Bart, a 43-year-old bachelor, worked in the hospital in the physiotherapy department and also cared for his dead sister's three children. He was the first born of 12 children and as such was responsible for the family. He had sustained head injuries in an accident 13 years before, which it was reported affected his behaviour at times. He related that his sister Nita had moved away from the village and family to follow some business and had become

involved with William's father who was reported to be a drunkard and who had shown no interest in William since the death of his mother. He was finding it difficult to care for William and had employed a maid to mind him; the first one he dismissed as she was beating him frequently. The current young maid was doing her best but did not know how to care for William. Uncle Bart spoke about a young girl whom he knew from William's father's village, and who was minding children there. It was decided to visit the father's village which was situated within the Arua municipality.

On this day William was limp and unwell and had a fever, and was refusing food. I offered him a drink but he directed me to put it down and then put his arms up to be lifted up. He then lay limply against me, lying very quietly in my arms. I wondered if this little boy was telling me that this is what he was needing, a pair of arms to comfort him since the death of his mother.

It was decided we would make a home visit to the village of William's father (pictured above) although he had had no contact with him since his birth. We were accompanied on this visit by James who was a nephew of Uncle Bart. He was a young man who worked

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in the palliative care unit inside PMTCT and he had taken a great interest in William. There were no attachment behaviours observed between Bart and William but William appeared to look to James more and he was more responsive to him.

When we arrived at the village we were met by hundreds of children who clamoured around the car. This was a poor area in Arua with many social problems. The customary chairs were placed under the mango tree and we were immediately surrounded by the whole village. I suggested we went inside the hut for some privacy and entered the dark hut. At first there was only the caretaker present as the grandfather had seen the car coming and disappeared. The father David was a teacher in Yumbe, a sub county about 3 hours from Arua town. We began to discuss about our concerns for William's health and future and slowly more and more men trickled into the house including an older uncle. The discussion went between clans and tribes and it appeared there had been several attempts by Bart to involve David in William's care, none of which had come to any fruition. Most of the important decisions are made in Uganda in this way by the village male elders meeting together. It is not seen that women have a place in these meetings and they are generally too busy with all the chores. The women are responsible for all the cooking, collecting water, cleaning, cultivating in the West Nile Region. Women have a very hard life here while it seems that the men sit round making all the decisions.

We made it clear that we were not there to force the family to take on the responsibility of William, more that we could clarify what the family wanted for William. After some time and much debate the uncle suddenly replied that we could leave him there with the caretaker. It felt like we were talking about a sack of potatoes. As she had four other children including a child with an

intellectual disability, I felt concerned that she would not be able to manage to give William the care he needed. However she was clearly sensitive to his needs and responsive towards him. I suggested that no decision be made about William today and that we try to discuss with David and the grandfather first. James then suddenly announced that if there was no-one else that he would like to take care and be responsible for William!

When talking with James later he told me that he was married and that his wife was working in Kampala. When I suggested that perhaps he should first discuss this decision with his wife, he looked at me aghast, saying that she had no say in it and that she will find out when she returns from Kampala.

There was another very strange twist to this story as it became known that James and David were very old friends and knew each other very well but were unaware of the connection to William

Response from Frances Salo Thomson

It was difficult at first to know how to say anything because it is such a sad story and I understand why the effect of working with so many children like him eventually can affect the worker so that they feel exhausted, drained and probably despairing. Then as I started rereading it, I was reminded of Linda Richter's video of very simple interventions, like the ones you describe, which turned around some children in an incredibly short space of time and then I wanted to get the message about the need for this work over to others who need to hear it: that these children are mourning and desolate and deprived in unimaginable ways in that they have lost the warm, loving touch of someone to whom they were meaningful, they are losing memories, they are losing a sense of themselves as lovable and meaningful and valuable and they are losing their voice because they know that people

around them cannot bear their sadness. So, even if you work faster at times, I guess that you still do it sensitively because of all that you know and have been through, that this resonance carries over into what the child hears and makes of what you offer, so it does not come over as an assault to the child but as someone urgently trying to find him or her in the way that their primary caregiver would have tried to have done. And they begin to feel meaningful and valued again, they feel that someone can bear the pain - after all, you wade straight into the pain and say in effect to the child, 'I can bear it, I can meet you there and share it with you'. At some level that is probably not quite conscious, the child probably knows that you are so respectful that you are saying a silent apology to the child for working so fast - I guess it's like what one has to do on the battlefield - that there may not be time for the refinements of a full anaesthetic and that it's actually better to get on and do something quickly that may save a life rather than wait and act more as a bystander.

