

# Perspectives in Infant Mental Health

Professional Publication of the World Association for Infant Mental Health

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## Is there a Need for Anthropologists in our Multidisciplinary Teams?

By Miri Keren, M.D., WAIMH President,  
Israel, ofkeren@zahav.net.il

After reading this new issue of WAIMH Perspectives, with the description of the work reported in Guatemala, South Africa, and New Zealand, as well reference to the previously published document from Australia, [Infants in Immigration Detention](#), I became convinced of the need to add the anthropological dimension to our clinical work. This is necessary if we want to understand and help populations, many vulnerable and disadvantaged, in their own communities, as well as refugees from war-torn countries who have experienced traumatic losses, including the loss of their homes, belongings and places of work. Not by chance, this issue of *Perspectives* comes out at a time when the magnitude of the “European refugees’ problem” reveals itself as a huge challenge, not only for politicians, but also for mental health professionals.

Let’s imagine that you receive referrals of infants and young children – refugees - who have recently arrived in your country. Their families have fled their own war-torn country, a place that is very different from your own. You have worries about developmental delays in multiple domains, relational disturbances and significant signs of trauma and distress. Where will you begin? How will you determine the needs and strengths of the infants referred? How will you best help refugee families to cope?

On the other hand, you may travel far away to study early child development as Peter Rohloff and his colleagues describe in a very interesting paper, [Field Report: Early Child Development in Rural Guatemala](#). Or, your work may be in your home country, as Kerry Anne Brown, Carla Brown,



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and Astrid Berg describe in their paper, [A Parent Group Initiative in an Intensive Care Unit in South Africa](#), about practices in a pediatric hospital in South Africa.

Confronted by cultures where young children and their families face tremendous health, relational, and cognitive difficulties, you may be challenged to understand and deliver services that are respectful of unique customs or beliefs.

Clinicians who are oriented toward Western culture and values might find their tools of assessment and treatment approaches inadequate when responding to infants and families whose cultural beliefs and attitudes towards life’s adversities are different from their own. Ethno-psychiatry has existed as a field for years, but has been quite marginal. It may become a flourishing domain.

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WAIMH, as a world association, is an organization where professionals from different disciplines and cultures bring their own views and clinical understanding. Still, tools of evaluation and therapeutic approaches primarily reflect Western practices and beliefs. In situations of war and humanitarian catastrophes, some may open their practices to very young children and families who have suffered displacement and are seeking help, far away from their native homes, and some may go to other countries to help children and families in need. For all, knowledge about each individual's culture will be as important as knowledge in crisis intervention or treatment techniques. Just as the general practitioner needs to take advice from the expert in cardiology, we may each need to take advice from anthropologists or have them as members of our multidisciplinary teams!

We will have a chance to discuss these important issues in Prague this year when you come to the [15th WAIMH Congress Infant Mental Health in a Rapidly Changing World: Conflict, Adversity, and Resilience](#). Indeed, in light of our theme and recent events around the world, we have planned a Pre-Congress Symposium on WAIMH policy in times of peace and of humanitarian catastrophes.

Also related to the issues of policy, we include the [WAIMH Position Paper on the Rights of Infants](#). The version that was presented in Edinburgh in 2014 (at the WAIMH Congress Presidential

Symposium) has been amended in response to members' comments and refined by WAIMH Board Members. Its present version is published in this issue of Perspectives. In addition, the WAIMH office will send a copy of the paper to each Affiliate President. Our wish is that each Affiliate starts using it with its local health policy makers and gives us feedback. After one or two years, we will decide whether WAIMH should move the policy document from a Position Paper to a Declaration (with its legal implications). As you will see, the infant's right for culturally sensitive assessment and treatment is mentioned in the WAIMH paper.

Of additional importance, the assessment manual, Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood, Revised (DC 0-3R), is under revision by the National Center for Infants, Toddlers and Families ZERO TO THREE in collaboration with WAIMH members. It will be presented during the WAIMH Pre-Congress day, with special attention given to the cultural aspects of diagnosing very young children.

Join us, meet, and discuss important clinical, policy, and research issues in Prague, the bridge between Eastern and Western Europe!

Warm regards to all of you.

# WAIMH Position Paper on the Rights of Infants

Edinburgh, 14-18 June, 2014 (amended March 2016)

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## Preamble and Rationale

We, as professionals and members of the World Association for Infant Mental Health (WAIMH) who work with infants and parents within different cultures and societies, affirm that there is a need to recognize specific Rights of Infants, beyond those which have already been specified in the United Nations Convention on the Rights of the Child (UNCRC, adopted 1990). We fully support the United Nations Convention on the Rights of the child, and the subsequent document from the United Nations Committee on the Rights of the Child, General Comment Number 7, published in 2005, concerning the implementation of children's rights in early childhood. We affirm that the UNCRC in addressing the rights of children, does not sufficiently differentiate the needs of infants and toddlers from those of older children, in that infants and toddlers are totally dependent upon the availability of consistent and responsive care from specific adults for the adequate development of their basic human capacities. There are unique considerations regarding the needs of infants during the first three years of life which are highlighted by contemporary knowledge, underscoring the impact of early experience on the development of human infant brain and mind.

Drawing attention to the particular needs and rights of the child in the first years of life is needed for several reasons. An all-too-common view is that the baby is "too small to really understand or to remember" and thus the baby's perspective is often not appreciated by health professionals and even by parents. Infants have unique nonverbal ways of expressing themselves and their capacities to feel, to form close and secure relationships, and to explore the environment and learn – all of which require appropriate nurturing since they are fundamental for building a lifetime of mental and physical health. Moreover, infant needs and rights are often overlooked in the midst of conflicted priorities for rights of older children and parents (such as in custody disputes). Further, specifying the unique needs and rights of the child in the first years of life is needed in order to motivate infant oriented actions and policies at both community and societal levels. In spite of the existence of the CRC, many societies around the globe still pay insufficient attention to infants, especially in times of stress and trauma.

Additionally, consideration of infant needs and rights could guide policies of supports for mothers, fathers and caregivers, and in giving value to babies in contexts of risk and violence.

As indicated in the WAIMH by-laws, our aims include "...to promote education, research, and to promote the development of scientifically-based programs of care, intervention and prevention of mental impairment in infancy". Our forming a Declaration of Infants Rights represent a significant step WAIMH Board has actually decided upon, that is to be action-oriented and to take explicit ethical stance and advocacy positions.

This Declaration is divided into two parts: the Infant's basic rights, that should be endorsed everywhere, regardless of society and cultural norms, and the principles for health policy that are more sociocultural context- dependent.

## I. Basic Principles of Infant Rights (Birth to three years of age)

1. The Infant by reason of his/her physical and mental immaturity and absolute dependence needs special safeguards and care, including appropriate legal protection.
2. Caregiving relationships that are sensitive and responsive to infant needs are critical to human development and thereby constitute a basic right of infancy. The Infant therefore has the right to have his/her most important primary caregiver relationships recognized and understood, with the continuity of attachment valued and protected--especially in circumstances of parental separation and loss. This implies giving attention to unique ways that infants express themselves and educating mothers, fathers, caregivers and professionals in their recognition of relationship-based attachment behaviors.
3. The Infant is to be considered as a vital member of his/her family, registered as a citizen, and having the right for identity from the moment of birth. Moreover, the infant's status of a person is to include equal value for life regardless of gender or any individual characteristics such as those of disability.
4. The Infant has the right to be given nurturance that includes love, physical and emotional safety, adequate nutrition and sleep, in order to promote normal development.
5. The Infant has the right to be protected from neglect, physical, sexual and emotional abuse, including infant trafficking.
6. The Infant has the right to have access to professional help whenever exposed directly or indirectly to traumatic events.
7. Infants with life-limiting conditions need access to palliative services, based on the same standards that stand in the society for older children.

## II. Social and Health Policy Areas to be informed by these Principles:

1. Policies that support adequate parental leave so that parents can provide optimal care for their infants during the crucial early years of life.
2. Policies that minimize changes in caregiver during the early years of development.
3. Policies that promote the provision of informational support to parents regarding the developmental needs of their infants and young children.
4. Policies that recognize the importance of facilitating emotional support for mothers, fathers, and caregivers, as an important component of fostering the optimal development and well-being of the infant.
5. Policies that promote access to evaluation and treatment of risks to development by trained professionals who are culturally sensitive and knowledgeable about early development and emotional health.
6. Infants with life-limiting conditions need access to palliative services.
7. The provision of adequate circumstances, including time for mothers, fathers, caregivers to get to know their infants and become skilled in providing for their infant's care and comfort, throughout the support of their family and community. The right for parental leave, and its duration, should be valorized by the society, in a way that fits its contextual reality.
8. The provision of access to relevant early educational and psychological opportunities and programs that promote good-enough relationship experiences and thus, enhance cognitive and socio-emotional development.
9. Policies that ensure the provision of prompt access to effective mental health treatment for mothers, fathers, and caregivers that alleviates infants' suffering and insure optimal development for the child.
10. Policies that allocate resources for training and supervision for caregivers in babies' institutions, foster care professionals and foster parents, as well as resources for assessing and treating foster care infant's emotional and developmental status.

