

Kayf al Haal كيف الحال How Are You

An International Collaboration to Improve Cancer Care in Iraq
A Project of The Iraqi Children's Art Exchange and
Children's Welfare Teaching Hospital, Medical City, Baghdad

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A Working Prospectus

Kayf al Haal/How Are You: An International Collaboration to Improve Pediatric Cancer Care in Iraq

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On the cover: the 7 year old boy Ahmad Ismael in his bed,
Al Mansour Pediatric Hospital (2001)

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INTRODUCTION

According to WHO statistics, Iraq has the highest rate of pediatric cancer and leukemia in the world. War, economic sanctions, ongoing violence and instability have made it difficult if not impossible to tackle this very serious health crisis in the last decades; impossible for Iraqis and difficult for the international community. Many Iraqi doctors have left the country since the first Gulf War in 1990; many others have been killed. Those who stayed in Iraq struggled to meet ever increasing and critical medical needs with dwindling medical resources, including medicines and medical supplies, equipment and trained personnel.

The Iraqi Children's Art Exchange has been using art and documenting photographs to advocate for Iraqi children --especially those with cancer and leukemia-- since January, 2001. Now, we are poised to facilitate a project that promises concrete medical help from the international community, working in collaboration with doctors on the pediatric cancer unit at Children's Welfare Teaching Hospital in Medical City Baghdad. Help can be a delicate matter. We know from our experience and from the literature emerging from the growing network of international NGOs and humanitarian organizations, that working together successfully, across the divides of language, culture and politics requires more than good intentions. Learn about the local context, ask lots of questions and listen with humility recommends the Partners in Health (PIH) *Program Management Guide* (2011). ICAE has been doing that for some years. To the extent that Westerners, with limited direct access to Iraq can, we understand the context in which the doctors have been working over these last decades. We believe we understand the challenges and frustrations of parents who have not been able to protect, provide or care for their children amidst the chaos in Iraq. And, we understand children.

What follows is our vision of "help": a working prospectus for a transcultural project.

PROJECT GOALS

To improve medical care and outcomes of pediatric cancer patients in Iraq. To create opportunities for international partners to work with Iraqi doctors, hospitals and civil society organizations in developing and sustaining projects and programs to identify and help meet the needs of pediatric cancer patients, their families and the doctors, nurses and medical staff who care for them.

BACKGROUND INFORMATION

I. Children and Healthcare in Iraq

At the center of the story is the child. Legacy of a family and community, children are the seed stock of a nation. They are our most precious and yet most vulnerable resource. Every child is dependent on a community of adults --parents, teachers, doctors, civic and religious leaders-- to care for, protect and guide them through childhood into youth and adulthood. Sometimes, despite our best intentions and overwhelming sentiment, adults cannot fulfill our obligations or meet our responsibilities for children. Our capacity --as individuals or as a community- to care for them is dependent on myriad economic, social and political factors; local, national and international events that are often out of our control. When the world we inhabit is beneficent, children can thrive and prosper; when life around us is stressed, when events are catastrophic, everyone suffers, including children.

And so it has been in Iraq. UNICEF sums it up this way, "Twenty five years of sanctions and conflict has made Iraq a difficult and dangerous place to be a child." Indeed decades of economic, political and social instability have made it difficult if not impossible for Iraqis to meet children's most basic needs for security, food, housing, education and healthcare. And this has taken an enormous toll.

What is enormous? According to UNICEF the Under Five Mortality Rate (U5MR) in Iraq "...the single most significant indicator of the state of a nation's children..." increased by 160% in the decade 1990-2000. Overall, children declined in only 17 of 143 countries in that decade. The country whose children experienced the greatest decline was Iraq, where the number of deaths recorded for children under five years of age climbed from 50 per 1000 live births in 1990 to 130 deaths in 2000. The next greatest decline 74%, was in Botswana which at that time had the world's highest rate of HIV/AIDS infection. This is what we mean by "enormous toll".

And, there was more bad news. Iraqi doctors began to notice a significant increase in pediatric cancer/ leukemia cases beginning in the mid-nineties. Evidence has been anecdotal because the health care system, like all systems in Iraq, was collapsing under the weight of UN Sanctions and the devastation of the first Gulf War. Ongoing instability has made it difficult to collect and verify data, develop national strategies, carry out research or publish studies. Nonetheless, reports are beginning to appear. "*Trends in Childhood Leukemia in Basrah, Iraq (1993-2007)*" published in The American Journal of Public Health (2010, Hagopian, Lafta, Hassan, Davis, Mirick, and Takaro) concludes that childhood leukemia rates more than doubled over fifteen years in Basrah, from 3 per 100,000 to 8.5 per 100,000. In Baghdad, Dr. Mazin Al Jadiry reported that the number of cancer/leukemia in-patients diagnosed at the Children's Welfare Teaching Hospital had doubled from 110/month in 2005 to 218/month in 2009. The problem is worse in some cities. The International Journal of Environmental Studies and Public Health (2010) reported cancer rates in Fallujah had increased fourfold, noting this is twelve times higher than found in comparable populations in Egypt, neighboring Jordan or Kuwait. In 2004 WHO listed Iraq as number one in the world for pediatric cancer deaths, 21.6 per 100,000.