Anyway, the proof is in the pudding — William meets you in an attuned way — you have given him back enough life that he can robustly claim you when he says 'Where's my piggy?' Then he is able to make the move to James; there may also be a way in which you also convey that the child can use you to nurse himself back to life, like a breast, but you are not needing him to attach to you to act out a rescue fantasy, that you are doing it in order to give him enough feeding in order to pass him back to his people - and I would think that something of the fact that you make such an effort to reattach him to his family by doing the home visit and sitting through all that you have to sit through to get a satisfactory conclusion, probably helps kindle some-

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thing in people's minds so that they can reach out to reclaim this abandoned orphan/waif.

I am not sure that it is so crucial that the children don't know your language, although I can see how frustrating it could be not knowing theirs - because I think the language of affects is universal and when you talk to the child about how sad he is, he knows that you are sad in yourself and for him, and I think he feels he has 'come home'.

You may be, as you say, responding to your own urgency and feelings of being overwhelmed at times but your talking to William about his dead mother actually released his language, i.e. you got something more symbolic going, something that enabled the trauma to start being very slightly addressed on the edges of it. I still feel that not to take the opportunity when there is even a tiny opportunity, when everything wells up inside you and tells you so that you know that this is what has to be done and said, then not to listen to that and act on it is to dishonour the child. Because otherwise you would leave him to a silent abyss where nobody can reach him, nobody wants to reach him, and from which there is rapidly no turning back. I suspect the child may know that it is a Band-Aid intervention on your part because neither of you have the luxury of a Rolls-Royce intervention but it is life-saving enough - these children intuit something of their living in an emotional war zone in an emotional desert, and you offering them a drink of water from an oasis gets them through the desert because you are able to say, 'If I can't accompany you the rest of the journey, maybe you can now look for someone who can'.

William's regression and feeding re-enactment

Reports had been coming in that there were many improvements in William both in the group and at home. It was reported that he was talking more and

had even said 'I want to go to Nursery group.' When I visited the group today Paul was very preoccupied with the older children, reading them a story about germs and their white blood cells. William was sitting alone and looking desolate, and as I talked to him from across the room he looked across at me and almost willed me to go and sit next to him. I sat down next to him talking to him that I had heard that he was now talking more to everyone and that he liked coming into the group with Paul. The next thing he lay across me in a feeding position with his head towards my breast. It was some time before I realized that he was re-enacting the feeding position with me and he even began playing with my necklace with his hand raised as seen with suckling behaviours. I was not sure how to progress with William but I feel that he is using me as a surrogate mother even though I have little contact with him; perhaps he recognizes that I can provide this for him at the moment. He is seeking close contact from Paul and others but I was surprised by his behaviour today as he seems to regress in my presence.

Response from Frances Salo Thomson

I think this intervention is okay as it's clearly initiated by William and in any case there are so many limitations and boundaries on you being able to do anything more; there's no risk that he'll be flooded or tantalised by something he can't really have. I have also thought, if you look at the two earlier photographs of you, that in a way he was already doing it (lying at the breast) although you may have felt it was more you holding him tight rather than him lying himself across your breast as a baby - and perhaps in his re-creating some moments to achieve shared comfort at this time he is bringing his own infant-led meaning to it and also getting nurture and succour. I wondered whether your cuddling reminded him more of his mother

than the cuddling he gets from the male uncles or from the young girl looking after him because there's something about your motherliness that transcends culture and words and speaks to him nonverbally.