## Appendix A.

WAIMH endorses the 10 principles of the UN Convention on the Rights of Children (as passed by the General Assembly of UN in 1989, and activated in Sept. 1990 with 54 Articles in total) that is:

1. The child shall enjoy all the rights set forth in this Declaration. Every child, without any exception whatsoever, shall be entitled to these rights, without distinction or discrimination on account of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status, whether of himself or of his family.
2. The child shall enjoy special protection, and shall be given opportunities and facilities, by law and by other means, to enable him to develop physically, mentally, morally, spiritually and socially in a healthy and normal manner and in conditions of freedom and dignity. In the enactment of laws for this purpose, the best interests of the child shall be the paramount consideration.
3. The child shall be entitled from his birth to a name and a nationality.
4. The child shall enjoy the benefits of social security. He shall be entitled to grow and develop in health; to this end, special care and protection shall be provided both to him and to his mother, including adequate pre-natal and post-natal care. The child shall have the right to adequate nutrition, housing, recreation and medical services.
5. The child who is physically, mentally or socially handicapped shall be given the special treatment, education and care required by his particular condition.
6. The child, for the full and harmonious development of his personality, needs love and understanding. He shall, wherever possible, grow up in the care and under the responsibility of his parents, and, in any case, in an atmosphere of affection and of moral and material security; a child of tender years shall not, save in exceptional circumstances, be separated from his mother. Society and the public authorities shall have the duty to extend particular care to children without a family and to those without adequate means of support. Payment of State and other assistance towards the maintenance of children of large families is desirable.



7. The child is entitled to receive education, which shall be free and compulsory, at least in the elementary stages. He shall be given an education which will promote his general culture and enable him, on a basis of equal opportunity, to develop his abilities, his individual judgement, and his sense of moral and social responsibility, and to become a useful member of society. The best interests of the child shall be the guiding principle of those responsible for his education and guidance; that responsibility lies in the first place with his parents. The child shall have full opportunity for play and recreation, which should be directed to the same purposes as education; society and the public authorities shall endeavor to promote the enjoyment of this right.
8. The child shall in all circumstances be among the first to receive protection and relief.
9. The child shall be protected against all forms of neglect, cruelty and exploitation. He shall not be the subject of traffic, in any form. The child shall not be admitted to employment before an appropriate minimum age; he shall in no case be caused or permitted to engage in any occupation or employment which would prejudice his health or education, or interfere with his physical, mental or moral development.
10. The child shall be protected from practices which may foster racial, religious and any other form of discrimination. He shall be brought up in a spirit of understanding, tolerance, friendship among peoples, peace and universal brotherhood, and in full consciousness that his energy and talents should be devoted to the service of his fellow men.

Additionally, WAIMH endorses the points published in 2005 by the UN Committee on the Rights of the Child as "General Comment No. 7", that emphasizes the need to include all young children i.e. at birth throughout infancy, during the preschool years, as well as during the transition to school. Through this general comment, the Committee made clear that young children are holders of all rights enshrined in the Convention and that early childhood is a critical period for the realization of these rights, where parents and state parties play a major role. Assistance to parents is also mentioned as a right of the young child. A special section is dedicated to young children in need of special protection.

## Appendix B.

As a background for the Declaration of Infant's Rights, WAIMH also endorses the United Nations Millennium Development Goals that include:

1. The eradication of extreme poverty and hunger.
2. The achievement of universal primary education.
3. Gender equality and women's empowerment.
4. The reduction of child mortality.
5. Improvement of maternal health.
6. Combating HIV/AIDS, malaria and other diseases.
7. Ensuring environmental sustainability.
8. Ensuring global partnerships for development.

## Key documents underpinning the Declaration

- Bartlett, S. (2005). "An Alternative Model for Responding to Children in Poverty: The Work of the Alliance in Mumbai and Other Cities." *Children, Youth and Environments* 15(2): 342-355.
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## The World in WAIMH

By Joshua Sparrow, Brazelton Touchpoints Center, Boston, United States,

E-mail [joshua.sparrow@childrens.harvard.edu](mailto:joshua.sparrow@childrens.harvard.edu)



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In this issue of Perspectives in Infant Mental Health, the World in WAIMH column features a field report from Guatemala on a home visiting program for the families of infants and young children with developmental delays due to chronic malnutrition. In a significant departure from traditional Euro-American projects in developing countries, the authors describe a collaborative approach to program design, implementation and evaluation. With their local professional, community and family partners, they take on the challenges of geographic distance, differences in language and culture, and limited applicability of Euro-American assessment tools common to so many such projects. Using a co-constructive, reflexive approach, the authors and the families they work with are learning together about how to help children thrive in settings where health and survival are threatened.

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## Field Report: Early Child Development in Rural Guatemala



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By Boris Martinez, Wuqu' Kawoq/Maya Health Alliance, Santiago Sacatepéquez, Guatemala

Meghan Webb, Wuqu' Kawoq/Maya Health Alliance, Santiago Sacatepéquez, Guatemala

Patricia Rodas, Universidad del Valle de Guatemala, Department of Psychology, Guatemala City, Guatemala

Ana Gonzalez, Universidad del Valle de Guatemala, Department of Psychology, Guatemala City, Guatemala

María del Pilar Grazioso, Universidad del Valle de Guatemala, Department of Psychology, Guatemala City, Guatemala

Peter Rohloff, Wuqu' Kawoq/Maya Health Alliance, Santiago Sacatepéquez, Guatemala and Division of Global Health Equities, Brigham and Women's Hospital, Boston, MA.

Direct correspondence to Peter Rohloff ([peter@wuqukawoq.org](mailto:peter@wuqukawoq.org)). This work is supported by a grant from Grand Challenges Canada (SB-1726251050).

Guatemala is a Central American country with a population of around 15 million people. Importantly, it has one of the largest indigenous populations in all of Latin America, with about half of the population self-identifying as indigenous Maya (Ministerio de Salud Pública y Asistencia Social, Instituto Nacional de Estadísticas, & ICF International, 2015). Guatemala is also one of the most impoverished nations in Latin America, with the indigenous Maya population being the most affected by this poverty.

In Guatemala chronic malnutrition, also known as “stunting,” affects 46.5 percent of children under five years-old (Ministerio de Salud Pública y Asistencia Social (MSPAS), Instituto Nacional de Estadísticas (INE), ICF International, 2015) – the highest rate in Latin America and the fourth highest in the world (World Food Program, 2015). Stunting, a proxy for chronic malnutrition is defined as height or length for age more than two standard deviations below average based on the 2006 World Health Organization Multicentre Growth Reference Study. Chronic malnutrition results from a wide range of social, environmental, and biological factors including poverty, lack of education, food insecurity, limited access to health care services, and recurrent infectious diseases (Caulfield, Richard, Rivera, Musgrove, & Black, 2006; Reinhardt & Fanzo, 2014). Inequities in the burden of malnutrition are evident. For example, 58 percent of indigenous children are stunted versus 34 percent of non-indigenous children. When income is also factored in, the disparities are even more apparent. Among the poorest quintile of the population, stunting affects 66 percent of children, compared to 17 percent among the richest quintile (Ministerio de Salud Pública y Asistencia Social, Instituto Nacional de Estadísticas, & ICF International, 2015). These rates are so astonishingly high that, according to one study, children from rural, impoverished communities in Guatemala are the most malnourished population in the world (Black et al., 2013).

Stunting is a critical public health issue, especially for those working on Early Child Development (ECD) in Guatemala. Studies conducted in various populations and countries have established that stunted children experience developmental delays during early childhood and cognitive deficits that persist into adulthood (Prado & Dewey, 2014; Stein, Melgar, Hoddinott, & Martorell, 2008). Stunted children are also less likely to be economically productive adults, primarily because of lower levels of achievement during schooling (Grantham-McGregor et al., 2007). The life-long effects of stunting, therefore, contribute to the

intergenerational cycle of poverty.