By comparison: the rates for leukemia and brain tumors, the most common childhood cancers in the US, have remained steadily in the range of 3.7 to 4.9 cases per 100,000 since 1985 according to the National Cancer Institute. And, the survival rate in the US is now 79.6% compared to Iraq where the survival rate is below 50%.

II. Children's Welfare Teaching Hospital, Medical City Baghdad and the Iraqi Children's Art Exchange

The Iraqi Children's Art Exchange(ICAIE) uses art, art-inspired projects and documenting photographs to create a dialogue -- across language, culture and politics-- between Iraqi children and youth and children and youth in the U.S. We encourage and support drawing, painting and sculpting for the sheer pleasure of it. Beyond that we recognize art as an important language of childhood, one that offers children and youth an opportunity to express themselves, to speak to each other and to the wider community, and to have their views taken seriously.

ICAIE began in December 2000 with a visit to what is now Children's Welfare Teaching Hospital in Medical City Baghdad. There we met Drs. Salma Al-Haddad and Mazin Al-Jadiry who helped facilitate our first art exchange, giving children on both sides the opportunity to "say" something to each other. We have maintained a working relationship with these two doctors over the last thirteen years. Despite enormous personal and professional challenges, they have stayed on at the hospital where they continue striving to provide the very best, up-to-date medical care available to their patients. The Iraqi

medical system, once boasting the best doctors and hospitals in the Middle East has been devastated, unable to meet the increasing --and increasingly serious-- medical needs of the population. In a 2011 paper authored by Drs. Salma, Mazin and four others they list shortages of professional manpower, infrastructure, diagnostic and therapeutic facilities, supportive and palliative care, drugs and medical supplies at their hospital. (J Pediatr Hematol Oncol 2011; 33:S154-S156)

In the face of this, they nonetheless created opportunities for improvement by reaching out to international organizations, institutions and individuals, and responding positively to appropriate proposals from internationals. It has had a positive impact on the doctors and on patient outcomes. "...exposure to internationally accepted current practices, has encouraged Iraqi pediatric oncologists to implement improved patient management practices in their daily work," they wrote, and encourages "... a multidisciplinary approach to the management of childhood cancer."

Drs. Mazin and Salma partnered with ICAE In 2010 to develop a small arts-based psychosocial project on the unit with the help of our Outreach Coordinator who was working temporarily in Baghdad. We bought books and art supplies, games and puzzles, and plastic tables and chairs to create a mobile activity/play space for children. A part time coordinator was hired. Despite our best intentions, the project did not work well, and it was stopped some six months after we began. Somewhat discouraged, but not defeated the doctors packed away the furniture and supplies. Now, we propose to build on our ideas from that first project, creating a better, more sustainable project informed by what we learned with the first attempt.

One thing was clear, our intervention could not focus solely on the sick children; any addition or change in routine or programming affects everyone on the unit. We recognize that Iraqi children and the community of adult caregivers they depend on, including doctors and other medical personnel have suffered a great deal. Their capacity to carry on in the face of ongoing challenges has been compromised, depleted under the weight of years and years of scarcity, isolation, violence and instability.

Kayf al Haal/How Are You is a renewed response to this situation, a collaboration that takes a holistic approach to helping meet the needs of the community of people on the pediatric cancer unit at Children's Welfare Teaching Hospital: children with cancer, their families, doctors and other medical personnel.

PROJECT COMPONENTS

Kayf al-Haal is a transcultural collaboration framed in resilience theory. Our goal is to supplement and support medical care for Iraqi children hospitalized with cancer and leukemia, using a holistic approach and strategies that consider the many needs and challenges faced by patients as well as caregivers. Our approach is multidisciplinary, crossing traditional lines to borrow and integrate theory and best practice in child development, psychology, arts, science and medicine. We are inspired by the emerging fields of Arts in Healthcare and Medical Humanism. The project sits at an intersection of resilience, psychosocial intervention and art.

I. RESILIENCE*

We are developing our approach in collaboration with The Resilience Research Center (RRC) at Dalhousie University in Halifax Nova Scotia. They describe resilience as: *the capacity of individuals to*

navigate their way to resources that sustain well-being; the capacity of individuals' physical and social ecologies to provide those resources; and the capacity of individuals, their families and communities to negotiate culturally meaningful ways for resources to be shared.. (Ungar 2008)

Resilience:

- * offers a positive view of the human condition, of our capacity--as individuals and communities of people-- to endure, to carry on, to thrive and triumph in the face of adversity;
- *creates a framework for respectful, considerate collaboration across age, class and culture;
- *offers one way to measure outcomes

II. PSYCHOSOCIAL PROGRAMS

We are developing our ideas in the context of work done by the International Organization of Migration(IOM) and a paper authored by Guglielmo Schinina, *Psychosocial Status of IDP Communities in Iraq, An Assessment* (August/September 2005). Psychosocial programs, he writes, respond to people's interconnected social and psychological needs, addressing them in an integrated manner. Thus, psychosocial: "...aims to focus on the interrelation between psychological and social components, such as to find ways to work with the individual within a group and to nurture the group to take care of its group identity and that of the individuals contained within it. So the psychosocial programs work on the capacity of relation and communication towards the readjustment of the role of individuals, groups and communities inside a society."