It has taken me some time to be able to come back and complete William's story. Following my last intervention William commenced his ARV Treatment under the care of James. That week he was 'adopted' by some of the counsellors and spent much time with them and seemed to be happy with any pair of arms he could receive. He also began to protest if this was removed from him preferring to have one on one contact.

After some discussion James arranged for an 'aunty' to come and provide care for him. Sadly William's condition deteriorated and he was admitted into hospital. He spent a few days fighting for his life and in that time he had many visitors. When Paul visited him he sat on his bed and lay between his legs as he had done in the *tukul*. There were many people who cared about him and visited him in hospital and it was like William's fan club.

After his death there was much sadness from everyone who was involved with William including myself. It seemed so unfair for this little boy to find his place in the world only to be taken away from it. However when James spoke to me following his death he thanked me for allowing him to have the time and communication with William that he had. I wondered about encouraging people here to become close and care about one another as there was much distress from everybody. However I have been with too many African babies dying alone in this setting and I was reassured that William had died while surrounded by people who cared for him.

Response from Frances Salo Thomson

I guess the only consolation one can

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Experiences with Médecins Sans Frontières (cont.)

have is that as he was dying he would know that he was loved and not alone which I am sure would comfort him, unlike as you say, those infants who die alone either physically or emotionally.

It has been a rewarding but often challenging experience working in Arua in an HIV program, with many frustrations and feelings of being 'stuck'. It was necessary for me to reflect often on my expectations on the staff and in their ability to work in a different way. There have been many changes implemented in the program in terms of counselling and the staff are now beginning to see the value of moving away from task oriented sessions to a more relationship-based counselling and being responsible for their own patients. This is enabling them to have more autonomy in their practice and to know their patients better which identifies any barriers to adherence early in the treatment. The implementation of a youth group for children with HIV aged 10 years to 18 years has put disclosure on the agenda and has enabled the children to be free to talk about their disease.

More recently, I have been asked by MSF to put in a proposal for an infant mental health intervention in the nutrition ward.

Acknowledgments

My sincere thanks to Frances Salo Thomson for being a lifeline for me when I was feeling overwhelmed and helping me to keep my feet firmly on the ground.

My thanks also to MSF for enabling me to have these enriching opportunities. This article has been an account of my personal experience and not official MSF activity.



William's 'fan club' following his death in hospital. Surrounded by many that cared for him however briefly

The phenomena of early crying and colic

Presented by Dr Ronald Barr for the Centre for Community Child Health at the Royal Children's Hospital Melbourne, 2 March 2009

This report by Pam Linke

Dr Barr presented findings from his many years of research into infant crying and colic across cultures. From this research he poses an argument that early infant crying is not only "normal" but adaptive, with "colic" crying at the high end of the range and little crying at the low end of the range, just as there is a spread of normal infant weight or height. He defined colic as age dependent, unpredictable and unsoothable crying, peaking at about eight weeks of age. He believes that the common assumption that there is something wrong or out of step with colic is not correct and may be damaging in that it gives parents a message that they should be able to do something to prevent it. Dr Barr's research across different Western cultures and a hunter-gatherer culture showed that all of the cultures have the same early crying pattern no matter what style of parenting is used. The only culture where there was less early crying was among the Kung San hunter-gatherers who carry their babies all the time and have a very short response time to crying. Even with these people the same patterns of crying occur although not for as long.

Dr Barr believes that with our early guidance to parents we give a message that parents should be able to work out the cause of the crying and find ways that would prevent the crying or calm the baby. He presented some data that showed parents are unable to distinguish what an infant cry means without external information such as the length of time after a feed. He believes that the assumption that parents can learn the cues that will always help them to know why their baby is crying and therefore have an appropriate response is not true and leads parents to feel more anxious and frustrated than they need to be. This may lead to problems such as shaking babies. He is researching this aspect currently.

He believes that health professionals working with new parents should stress that colic is on a "continuum of normal behaviour" and healthy, and remind parents that colic has a good outcome. (He noted that persistent crying after the age of 3 months can be associated with poorer outcomes for children).