Over the last eighteen months, we have been part of a novel program to study and understand the dynamics underlying early child development in a highly stunted indigenous Maya population. This program includes a partnership in which leaders from the indigenous communities where the work is being conducted, researchers from the Department of Psychology at the Universidad del Valle de Guatemala (UVG), and health care providers from the Guatemalan healthcare non-profit Wuqu' Kawoq | Maya Health Alliance (WK|MHA) equally contribute ideas, expertise, and energy. This coalition combines the expertise and methods of psychology, anthropology, and medicine to investigate the effects of stunting on ECD in these communities.

The work has posed several specific challenges. First, the Mayan communities with whom we are collaborating are largely non-literate, primarily speak Mayan languages (not Spanish), and live in large, extended families with alternative ideas about and approaches to infant and toddler-rearing. In other words, they are very different from the Western, educated, industrialized, rich, and democratic (WEIRD) populations for whom approaches to ECD are well established and documented (Henrich, Heine, & Norenzayan, 2010). Second, the partnering indigenous communities are remote Kaqchikel Maya agricultural settlements, often two to three hours away from the nearest town on challenging, unpaved roads. Additionally, the population of children with whom we are working has a high prevalence of stunting. Indeed, in many of the small villages where we are working, there are no children who are not stunted. This means that, even given the caveat that no culturally appropriate developmental norms have been established for our population, there are often no children at all in a given community who are developing normally. Under these conditions, where illness and developmental delay becomes the “norm” (Chary et al., 2013), the major task confronting our community-researcher collaboration is fostering a dialog whereby, together, we can imagine a future where improved conditions prevail and children thrive.

To address these challenges, we've implemented a community-based program designed to bring ECD-focused programming to these rural Maya communities. The basic structure of the program is simple, designed to function as an “add-on” to existing nutrition-focused activities that were already

being conducted by our service provider collaborator, WK | MHA. Community health workers from WK | MHA travel door to door, in collaboration with community leaders and groups of caregivers, to identify children who are either likely to be developmentally delayed or at high risk of developmental delay due to their nutritional status. Most children identified in this way are under 2 years of age and belong to families where the male heads-of-households work full-time in subsistence agriculture while female heads-of-households are the primary caregivers (often assisted by their older children or other females in the extended family) and also help out financially by weaving textiles or by helping in the fields themselves.

In our qualitative needs assessments prior to launching the program, a major theme that emerged from conversations with primary caregivers was how they tended to feel overwhelmed by domestic responsibilities and financial liabilities and “didn't have time” to think about child development. Therefore, our community health workers make home visits to visit these families once every one to two weeks. They do not provide prescriptive advice about child development, nor do they conduct structured assessments of developmental outcomes. Rather, their goal is to function as a conversational catalyst for the primary caregiver and any other members of the family who are present. They position themselves as learners, allowing the child's caregivers to teach them about how their child is developing, and serving as a sounding-board for articulating goals. In this way, our hope is to achieve moments of shared insight, whereby caregivers and health providers alike become excited about a given child's development and future potential.

From a research perspective, a major goal for this initiative is shared bilateral learning about child development. Here, Maya caregivers and community leaders teach our research team about their children's health and development and about local child rearing practices, and they share their hopes and plans for their children's future. In return, our team of psychologists and anthropologists (from UVG and WK | MHA) shares expertise on child development and developmental assessments gleaned from other populations and other contexts. Together, and through a process involving multiple iterative cycles of team-building, simulations, and reflexive debriefings, we are working to analyze the data emerging from the project in order to build a culturally appropriate toolkit for developmental assessments.



This includes elements of “what works” from standard Western tools such as the Ages and Stages Questionnaire or the Bayley Infant Scales of Development (after multiple iterations of rigorous translation and interpretive work between English, Spanish, and the Kaqchikel Maya languages), as well as other elements derived directly from caregiver feedback or from analyses by our anthropologists, such as direct unstructured observation or cultural consensus modeling of infant and child behaviors (Romney, Weller, & Batchelder, 1986; Wehr, Chary, Webb, & Rohloff, 2014). The ultimate goal of this shared learning is to help reorient the field of ECD in Guatemala in favor of culturally- and linguistically-appropriate accompaniment, along a trajectory that favors the generation of shared insights and goal setting.

The program is still in its early stages. Over the last six months, we’ve enrolled over 300 severely stunted children in the intervention. We just graduated our first “cohort” of 50 children last month and are in the process of analyzing nutritional and developmental outcomes. However, since the very first days of the initiative, the qualitative results have been remarkable. In particular, we’ve noticed incredible changes in how caregivers talk about child development. After just a few months of receiving home visits, caregivers seem hardly able to contain their excitement as they begin to talk to health promoters about all the things their child has learned how to do since the last visit: “now my child is able to walk on his own;” “now she is able to say two more words!” Caregivers have also, somewhat to our surprise, greatly enjoyed participating in formal developmental assessments. When our psychologists have just finished administering a lengthy assessment, typical feedback has been, “I never knew my child could do that!” or “I’ve learned new ways to play with my child!”

With these small steps, which include both research and intervention components, we are excited to see the beginning of a new type of dialog about ECD with caregivers from a marginalized, vulnerable population. Over the long term, we hope that this and similar projects will stimulate the field of ECD in Guatemala, and will help us to move towards robust ways of assessing ECD in indigenous populations. Furthermore, the work will also begin to help quantify the developmental impact of widespread stunting data, which we can use to improve the efficacy of our advocacy and policy initiatives as well.

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# 15<sup>th</sup> World Congress of the World Association for Infant Mental Health

May 29 – June 2, 2016  
Clarion Congress Hotel  
Prague براغ פראג  
Czech Republic



## Infant Mental Health in a rapidly changing world: Conflict, adversity, and resilience

### Pre-Congress Institute I

Sunday May 29, 2016, 10:00-15:00

Infant Mental Health Policy Under Stable  
and Peaceful Conditions and During  
Humanitarian Crises

[MORE INFORMATION](#)

### Pre-Congress Institute II (in association with Zero to Three)

Sunday May 29, 2016, 10:00-16:00

Diagnostic Classification DC 0-5

[MORE INFORMATION](#)

For more information, please  
look in the [Congress website](#).



## Affiliates Corner

Greetings to all WAIMH Affiliates. This brief update has four main foci: an invitation to share our affiliate newsletters with other AC presidents and their executives; information about the upcoming AC biennial meeting in Prague; information about the Affiliate Council President/executive administrative meeting, Prague, 2016; information about the AC voting survey conducted in 2015.

### Affiliate Newsletters

We are aware that many affiliates write informative and interesting newsletters. While some of the news is relevant to the local group, often times the information would be of interest to other AC Presidents and their executives, for example, feedback with regard to regional conferences and or issues on policy. As such, we encourage you to share your newsletters with the Affiliates Council.

### The Biennial Affiliates Council Meeting: Prague, 2016

A full meeting agenda was sent to you May 11, 2016.

If you are not able to attend the meeting, we invite you to contribute your thoughts and ideas concerning the agenda items via email. We ask that these contributions are received by May 20. The contributions will be collated and shared with the membership at the meeting in Prague.

### Affiliate Council President/executive administrative meeting, Prague, 2016

This meeting is open to all AC Presidents and members of their executives, and to groups that are recognised as WAIMH study Groups. The purpose of the meeting is to provide an opportunity to discuss any administrative issues pertaining to your affiliate and its relationship with WAIMH.

If you are aware of an issue/question that you would like to discuss, please forward this to Anna and Maree. We will collate the questions and plan the meeting so that all the questions get acknowledged and addressed.

Please forward any items you would like to have discussed by: 20 May 2016

### Findings of the AC Voting Survey

A report on the findings has been collated and was sent to all AC Presidents.

#### Summary of Dates:

Forward items for the Affiliate Council President/executive administrative meeting by 20 May, 2016.

For those unable to attend the biennial meeting, contributions/comments about the agenda items to be received by May 20, 2016.

Maree Foley

WAIMH Affiliates Council Chair

Contact: [maree.foley@xtra.co.nz](mailto:maree.foley@xtra.co.nz)

Anna Huber

WAIMH Affiliates representative

Contact: [ahuber@familiesinmind.com.au](mailto:ahuber@familiesinmind.com.au)



Photo from the WAIMH Affiliate Council biannual meeting in Cape Town, 2012. Photo by Minna Sorsa, WAIMH Central Office.