A psychosocial approach:

- *is multi/inter-disciplinary;
- *doesn't tend to psychologize or pathologize individuals or communities, rather it frames them as normal in the context of the abnormal and difficult --even catastrophic-- situation they face;
- *recognizes suffering as a characteristic of individuals and communities in war-torn communities such as Iraq, tying their suffering to a variety of stresses and needs created by their situation --loss of economic and social structures, loss of systems of social and cultural meaning, instability and precarious living conditions --, rather than to what some might label psychological trauma or PTSD;
- * seeks to empower individuals and communities rather than make them dependent on helping organizations

III. ART

"The child meets the world mainly through the senses of touch and sight, and typically he soon responds by making images of what he perceives. The tie between stimulus and response is deeply rooted in all organic behavior... Its main psychological function is evident. The picture, far from being a mere imitation of the model, helps to clarify the structure of what is seen. It is an efficient means of orientation in a confusingly organized world." Rudolf Arnheim, *Beginning with the Child*

Every day, all around the world --in the global south and in the north, in the east and in the west-- parents, teachers, therapists, social and humanitarian aid workers give children art materials, with no particular instructions. We provide opportunities to paint and draw, cut, paste and sculpt for the sheer pleasure of it. Beyond that we recognize art as an important, powerful and expressive language --a tool-- of childhood. It is one way children explore and respond to the oftentimes baffling world around them, a way to begin to understand that world and their place in it. It is also, according to Brent and Marjorie

Wilson, a way to "...engage in world making, to document the present, explore the past, and anticipate the future, to invent scenarios and control events..." And so we organize spaces and provide materials. We make ourselves available; we discuss and respond. We encourage and support their efforts. Through this, we develop a relationship and we begin to know the child. And the child begins to know the world, and to know us, as individuals and as a community of caring adults they can trust and depend on.

Art in this sense, supports the healthy social, emotional and cognitive development process of children. Many parents, teachers and humanitarian workers sense this intuitively. Loris Malaguzzi went further, developing an arts-inspired philosophy and pedagogy for early childhood centers in Reggio Emilia Italy after WW II. His thinking is reflected today in Reggio-inspired schools, projects and programs at every level, all over the world, including those designed and implemented by ICAE over the last twelve years. Children are defined as powerful, rich in resources, competent and social. Children learn about themselves and the world by reaching out and interacting with adults --parents, neighbors, classrooms, schools, communities, nations and eventually the wide world around them. Knowledge is co-constructed.* And art, is one of the primary languages of communication in this process, facilitated by the availability of a range creative materials.

A Reggio-inspired psychosocial intervention will supplement and support medical care for children at Children's Welfare Teaching Hospital in Baghdad. They are sick, but they are still children, with the same needs for: time and a place to play, because this is children's "work"; appropriate materials to help develop and sustain the cognitive, social and emotional skills and competencies needed in the worlds they inhabit inside and outside of the hospital; and a community of caring adults to support their growth and development.

IN CONCLUSION

The project, framed very broadly, seeks to improve the overall well-being of the people who inhabit this hospital ward. What we are proposing is an action research plan where we will be gathering information/knowledge as we go along so that we can better understand and respond to needs of children and their adult care-givers. Art, and this particular philosophy/pedagogy of art and children, fits very comfortably with the other two elements, rounding out a project that: sees human capacity and resilience in both children and adults; is co-constructed across age and culture; and is developed in response and consideration of the entire community of people on the hospital unit: patients, families, doctors and medical staff.

* Rinaldi, C. (1998). Projected curriculum and documentation. In C. Edwards, L. Gandini & G. Forman (Eds.), *The hundred languages of children: The Reggio Emilia approach - Advanced reflections* (pp. 113-125). Norwich, CT: Ablex Publishing.

*The Resilience Theory (Nadhariyet Al Nuhoodh): Selecting the word (Nuhoodh) to translate (Resilience) came as a result of ongoing research into whether this theory is known to Iraqi researchers or other Arab researchers in the same field. We have found that it is unknown to specialists in Baghdad - Iraq. On the other hand we have found that in other Arab websites and word of mouth sources (Resilience) was translated into (Nadhariyet Al Muroonah) meaning (flexibility) which turned out to be an exact translation of the Theory of Elasticity. Thus, in order to avoid any confusion between the two theories we found that the most suitable word in Arabic to describe the human condition, which portrays the person shaking the dust off himself and rising again to return to the normal life he/she used to lead prior to experiencing a state of shock or disaster, whether natural or by war.