He is currently researching whether giving early parental information which redefines colic as normal and adaptive and not something that parents should be able prevent or cure may lead to a reduction in parental stress and hence in shaken babies.

For anyone interested in finding out more about his work, some of his research papers are listed on the website of the Child and Family Research Institute in Vancouver, of which he is the director.

See: www.cfri.ca

NATIONAL NEWS

Our most exciting news is the launch of the ACT branch of AAIMHI which is to take place on June 11. The branch will be launched by Dr Sue Packer, who is a Community Paediatrician and the Head of the Child at Risk Assessment Unit at Canberra Hospital. Dr Packer is well known for her advocacy for children and we are proud to have her to launch the branch. Attendees at the launch will be offered a year's membership to AAIMHI. We look forward to working with our new branch and especially thank Anna Huber and her team for their hard work in getting started.

We are also proud that Associate Professor Campbell Paul has been elected to the Board of the World Association for Infant Mental Health. This is a great honour as there were many distinguished candidates and it is also an acknowledgement of the part Australia plays in the world body.

I attended a meeting in May of the Coalition of Organisations Committed to the Safety and Wellbeing of Australia's Children. The meeting was held to discuss the new National Framework for Protecting Australia's Children. The meeting made some recommendations to the Government for the implementation phase of the plan, including a recommendation for a focus on the needs of infants. This does not preclude any member organisation from doing their own advocacy but does have the benefit of the joint voice of the 66 member organisations.

We responded to the ABC program *Bringing up Baby*, as did many other organisations that advocate for children. There was a partial response from the ABC who put up a disclaimer at the start of each following program acknowledging that their "expert" nurse was unqualified, but it did not prevent the subsequent programs from being aired. We also put out a media release about the needs of babies after a tragedy such as the bushfires and this was picked up by the press in Victoria. We encourage State branches to respond to issues in your own states that are relevant to infant mental health. Even if it doesn't always seem that you have made an impact it does keep the needs of infants in the minds of decision-makers.

And finally, we look forward to seeing lots of our members at the national AAIMHI conference in Victoria this year. If you are there we invite you to come to the AGM and have a say in the future of AAIMHI.

Pam Linke

National President

STATE REPORT - SA

Earlier in the year the SA Branch had a planning day. We reviewed our achievements for the last year – much of our energy had gone into the conference, but we had found some time to do other things like running another Marte Meo workshop and writing a joint submission with NIFtEY, SA Branch and ECA, SA Branch to the Productivity Commission Enquiry into paid parental leave.

At the planning day we set some priorities around our ongoing 'Advocacy' agenda. We decided to continue with two we had set from the preceding year, as we had not proceeded very much due to the time taken by organising the conference. These were continuing to advocate for the needs of infants in childcare, and promoting infant mental health to GPs. Two subgroups were formed and we have started to develop plans in this area. In the next newsletter we will hopefully have developed some action which we can report on. As part of trying to involve our membership we are putting out a summary of our planning day and actions that came out of it, inviting members to participate in the issues they are interested in.

The SA Branch has had an ongoing commitment to putting on training for people working in the Infant Health area. The beginning of 2009 was no exception to this. We put on another 2-day Marte Meo training session. This is the third Marte Meo training we have put on now. At the February training some people achieved Practitioner Level. The training in March was provided by Josje Aarts, while a small group of people who are working towards Colleague or Therapist level met with Maria. Maria will be doing another one day Introductory training in November as part of the Helen Mayo House conference, and AAIMHI will be putting on another two day training in Feb. We will be promoting this through the AAIMHI membership, so if you are interested more information will be coming through later in the year.

We also brought Bonnie Harris, Parent Educator and author of *When your Kids Push your Buttons* and *Confident Parents, Remarkable Kids*. She ran a one-day introductory training, followed by a three-day workshop. While the numbers were small, those that attended found it very interesting and useful. We will be shortly holding a feedback session from this training, as part of the information and network forums that we try to hold a few times a year.