# From the IMHAANZ President

By Denise Guy, President IMHAANZ

City missing, New Zealand

Kia Ora Koutou

He taonga rongonui te aroha ki te tangata  
*Goodwill towards others is a precious treasure*

There is plenty of good reading in this newsletter, perhaps not for the beach but definitely in a quieter moment in January. Memories of Conference 2015 in Queenstown will be revived as you check out the responses to the survey. Many thanks to those who provided feedback appreciating the presentations, keynotes, learnings and connections made and providing us with constructive thoughts and ideas for future Conferences. IMHAANZ is planning that our next 3 day Conference will be in early 2018.

We publish a paper completed by Wendy Tyghe as part of her course requirements with the Masters in IMH course at the NSW Institute of Psychiatry and thanks to Martha Birch for making this possible.

In the New Year we will be making the 16 short films, created by Zero To Three, that are the "Magic of Everyday Moments" available to Regional Network groups for viewing. This has been made possible by donations given when Janet Gregory a founder member of IMHAANZ died. We thank her family and its fitting to support an educational resource for members.

## Executive News

In October the Executive discussed raising the cost of Membership of IMHAANZ. It has been unchanged since 2006 when we became an Affiliate of WAIMH. It was agreed to increase the membership from \$35.00 to \$40.00 beginning January/February 2016.

We have also moved forwards on plans to re-develop the website and this work will begin late January. This is exciting and our primary focus will be a website that is responsive, educational and informative for members and visitors to the site.

The Executive have begun a considered and helpful conversation with AAIMHI Executive and the WAIMH Affiliates Council around the appropriate use members may make of their IMHAANZ membership. We

plan work on a guidance document much like AAIMHI is currently developing. In the meantime we would be clear that IMHAANZ membership may not be used to endorse or promote products, publications or individuals.

## Publications

From time to time we ask the membership for input into a response from IMHAANZ regarding documents being developed by different organisations. Thanks for the time and thought people have given to such requests.

In October the Ministry of Health released 'Supporting Parents Healthy Children - Supporting parents with mental illness and or addiction and their children: A guideline for mental health and addiction services [2015]'. IMHAANZ welcomed the development of this national guideline which provides a positive mandate for identifying, protecting and intervening for children with parental mental illness and service focussed service provision. Thanks to Tanya Wright, Liz MacDonald, Kelly Jones, Carol McArthur, Dave Owens, Marion Doherty and Clare Shepherd and her colleagues at the MoE all of whom contributed to development of the IMHAANZ response. The specific vulnerability of infants, their maximal dependence for care and the clear, and the acute impact parental mental illness can have during infancy, has been highlighted. The documented is directed to mental health and addiction services so one of the other messages made by members that COPMIA is relevant to the Education and NGO sector concerned to support the parents they see with mental health and addiction problems and to advocate for their children was not picked up but needs attention.

IMHAANZ will continue to be responsive to requests from organisations for Infant mental health expertise and guidance and very thankful to members supporting this work.

I would recommend reading the following Reports for their relevance to those of us working with infants, toddlers, preschoolers and their families.

\* The Office of the Children's Commissioner



"STATE OF CARE 2015 - What we learnt from monitoring Child Youth and Family"

\* Modernising Child, Youth and Family Expert Panel: Interim Report 31.07.15

The imperative for working early and knowledgeably with infants, their parents and caregivers and relevant systems [including health, education, home care and child protection] is repeatedly underlined.

## News from Australia

The National Australian IMH organisation, AAIMHI, has recently published a new Position Paper: 'Infants in Immigration Detention'. This was accompanied by a media statement recommending the immediate release of infants and their parents from detention. This paper can be accessed from: <http://www.aaimhi.org/viewStory/Policies+and+Submissions>

Martha Birch who has been coordinating the Perinatal and Infant Mental Health training programme at the NSW Institute of Psychiatry has recently retired and those of you who know Martha would wish her well with future endeavours. She remains on the NSW Branch and National Committees of AAIMHI.

Special thanks to the Executive for their hard work, enthusiasm, tenacity and humour through this year and to members and interested non-members thank you for your ongoing support.



# First infant Mental Health Conference in Johannesburg, South Africa

## Dialogues in a Multidisciplinary Context

By Katherine Bain, School of Human and Community Development, University of the Witwatersrand, South Africa

Infant mental health as a field of focus in South Africa has been gathering momentum in the past two decades. The first ever infant mental health conference to be held in South Africa was arranged by Professor Astrid Berg and held in Cape Town in 1996. The second was when Cape Town proudly hosted the 13th Congress of WAIMH in 2012. October 2015 saw the first infant mental health conference held in Johannesburg, South Africa.

Organised by the Gauteng Association for Infant Mental Health (GAIMH-SA: a WAIMH affiliate), the conference was co-hosted by the University of Witwatersrand's School of Human and Community Development and funded by the DST-NRF Centre of Excellence in Human Development. The aims of the conference were to highlight infancy as a crucial developmental period amongst practitioners, to promote early interventions targeting perinatal mental health, and to encourage multidisciplinary collaboration. The non-governmental organisation (NGO) sector was also included, as much of the work in this field in South Africa is being carried out by these organisations, often in collaboration with various University Departments. Mother-baby home visitors gave moving case study presentations that highlighted the everyday realities of poverty and the effects of trauma that many South African mothers and babies

manage. These presentations brought faces and stories to the research subjects in the more academic presentations.

Due to student protests regarding fee increases, the conference venue had to be changed at a week's notice. Amid jokes about scheduled hospital births turning into unplanned home births, the conference 'birth' was moved from the University of the Witwatersrand to Ububele, a Johannesburg NGO. The inconvenience was managed in true African style, with little fuss, and an understanding that the student protests were a hopeful example of youth who can speak for themselves, asking for their needs to be met. Ububele was a gracious host and, as an NGO instrumental in highlighting the importance of

intervention during infancy, a fitting venue.

Research in sub-Saharan Africa has highlighted poor child development outcomes associated with deprivation (see Lancet special edition on child development, 2007). Early intervention is required in order to facilitate positive, long-lasting treatment effects. However, as is the case in many developing countries, funding in South Africa focuses on decreasing HIV infection and infant mortality rates, as opposed to the promotion of infant mental health (IMH). High rates of HIV infection in sub-Saharan Africa continue to pose a threat to the well-being of infants born to HIV-infected mothers. Plenary presenter, Peter Cooper (Academic Head: Paediatrics and Child Health, University of the Witwatersrand)



Photo: Adobe Stock.



gave an overview of progress in the area of infant HIV infection in last 25 years. Following the historic South African Constitutional Court Ruling of 2002, that legislated the introduction of antiretroviral therapy (ARVs) to prevent mother to child transmission (MTCT), rates of MTCT have decreased from approximately 30% in the year 2000 to recently estimated rates of approximately 3%. Exclusive breastfeeding is encouraged as mothers are provided with ARVs for the duration of breastfeeding. The current early provision of ARVs for HIV-infected infants has resulted in a decrease in infant mortality and improved developmental outcomes. However, Joanne Potterton's (Physiotherapy, WITS) presentation highlighted the continued risk facing HIV infected infants. While early ARV treatment was found to contribute to some developmental gains, infected infants remain developmentally delayed when compared to uninfected infants. She presented findings from three studies on HIV encephalopathy that compared the developmental levels of HIV-exposed and infected (HEI) and HIV-exposed uninfected (HEU) infants, finding that compared to HEU infants, infected infants demonstrated significant delays in all areas of development from four months of age. These developmental challenges of infancy, despite adequate viral suppression, were found to extend into childhood, with HEI pre-school age children continuing to demonstrate increased rates of developmental delay.

Amina Abubakar (Psychology, Lancaster University, UK; Centre for Geographic Medicine Research, Kenya), in her invited plenary, presented her research on executive function (EF) in the context of HIV exposure. EF regulatory control plays an important role in both cognitive and social development, and hence academic achievement. Functional brain imaging and scans have found that EF-related brain regions (predominantly pre-frontal cortex) are especially susceptible to HIV-related damage. Abubakar highlighted the dearth of research in African populations and stressed the importance of early detection of these dysfunctions in at-risk paediatric populations, in order to identify those children in need of early intervention. She also delighted the audience with descriptions of the difficulties a researcher faces when using biscuits as enticements for toddlers during assessments.

ARVs also came under the spotlight. Tarryn Stevens' (Speech Therapy, WITS) study comparing the effects of Nevirapine and Efavirenz on language development in HIV-exposed uninfected infants exposed to either Nevirapine or Efavirenz through

MTCT, found the mean language scores of infants exposed in utero to Nevirapine to be significantly higher than those exposed to Efavirenz. No correlations between the child's language abilities and maternal factors were found. These presentations highlighted the progress made in the field of paediatric HIV, but also the gaps in knowledge and questions that remain with regards to the treatment of paediatric HIV.

The increasing homogenisation of the field of infant development is a recent concern in the literature (Pence & Nsamenang, 2008). The notion of the 'global child' and a 'one size fits all' model of parenting were challenged at the conference. Gillian Mooney (University of the Witwatersrand) presented a meta-analysis of the journal *Developmental Psychology*, from the year 2000 to the present, and concluded that much of what we 'know', in the developmental psychology literature, is based on the experiences of white, middle-class American children and their mothers. She found the focus to be on older children (predominantly adolescents), and very little on the roles of fathers was noted.

The conference did not follow this trend and a number of presentations highlighted the importance of culture and context in understanding parent-infant dynamics and in the development of interventions. Astrid Berg's (University of Cape Town and Stellenbosch University) plenary presentation emphasised the presence of a number of 'potential barriers, such as language, different world cosmologies, as well as hardships of daily living' that exist in multicultural intervention contexts. She highlighted the importance of reflective practice in clinical work. In order to allow the dynamics of cases to be uncovered and understood, she recommended a stance of inner and outer reflectiveness and detailed observation. A number of presentations considered local contexts, understandings and practices around infancy and child-rearing in a reflective manner. Katherine Bain (Psychology, University of the Witwatersrand) and Jade Richards (Ububele psychologist) presented on levels of knowledge regarding the relational needs of infants amongst mothers from a low-income Johannesburg Township, Alexandra. Strong culturally-linked inclinations towards the denial of any negative maternal affect, post-birth, were found, such as 'babies are gifts, mothers cannot be sad'. This highlighted the need for further research in order to determine possible associations of this denial of negative affect to rates of maternal depression found in higher-risk South African populations (36%). These rates are three times those found in developed countries (10-12%) (Hartley et al., 2011).

The need to increase parental knowledge regarding infants' sentience and awareness was also highlighted in a presentation by Katharine Frost (Head of Ububele's Parent-Infant Programme) and Zanele Vilakazi (Lay Counsellor, Ububele). They explored the introduction of the Brazelton Neonatal Behavioural Observation (NBO) to highlight the infant's capabilities in parents' minds, in a local Johannesburg township setting.

An example of contextually relevant intervention was a presentation by Jade Richards and Nicola Dawson (Ububele psychologists), who noted that the importance of supporting the mental health of the primary caregivers of infants, that is recommended in parent-infant intervention, often neglects to include caregivers of infants that work in shelters for abandoned infants. The impermanence of relationships between care workers and infants in shelters has been highlighted in the literature as highly problematic, yet is often unavoidable as workers retain a defensive distance to protect themselves against multiple losses as babies are adopted, move homes or care workers change employment. It can seem counter-intuitive to care workers and professionals alike to encourage bonding in these cases, but it is known that this is what the babies require. Richards and Dawson explained how the therapy space encourages thoughtful reflection around the infant's experiences, traumas and individuality, in addition to the influences of the caregiver's own attachment history on the relationship. It also provides support to the caregiver and the infant around feelings of anticipated and real loss. Since the service is new, it also provided a chance to think through the possibilities of using the therapy space as one in which the loss and change-over of caregivers is managed. Questions around the possibilities of continuing the space with new caregivers when current caregivers leave were considered.

Ububele's Baby Mat service (Frost, 2012), was another example of contextually responsive intervention. The Baby Mat service consists of a literal mat on the floor of (currently seven) Baby Wellness clinics in Alexandra and Hillbrow, staffed by a dyad consisting of a psychologist and a trained counsellor/translator. The dyad invites mothers in the waiting room to bring their infants to sit on the mat to discuss any concerns they may have. The dyad then waits on the mat. Over time, the service has grown as mothers have become accustomed to the service and see it in use. The service functions as an effective short-term intervention, providing mothers with a space to reflect around their experiences and those of their infants,

and as a screening and referral service for cases requiring additional intervention. Presenters explained how staff on the Baby Mat adopt a non-judgmental stance and that 'the culturally-informed frames of reference' that are brought by mothers are 'neither elevated nor dismissed', but rather engaged with from a wondering and curious stance, which 'helps those who visit the Baby Mat to find symbolic meaning in the presenting problem by exploring the internalised meanings of cultural attributions and reflecting on these'. The baby mat presentations highlighted the complex layers of meaning-making involved in cross-cultural interventions that involve multiple cultural, language and racial configurations on the mat. 'Good-enough' mothering as a contextually-bound and culturally-informed conceptualisation was explored and the importance of considering mothering in light of historical racial experiences when intervening was emphasized. It was demonstrated that meaning-making is a collaborative process and the importance of a multicultural supervision group was highlighted.

The complexities of the navigation of cultural differences was highlighted in Cora Smith's (Chief Psychologist; Charlotte Maxeke Hospital; University of the Witwatersrand) plenary presentation that gave an account of the ethical dilemmas of attachment and custodial rights in baby swap cases. A case was presented where infants were given to the incorrect parents after birth. The mix-up was discovered approximately three years later after a paternity test was conducted in a child maintenance case. These parents then sued the hospital and petitioned for the return of their biological child. The presentation captured the intensity of conflicting emotions and opinions in both sets of parents, with one set wishing to return their child and have their biological child returned, and the other wishing to keep their 'wrong' child. The immense task of balancing the best interests of the children and their respective parents in this case, was complicated by various parental conflicts and custody issues, in addition to parental cultural beliefs. A thoughtful account of the process of differentiating between 'valid' cultural beliefs and those manufactured for the purpose of manipulating legal outcomes was addressed. In this case, the court appointed a 'cultural expert' to comment on the beliefs regarding ancestors requirements that were presented by parents in order to give due consideration to those beliefs deemed to be pertinent to the case. Importantly, the court's finding that the children's attachment needs (for their psychological parents) required

prioritising over the biological parents' constitutional rights for control over their biological offspring, was a recognition of children's needs for consistent, on-going relationships to caregivers by the South African courts. The children remained with the parents with whom they had been since birth, with supervised visitation by biological parents.

Presentations on the two local Mother Baby Home Visiting Programmes (one in Cape Town and one in Johannesburg) also highlighted the need for cultural and contextual sensitivity. Mireille Landman (Parent Centre, Cape Town) presented on the lessons learned from 20 years of running a community-based parent-infant home visiting attachment intervention in Cape Town, Thula Sana. Her account of emotionally difficult, yet essential work with mothers and infants living in contexts of poverty, substance abuse and trauma, being done by underpaid lay counsellors, supported by supervisory staff burdened by funding uncertainties, provided insight into the challenges faced by these organisations. The fact that much of the early intervention in South Africa is carried by non-governmental organisations (NGOs) who function under uncertain financial circumstances, highlighted the tenuous situation of services for children under three and their parents in South Africa.

However, there is a growing recognition of the need for infant mental health services in the public health sector and there were a few presentations that evidenced this. The formativeness of infancy in the formation of neurodevelopmental trajectories, especially within third world settings where children are surrounded by epigenetic risk factors was highlighted by presenters from the public health sector. Helen Clark (Head: Child and Adolescent Psychiatry, Baragwanath Hospital, University of the Witwatersrand) emphasized the effects of deprivation on parenting and highlighted a tendency toward an external caregiver locus of control in parents presenting with their young children at Baragwanath Hospital. The tendency to place the focus on the child as the problem, as opposed to the child-caregiver relationship, increases the demand for a child based intervention. The need for interventions that focus on the parent-infant relationship was emphasised and Dr Clark announced the establishment of a 0-3 clinic at Baragwanath Child Psychiatry Unit from 2016. Janice Cowley (Occupational Therapist), Bianca Veira (Speech and Hearing Therapist) and Melanie Esterhuizen (Psychologist) from South Rand Hospital, in southern Johannesburg, highlighted the

complexity of biopsychosocial influences on development and stressed the importance of transdisciplinary treatment. They described the development of an early intervention multidisciplinary team, comprising Speech Therapy and Audiology, Occupational Therapy, Psychology, Physiotherapy and Dietetics, at the hospital. Monthly visits to the team allow for infants and caregivers to receive a number of treatments in the same visit, and the shared space and effective communication between disciplines allows for easy cross-referrals. The service was shown to minimise travel costs for patients, improve service delivery and outcomes, to empower parents, and to provide cross-discipline professional education for professionals.