We have received some new memberships which seem to be a direct result of the training which is encouraging. We continue to be an active branch, with a number of new members wanting to be involved on the committee. We are now planning for our AGM where it seems we will have some new committee members.

Sally Watson

President SA Branch

BOOK REVIEW

Infants of Parents with Mental Illness: Developmental, Clinical, Cultural and Personal Perspectives. **Anne Sved Williams & Vicki Cowling (Eds), 2008.** **Sydney: Australian Academic Press**

Groan. That's what I did when I remembered that I had agreed to review *Infants of Parents with Mental Illness: Developmental, Clinical, Cultural and Personal Perspectives* for this AAIMHI Newsletter. It had seemed like such a good idea when I volunteered last year. But now – at the end of summer, when the sky is blue, the weather is warm and the beach beckons – it seemed like a dumb thing to do.

Then I opened the book. And I couldn't put it down. While the title lead me to think I would find dry material, what I found was a book rich with insight, fascinating research, stories and thought-provoking material.

Broken into seven sections, *Infants of Parents with Mental Illness* examines the effects of a person's mental illness on their experience of being a parent, and on their infants' experience and development. But it doesn't stop there – the book deeply examines the question of how best to assess the needs of these families, and how to work with them to improve outcomes for infants. And while the bulk of the material does relate to families where parents have a mental illness, it also considers other related psychosocial circumstances that may impair parental functioning, such as drug and alcohol abuse, domestic violence, and trauma due to mandatory detention.

The book's seven sections are:

1. *In the beginning*, which examines the perinatal period, including anxiety and depression that can arise at this time.
2. *Assessing the situation*, which considers how to assess attachment disorganisation, parents' protective capacity, and also provides a child protection perspective on high-risk infant assessments.
3. *Fathers*, which looks at the experiences of partners of mothers with a mental illness, and the importance of including fathers in the assessment and treatment process.
4. *Personal perspectives*, which tell the stories of the experiences of grandmothers of infants whose parents have a mental illness, mothers who have a mental illness, and adults who grew up with parents with a mental illness.
5. *Political and cultural influences*, which examines the needs of Aboriginal children and their families, as well as children in refugee and asylum-seeking families.
6. *Working with infants and their parents with specific disorders*, including parents with schizophrenia, borderline personality disorder, parents who misuse drugs, and those in a mother-baby inpatient unit.

7. *Working with infants and their families in particular settings*, including sick babies in a paediatric hospital setting, and working with infants and their parents with mental illness in childcare settings.

Each chapter is written by a different expert, and the authors come from a variety of disciplines and backgrounds, including psychiatry, social work, occupational therapy, psychotherapy, early childhood education, nursing, infant mental health and child protection. This rich array of contributors helps create a book with diverse appeal.

Almost all of the chapters pay attention to the issues of assessment and intervention, and make use of case studies to bring these topics to life. This intertwining of research and theory with detailed vignettes is one of the factors which make this book so absorbing.

It would be impossible in this short review to highlight the key ideas in this book, because each chapter has its own specific focus and the book covers such a wide range of topics. However, I can offer some bite-sized samples.

In Chapter 1, *Increasing knowledge, increasing hope for infants?*, Anne Sved Williams provides a clear and succinct account of the basis of emotional health for infants, explaining how 'Those parents who can sensitively tune into their infants and better provide them with relief from stress will help those infants' brain growth and the associated external signs: more exploration, enhanced learning, calmer behaviour and better coping mechanisms when anxious' (p. 5).

In Chapter 4, *More than a question of safety: Assessing attachment disorganisation and protective capacity in high-risk parent-infant dyads*, Jennifer E. McIntosh addresses the question: 'Do we have a biological right to parent our own children?' She says 'It has taken the sobering force of neurobiological evidence to confirm the enduring neurological trauma done to a young child who is not permitted a responsive, intimate, protecting relationship with a caring adult. This implies an imperative for preference of attachment above biology in the developmental health of the young child' (p. 49). She provides a powerful and coherent argument for 'legislative efforts to uphold the right of the child to early psychological security within an organised and continuous attachment relationship' (p. 61).