A number of presentations also featured creative and culturally sensitive interventions in high-risk neonatal and paediatric intensive care units. Lynn Preston (Psychology, North West University) presented a review of studies highlighting post-traumatic stress reactions in parents of hospitalised infants. She presented evidence for the provision of support for parents with infants in neonatal intensive care units, with benefits for parents and professionals in these settings. Kerry Brown and Carla Brown (Occupational Therapy, Red Cross War Memorial Children's Hospital, University of Cape Town) presented the development of a parent group in the pediatric intensive care unit at the Red Cross Hospital to provide psychosocial support for parents and education on the neurodevelopmental needs of their infants. Novel methods of working with language and education diverse groups were presented. A study demonstrating the effectiveness of Kangaroo Mother Care (KMC) as opposed to standard incubator care, with regards to interactional patterns between mothers and infants was presented (Sian Green & Warwick Phipps: psychologists). The mothers in the KMC group, which encouraged skin-to-skin infant carrying, demonstrated significantly more effective interactional patterns with their infants than those in the incubator group. Miemie du Preez (Neonatology, Stellenbosch University, Tygerberg Hospital) highlighted the need to encourage maternal verbal engagement with premature infants, citing numerous studies that demonstrate shared reading (parents to infants) as a highly efficient way of safeguarding children from school failure. She presented an inspiring account of the development of a reading programme in the Tygerberg Hospital neonatal intensive care unit, using local languages and rhymes to create books for mothers to read to their infants during their hospital stay. Mark Tomlinson

(Psychologist & Professor, University of Stellenbosch) also presented on a book-sharing clinical trial running in tandem with the Thula Sana Mother-Baby Home Visiting Programme in Cape Town and due to start in Lesotho, a country neighbouring (locked within) South Africa.

A number of international speakers contributed to the conference. While Alessandra Piontelli (University of Milan) was unfortunately unable to travel at the last minute, her presentation was conducted via 'voice over powerpoint'. Her lively sense of humour and fascinating visual material made up for her lack of presence, as she challenged a number of popular notions about foetal life and emphasised that our knowledge of foetal experience is still very uncertain. Louise Emanuel (Tavistock Clinic, London) presented clinical work with families in which the toddler's hatred of his/her new sibling is murderously intense. She explored states of persecutory anxiety, sadism and rage in toddlers towards a younger sibling and the technical dilemmas faced when these conflicts are enacted in the therapy room. Her descriptions of the manifestation of this rage in the therapy room captured the extreme paralysing countertransference elicited, which she explored drawing on Donald Meltzer's (1968) paper: 'Terror, persecution and dread'. Using Freud's (1915) description of how 'the shadow of the object falls on the ego', Emanuel linked these sadistic attacks to the trans-generational transmission of unresolved parental loss and trauma. She explored how parents' own experiences of repressed rage can influence sibling fierceness and parents' reactions to their children's behaviour, for example, parents who project their rageful and sadistic impulses into their children, while remaining passive themselves, create a dynamic where the parents become victims alongside the new baby while the older child plays the role of tormentor. This kind of dynamic, awash with persecutory anxiety, can create collapses in strategy and a paralysis, in both parents and therapist, of which the therapist must remain mindful.

Often absent in the literature and in the therapy room, fathers were also considered in a number of presentations that ranged from the theoretical to the applied. High rates of 'father absenteeism' have been highlighted in both local and international literature (Magruder, 2010; Posel & Devey, 2006; Richter & Morrell, 2006) and many reasons have been postulated for these shifting paternal roles. Tessa Baradon's (Anna Freud Centre, London; Visiting Adjunct Professor, University of the Witwatersrand) paper moved away

from a 'father-blaming' stance and asked pertinent questions with regards to the marginalisation of fathers. She questioned the positioning of fathers in the theory, as a support to the mother and infant, rather than as a subject with a relationship with their infants in their own right, and highlighted the tendency of practitioners themselves to marginalise fathers in the practice of parent-infant psychotherapy. The exclusion of men from more 'nurturing spaces' led to interesting discussion and it was questioned whether the increasing feminisation of the helping professions was another manifestation of this exclusion of men. Baradon emphasised the need for a paradigm shift that engages fathers and invites them back into the caregiving space.

Changing constructions of gender and family structure were considered in Nick Davies' (University of the Witwatersrand) presentation on paternal function, based on a paper co-authored with Gillian Eagle (University of the Witwatersrand). He proposed a need to avoid conflation of the paternal function with maleness and masculinity and to consider the paternal function as distinct from the role of the father. He proposed that when separated from the notion of fathering, a space is opened up 'to consider alternative sources of paternal functioning and the related importance of the position of third persons or objects in infant development'. In the context of high levels of father absenteeism, the idea that the 'paternal function' could be performed by people in the infant's life other than the father is heartening.

Common to Africa is the notion of multiple caregivers. Nicola Dugmore's (Chairperson of GAIMH-SA) presentation noted the co-rearing of many South African infants by nannies, who are often employed as domestic workers in the infant's home. She highlighted the dearth of research into 'the impact of these caregivers on the infant's early life and development'. Her presentation used a variety of infant observation notes to comment on 'the triangulated relationship that develops between infant, mother and nanny'. Judy Davies' (private practice, Cape Town) paper also focused on issues of substitute care. She used psychoanalytic and infant observation literature to suggest guidelines that can help parents choose appropriate substitute carers for their children. Her presentation also included aspects of Jacklyn Cock's (1988) chapter entitled 'Trapped Workers: The case of domestic servants in South Africa' and local psychoanalytic studies on the influence of nannies on children (Goldman, 2003; Wulfsohn, 1988).

Mark Tomlinson's (University of Stellenbosch) plenary presentation highlighted the need for further research into early intervention, particularly in order to determine more clearly who benefits from what kind of early intervention, and why, in order to streamline types and costs of interventions. This need for local research to direct and inform future policy in the departments of Health and Social Development was also highlighted by Zanele Twala, the Director and Sector Expert on Early Child Development in the Department of Planning, Monitoring and Evaluation in the Presidency. The conference was felt to be an important milestone in the journey toward meeting these research needs.

Overall, the conference brought together a number of professionals and lay counsellors in the field of infant health and highlighted the importance of mental health. The closing discussion of the conference emphasised that in order for the field of infant mental health to continue to grow and gain space on the agenda in South Africa as a developing country, interventions will need to take into consideration the reality of limited government funding. Much of the responsibility for infant mental health will continue to fall onto communities, NGOs and the professions themselves to find practical solutions. The conference closed with a call to action and in particular, for more collaboration between private, public and NGO sectors.

*GAIMH-SA is an affiliate of the World Association for Infant Mental Health (WAIMH). For more information, please visit the GAIMH-SA website at [www.gaimh.co.za](http://www.gaimh.co.za)*

\*The support of the DST-NRF Centre of Excellence in Human Development towards this research/activity is hereby acknowledged. Opinions expressed and conclusions arrived at, are those of the author and are not necessarily to be attributed to the CoE in Human Development.

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# A Parent Group Initiative in an Intensive Care Unit in South Africa

By Kerry Anne Brown, Occupational Therapist, Red Cross War Memorial Children's Hospital

Carla Brown, Social Worker, Red Cross War Memorial Children's Hospital

Astrid Berg, Division of Child and Adolescent Psychiatry

University of Cape Town and Stellenbosch, South Africa

Note: The initial plan was to run a group to meet caregivers' needs and we wanted to deliver the best service possible to reflectively respond to actual needs. Our intention was never to collect data for the purposes of generalisation/research, and the work was conducted only as a practice improvement initiative. Our aim was to improve our own clinical practise. Whilst running the groups we found useful lessons, and came to learn that there is no other literature to date of OT's and social workers running similar groups. This together with the interest from colleagues who felt that what we learnt might be clinically useful to others, we were prompted to write this article

## Introduction

While families' experiences in Paediatric Intensive Care Units (PICU) have been well documented in the literature (Flacking et al., 2012; Frazier, A., Frazier, H. and Warren, 2010; Johnson, n.d.; Latour et al., 2011; Latour, van Goudoever, & Hazelzet, 2008; Macdonald, Liben, Carnevale, & Cohen, 2012; Meert, K.L., Clark, J. and Eggly, 2013; Miles & Mathes, 1991; Romer, L. H., Nichols, D., Woods, B. H., Latour, J. M., & Mesman, 2008; Rushton, 1990; Scott, 2002), very few, if any pertain to a unit in an African setting. This contribution aims to bridge this gap and to explore the barriers, as well as the opportunities, that present themselves in the PICU of a tertiary hospital in South Africa.