In Chapter 12, *Children are our future: Understanding the needs of Aboriginal children and their families*, Helen Milroy explains how understanding cultural frameworks can greatly assist better outcomes for Aboriginal families, and explains

Continued on page 12

BOOK REVIEW (cont.)

how the Aboriginal view of health is 'holistic and interconnected with mind, body, spirit and nature in balance' (p. 125). She also gives a fascinating account of Aboriginal Family Systems, and explains why 'From a clinical perspective, it is important to map the family's kinship system as this will establish the broader nature of attachment relationships and what roles others play in the family system' (p. 128).

In Chapter 13, *Infants in refugee and asylum-seeker families*, Sarah Mares and Rosalind Powrie explore the developmental risk and protective factors impacting on infants and young children in families who, as a result of forced migration, seek refuge or asylum in countries other than their own. They explain how 'culture influences the expression of distress and illness and the way it is explained, 'labelled' and treated, and the acceptability and efficacy of treatment' (p. 144). They suggest that questions such as 'What do you call the problem, why is it happening and what do you think caused it?' help to elicit an explanation of symptoms in a way which can help practitioners understand a client's mental health problem from within a cultural perspective. They also explain that, when doing assessments with refugee families, 'A skilful balance is needed to allow parents to tell their story, without retraumatising them, while focusing on issues relevant to parenting and their children' (p. 151). This chapter also gives a heart-wrenching account of the impact of Australia's detention policies on families and children.

Another factor which makes this book unique is the stories of people personally affected by mental illness, or the mental illness of a family member. The chapters written by these people provide a poignant, and at times painful, glimpse into the realities of being a parent with a mental illness. One mother, Nichole, wrote with brutal honesty about the effects of her illness on her children: 'From the time my eldest son was born, I slowly replaced his unconditional love with fear, sadness, anger and confusion ...The reality of my life soon became his life, complete with all of the obvious damage that I alone would cause in times of madness and confusion, which lead to the emotional abuse and neglect of my children. Today, I am still a witness to the devastating effects that my life and my illness has had on my children, and for all they have had to endure' (p. 110). While Nichole's journey ends on a positive note – 'I am proud of the person that I am now. The wisdom and the insight that I have gained and experienced through my journey has given me the confidence to be able to help, sympathise and assist other people living with a mental illness' – she ends her chapter by sounding a cautionary note: 'let us never underestimate mental illness and the devastating effects that it can cause to our children when we are unwell' (p. 111).

The chapters written by people personally affected by mental illness also give a clear – and at times distressing – sense of what it can be like to be a client of mental health services

and how individual case managers and services can make a profound difference – positive and negative – to clients' experience and outcomes. One mother, Amy, describes how flabbergasted she was when she excitedly informed her case manager of her pregnancy, only to be told that it was the case manager's 'duty of care' to book her in for a termination (which Amy refused). She also describes how unsettling it was during her pregnancy to feel that the health professionals around her doubted her ability to be a good mother.

Amy also describes how in the end – after suicide attempts and many hospital admissions – becoming a parent transformed her: "I had always thought of myself as unworthy of being a mother to such a precious soul, but it dawned on me that day that if she had been entrusted into my care that I surely must be of some worth".

There is something for everyone in this book. While most obviously people working directly in the provision of mental health services to adults and/or children would find it a most worthwhile read, it would be of great interest to people from a wide variety of disciplines working with parents who have a mental illness and/or their children. For example those working in the fields of child protection, early intervention domestic violence, alcohol and other drugs and family support.

So while I did miss out on a few trips to the beach, reviewing this book has greatly expanded my knowledge about the needs of families where parents have a mental illness, and for that I am very grateful.

Beth Macgregor

AAIMHI NSW Committee Member

March 2009

Infants of Parents with Mental Illness: Developmental, Clinical, Cultural and Personal Perspectives can be purchased for \$51.95 (including postage and handling) from the Australian Academic Press website:

www.australianacademicpress.com.au