Red Cross War Memorial Children's Hospital (RCWMCH) is a 300-bed specialist health facility paediatric hospital in Cape Town. It is the only stand-alone paediatric hospital in Sub Saharan Africa offering a

full range of sub-specialties at quaternary and tertiary levels of care (Western Cape Government, 2015). The majority of patients and their families come from impoverished communities (Children's Hospital Trust Annual Report, 2012). RCWMCH has the largest ICU for children in Africa. It has a 22 bed PICU with a high turnover. 1300 children are admitted per annum with an average length of stay of 3 days. The largest age group of children admitted is below one year of age (RCWMCH PICU, 2013).

Despite constant presence, it was observed that parents often had minimal interaction or physical contact with their sick infants. We assumed that this would be very different to how they would have handled their children at home.

However, to appreciate the ordinary environmental context more fully, the culture from whence our children and families originate needed to be understood.

In our diverse setting, the African Xhosa culture predominates. Xhosa speaking patients make up about 60% of PICU patient turnover, the remaining 40% is predominantly Afrikaans speaking with a growing group of families from other parts of Africa who speak French /Portuguese or other languages including English. There is a wide diversity of cultural background in the RCWMCH PICU (for both staff and patients).

As staff we therefore needed to listen to mothers to give us insights into indigenous caregiving practices. It became apparent that parents had a wealth of existing knowledge and skills regarding their infants. For example Thula Thula is a well-known South African lullaby, frequently used to soothe infants and is a phrase that has become synonymous with being loving and soothing. It is in stark contrast to the PICU shrill alarms or beeps. Parents unanimously reported that the alarm bells were not only the first stimulus they noticed, but also the most disturbing.



## The Problem

The majority of parents were observed by the PICU Occupational Therapist (OT) and Social Worker (SW), to not talk, touch or interact with their sick infants; they were very rarely seen to be participating in care-giving activities. Thus it was thought that parents' existing knowledge and skills were being inhibited when their child was in the PICU.

The OT and SW working in the PICU were concerned about the long term effects on both the infant and caregiver's wellbeing and mental health from not touching or interacting during this time. This concern is amply supported in the literature. (Bowlby, 1973; Feldman & Eidelman, 2003; Latva, Korja, Salmelin, Lehtonen, & Tamminen, 2008; Robertson, 1958; Scher et al., 2009; Treyvaud et al., 2009)

While the negative effects of the separation of mother and infant have been documented (Bowlby, 1973; Robertson, 1958), the long term negative effects of reduced physical touch have been researched in more recent years. Physical proximity, including touch as well as emotional closeness were found to be crucial to the emotional, social and physical well-being of parents and infants in NICU's and PICU's alike. Not only were these factors important to the long-term infant-parent relationship, but also to the infant's physical development and health. (Feldman & Eidelman, 2003; Latva et al., 2008; Scher et al., 2009; Treyvaud et al., 2009)

Active parental involvement with the hospitalised preterm infant, particularly skin to skin contact, and supported parental involvement in caring for those infants have been demonstrated to result in positive neurobehavioral and neurodevelopmental outcomes, improved cognition and an increase in psychomotor organization (Als et al., 2004; Milgrom et al., 2010; Scher et al., 2009).

In addition, parental stress and mental health have been shown to have long term impacts on the child's emotional development and behaviour (Huhtala et al., 2012). Helping parents to interact with their infants may reduce their level of stress and give them a sense of competence and mastery. This will therefore have a positive effect on the child's behavioural and emotional development (Butler & Als, 2008; Davidge, 2009; Feldman & Eidelman, 2003; Latva et al., 2008; Scher et al., 2009; Treyvaud et al., 2009).

It needs to be emphasized that the medical excellence that has been achieved in critical care will not on its own determine

the eventual outcome for the child and the family. The interactions and relationships within healthcare teams, families and patients which in turn impact on parental levels of stress, as well as on their physical and emotional relationship, with their sick infant are of equal importance (Flacking et al., 2012).

The concern of the RCWMCH PICU OT and SW was thus well-founded as the PICU setting in the RCWMCH clearly revealed some barriers that made it more difficult for parents to interact with their children as they were accustomed to doing at home.

The PICU OT and SW therefore conducted individual interviews, pre and post group questionnaires, observations as well as open discussions in the group. This was a clinically informed intervention from which valuable information to improve clinical practice was gained. Prior to initiating an intervention available literature was studied in order to help inform their practice.

## The Family Centred Approach

The RCWMCH PICU OT and SW's response to the problem was to examine and put into practice the "Family-Centred Approach". The Family-Centred approach is recognised as the "best practice" in paediatric health care settings including the PICU (Frazier, A., Frazier, H. and Warren, 2010; Meert, K.L., Clark, J. and Eggly, 2013).

The core principles of family care practice acknowledge that the family is the child's primary support and strength; and that the family's information and perspective is important in care plans, clinical decision making and service delivery (American Academy of Pediatrics, 2003; Macdonald et al., 2012).

Macdonald et al (2012) found that although international PICU's may adopt the family-centred care model, the parents lived experience demonstrated that much work still needs to be done with regards to including the family. Parents reported that the most hurtful experience was being treated as visitors. They were distressed that the bedside was more of an office than a bedroom, that it offered little privacy, it favoured staff above parents and had many loud noises (Macdonald et al., 2012).

It was therefore important to understand the particular challenges in the RCWMCH PICU affecting the families in order to develop a service that could best address their needs. Current literature was therefore first explored to best guide clinical practice.

From the literature there were 3 areas in which the notion of a Family Centred Approach was challenged. Namely challenges to the physical relationship, the emotional relationship and the loss of caregiver role.

### 1. Challenges to the Physical Relationship

For the caregiver who accompanies the child, the impact of the clinical technologically rich environment of the PICU and its serious lifesaving interventions are immediately felt. Frazier and Warren (2010, p. 83) describe PICUs as "busy, crowded and over stimulating, short staffed, procedure orientated and hectic". The technological equipment is experienced as an intrusive bombardment of unfamiliar machinery, technology and sounds which are unanimously stressful and consistent with Dutch studies that the first things parents commented on were the alarms (Delva, Vanoost, Bijttebier, Lauwers, & Wilmer, 2002; Latour et al., 2011).

Other stressors were the changes in their child's appearance and behaviour and restraining technical equipment (Meyer, Snelling, & Myren-Manbeck, 1998).

### 2. Challenges to the Emotional Relationship

The circumstances, which precede a PICU admission for children and their families often involve crises of such severity that they cause fear and feelings of helplessness in parents (Meyer et al., 1998; Romer, L. H., Nichols, D., Woods, B. H., Latour, J. M., & Mesman, 2008). Similarly, Dyer (1995) goes as far as describing "the experience of the intensive care unit patient as comparable to that of a torture victim". PICU admissions have a higher possibility of the child dying compared to other areas of paediatrics (Ramnarayan, Craig, Petros, & Pierce, 2007).

Lee and Lau (2003) state that when a family experiences stress from a situation such as an ICU admission, the members of that family often feel disorganized and helpless; they may have difficulty in accessing resources that would assist with coping. Families can be overwhelmed with feelings of despair, anger at what has happened, guilt, denial and a real fear that they could lose their loved one (Verhaeghe, van Zuuren, Defloor, Duijnste, & Grypdonck, 2007).

The psychological effects of injury and illness are not only applicable to the

child but extend to the family system within which the child functions (Scott, 2002). For this reason all family members were considered and included in the intervention at RCWMCH as much as possible.

### 3. Loss of Caregiver Role

The disruption to the parenting or caregiving-infant role has been named as one of the most distressing factors of the PICU admission (Latour et al., 2011; Meyer et al., 1998). The PICU environment and process strips caregivers of their familiar parental and protective roles (Meyer et al., 1998).

Parents are the most important resource in reducing children's anxiety (Miles & Mathes, 1991). Therefore attempting to eliminate or reduce parental stress when in the PICU is even more important.

The above 3 challenges in the domains of physical and emotional relationships and the loss of caregiver role, were starkly illustrated in the RCWMCH PICU.

In view of this the RCWMCH PICU OT and SW identified the need for a parent group. This was an innovative intervention which has not previously been described.

## The Intervention

A unique intervention to involve as many family members as possible to address stressors was developed. This consisted of a weekly caregiver support group in which the families' needs were addressed. All caregivers and extended family in the PICU were invited and it was co-facilitated by the RCWMCH PICU OT and SW. It was an open group that covered three main areas: appropriate neuro-developmental information, orientation to the PICU and psycho-emotional support.

The therapeutic value of a group is well documented by Yalom (1995) as a powerful learning environment, which can facilitate a sense of hope through meeting others in similar situations who have overcome difficulties, observing and imitating behaviours of others.

The group ran weekly since its initiation in 2012. It had a flexible format that allowed reflection and adaptation to emerging needs. A description and analysis of the group over a year (from 2013 – 2014) will illustrate aspects of this intervention in this particular set of parents whose children were patients in the PICU during that time.

## Group Participants

All caregivers, friends and family present in the PICU or waiting room on the day of the group were invited to attend. In the South African context the involvement of extended family and friends in raising children is common (Amateng, A.Y., Heaton, T.B. & Kalule-Sabiti, 2007). Hence in this PICU group there was a huge diversity in participants, ranging from biological parents and grandparents to neighbours and aunts. On average, 17 caregivers attended the weekly open group which took place in a quiet room away from the busy and noisy PICU. The caregivers were mostly female with only 2 men, on average, attending per week. Medical, nursing and cleaning staff, allied health professionals, hospital chaplains and students were invited to attend. On average, one staff member/student attended per week.

The majority of participants were isiXhosa speaking, although English and Afrikaans were also spoken by some, so that all 3 languages had to be accommodated. The offering of beverages and snacks proved to increase group attendance, a fact that was anecdotally supported by NICU groups in the UK who termed their meetings 'pudding club' (personal communication from Great Ormond Street).

## Occupational Therapist and Social Worker Co-facilitation

The unique collaboration between the social worker and occupational therapist collaboration has had multiple successes: there was harmonious co-facilitation that was reflective and responded to emerging parent needs and it combined a psychosocial and neuroscience developmental focus on an appropriate level

The dual approach means that parents were afforded psychological and emotional support so that they were more contained to be able to have the capacity to understand medical, neuroscience and neurodevelopmental information.

## Pragmatic Techniques

Various techniques were developed to optimise support in these language and educationally diverse parent groups. Techniques used included: sharing information using dolls and visual media; creating tolerance and advocacy for cultural beliefs; facilitating engagement with their infants and empowering by advocating for PICU parent rights.

Caregivers reconnected with their infants' needs, obtained pertinent information about neuroscience for infants including (Berg, 2006; J. Bergman, 2010; N. J. Bergman, Linley, & Fawcus, 2004) Ayres' Sensory Integration (Mailloux et al., 2011) and neurodevelopmental techniques theory (Lubbe, 2008; Moore, Anderson, Bergman, & Dowswell, 2012) were enabled through the doll and pictures. Practical hands on techniques (nesting and safe handling) were demonstrated and practised.

The most fundamental learning however was listening to caregivers' narratives and learning from their dynamic emerging needs what was needed in the group.

As expected the journey to the PICU was frequently experienced as traumatic, as caregivers often had to go to several institutions before being referred to the tertiary PICU at RCWMCH (Hodkinson, Argent, Wallis, Reid, & Perera, 2016). Caregivers often needed to gather their infant and run in the middle of the night to the nearest medical facility without money or additional food or clothing. Asking a neighbour or relative stranger to look after siblings was common in these extreme situations.

As Maslow's hierarchy would dictate (Maslow, 1943), once hunger and thirst were satisfied and crucial information about the critically ill infant accessed then psycho emotional needs could be addressed.

Common beliefs, needs, fears and questions were elicited through observations, group discussions, pre and post group questionnaires and individual interviews. These were then used to improve group facilitation.

## Lessons learnt from the RCWMCH Caregivers

Our caregivers expressed fear, anxiety and anticipatory grief, reflecting findings around the world (Latour et al., 2011; Macdonald et al., 2012).

The common perception of an ICU was based on pre-existing knowledge of an ICU depicted on television. This contributed to the belief held by a large majority of caregivers that almost all patients would die once in an ICU. Some caregivers reported that they believed questions and discussions with medical staff would result in families being asked to turn off machines because machines/ventilators were only allocated to those that were terminal. This explained why many

caregivers reported that they were 'too scared to ask questions'. It also highlighted a truth that was difficult for staff to adjust to: not only were caregivers not touching their children due to fears of the pipes and tubes surrounding them, but because they felt that emotionally they needed to let go. Some caregivers felt they needed to detach from their infants as they believed their infant was dying or already dead.

The RCWMH PICU statistics demonstrate that in the last 2 years mortality has decreased from 10% to 3 to 7 % (RCWMH PICU, 2013). This made the caregivers' grim perception even more distressing to staff and highlighted the significance of sharing information to refute misconceptions.

Following the group, individual needs were addressed e.g. counselling, one-on-one intervention or referral to other services. Parental feedback and reflections from the questionnaires have shaped the group and translated into changes in practice in the multidisciplinary team (including parents) in the RCWMH PICU and other wards.

## Outcome

Following the implementation of the RCWMH PICU support group numerous other caregiver groups were started in other wards of the hospital. Based on caregiver's feedback, the PICU multidisciplinary team began investigating how best to implement neurodevelopmental supportive care in sustainable and pragmatic ways in this critical care setting.

The RCWMH PICU implemented a daily "Quiet Time" where nonessential procedures stop, lights are dimmed and noise is reduced. This quieter environment benefited infants, caregivers and staff. It reduced sensory bombardment allowing infants to sleep, caregivers to relax and staff to work. The success of the PICU group was noticed greatly over the Christmas period when there was a break in the group. During this time the nursing staff reported a dramatic increase in complaints, and through investigating the complaints truly learnt the value of the group in reducing anxiety, misconceptions and calming and containing caregivers.

## Conclusion

Caregiver feedback and reflections from the questionnaires have shaped the group and translated into changes in practice in the multidisciplinary team and throughout the hospital. In the PICU a more contained, informed caregiver is now able to engage

with their infant and re-establish their role. Caregivers are now close enough for their infant to smell, feel and hear them sing Thula Thula.

## Acknowledgements

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## From the Kauppi Campus

### -News from WAIMH Central Office

By Päivi Kaukonen, Executive Director,  
Tampere, Finland, [ed@waimh.org](mailto:ed@waimh.org),

Kaija Puura, Associate Executive Director,  
Tampere, Finland, [congress@waimh.org](mailto:congress@waimh.org)  
and

Minna Sorsa, Administrative Assistant,  
Tampere, Finland, [office@waimh.org](mailto:office@waimh.org)

Dear Colleagues,

The WAIMH World Congress 2016 will take place in Prague in a couple of weeks. The central theme of the Congress is Infant Mental Health in a Rapidly Changing World: Conflict, adversity and resilience.

We would like to remind you on two interesting Pre-Congress Institutes and the Congress Gala Dinner.

### Pre-Congress Institute I

Infant Mental Health Policy under Stable and Peaceful Conditions and During Humanitarian Crises



Sunday May 29, 2016, 10:00-15:00

[MORE INFO](#)

### Pre-Congress Institute II, organized in cooperation with Zero to Three

Diagnostic Classification DC 0-5

Sunday May 29, 2016, 10:00-16:00

[MORE INFO](#)

### Gala dinner

The Congress Gala Dinner will be a splendid mixture of local Czech culture, Middle East kitchen and Middle East music by the Heartbeat Performance Band. Place: Zofin Palace.

[MORE INFO](#)



### Sponsor a Delegate

Since the World Congress 2012 in Cape Town, South Africa, WAIMH has run a Sponsor a Delegate Programme in connection with World Congresses. The program started by an excellent initiative of Astrid Berg, the chair of the Local Organizing Committee in Cape Town. WAIMH has also this year launched the Sponsor a Delegate programme to support individuals from low and middle income countries to participate in the congress. A sponsorship contains the congress registration fee and four days accommodation for the congress.



The goal of WAIMH is to cover registration and accommodation expenses for as many participants as possible. The deadline for applications was 15th April. Yet, we keep the donation link open to individuals and our Affiliate associations. We encourage you to donate to the program and support young clinicians from low and middle income countries to participate in the Congress. Look for more info. ([LINK](#))

### Social media

WAIMH members and Affiliate Associations have wished for more international networking and discussion possibilities. We are answering to this request by increasing our presence in chosen social media channels. Please like us on [Facebook](#) and follow us on [Twitter](#). In near future, we will open up easier forms of discussion for you. Do you have existing news to share with colleagues? If you would like to help WAIMH in this process, and would like to volunteer for this program, and learn something new, contact the Central Office: [office@waimh.org](mailto:office@waimh.org).