

COH Community Services (COHCS), Inc. Organizational Profile and Strategic Plan

### **Background and History of COHCS**

Circle of Hope Community Services, Inc. (COHCS) started in August 2015 as a community mental health program for adolescent cancer patients at Philippine General Hospital (PGH). It is the nonprofit organizational arm of MedMom Institute for Human Development (www.med-mom.com), a transdisciplinary center in Metro Manila, Philippines that promotes optimal development through services, training, and research. MedMom Founder and Clinic Director, Dr. Lourdes "Tippy" Tanchanco, tapped members of MedMom's Psychological Services Team to look into the possibility of collaborating with the PGH Pediatric Hematology-Oncology Department in response to a social media post regarding the high incidence of depression among their teen cancer patients. Consultants and staff at PGH had become increasingly concerned about the growing number of teen patients who were experiencing hopelessness, despair, and the loss of will to live. There were those who would drop out of treatment, while others reportedly verbalized thoughts of suicide. In fact, elsewhere, depressive disorders and symptoms are found to be common in cancer patients, with up to 38% having major depression based on statistics in the United States. According to studies, these worsen over the course of cancer treatment, persist long after cancer therapy, reoccur with the recurrence of cancer, and significantly impact quality of life. Unfortunately, depression is frequently under-recognized and under-treated in oncology practice, with low-income patients being particularly unlikely to receive mental health treatment. COHCS founding members (Dr. Joanna Herrera, Dr. Rod Penalosa, and Dr. Carlos Pizarro) began discussions with the PGH team. Subsequently, focus group discussions were held with teens and parents in order to foster a deeper understanding of their experience and the contextual factors that could give rise to depression and other mental health issues among teen patients.

From the multi-sectoral consultation process, it became evident that the problem is multi-layered and complex. Among teen cancer patients, many expressed worry and guilt about burdening their families. While a diagnosis of cancer in itself already brings about tremendous emotional stress, difficulties are even greater for low-income families who are barely making ends meet in order to subsist. Hence, the accumulated stressors of dealing with cancer treatment and worrying about the impact of their disease on the family's finances seem to cause these adolescents to think that the way out of the problem is for them to opt out of treatment or to end their life. Other related experiences that exacerbate their situation include pulling out from school, losing contact with friends, feelings of emotional detachment and isolation, disruption of family life, and unresolved existential crisis ("Why me?"). Discussions with parents highlighted the distress they experience stemming from the fear of losing their child to cancer and the financial strain involved in seeking treatment. Even though most of the medical procedures are provided for free, there are still costs incurred for transportation, laboratory tests, and medical supplies. Often, one parent has to stop working in order to care for the sick child while undergoing treatment. This situation lessens the income capability of families. Moreover, parental availability in caring for other siblings is stretched thin, leading to parent-child conflicts that in turn create an emotionally toxic environment that negatively impacts the wellbeing of the entire family. Not a few parents shared their struggles about their other children feeling "left out" and developing resentment towards parents and their sibling with cancer. Among PGH Pedia Hema-Onco staff members, the need for burn-out prevention and management surfaced prominently. Being in the public medical sector puts medical and ancillary staff in a workplace setting in which they have to serve a big population of clients with limited resources. This mirrors the experience of families being "stretched thin"



at an institutional level. Staff are pressed to be resourceful, often having to go above and beyond their official responsibilities in order to help patients access needed resources. For pediatric oncology cases, the estimated 40% survival rate at PGH also implies that staff frequently experience loss and grief, which taxes their emotional resources. Eventually, they would resort to emotional detachment and numbing, as an attempt to manage overwhelming emotions. However, this is a maladaptive long-term strategy which has negative consequences on staff wellbeing and patient care.

Informed by discussions with community members, COHCS founders envisioned the COH-PGH model of care to be a comprehensive program that addresses not only the needs of the teen cancer patients but also the people who care for them (i.e. parents, other family members, and hospital staff). This involves holding the needs of a community in mind because the problems experienced by teen patients do not occur in a vacuum but within a matrix of relationships. Conversely, opportunities exist for strengthening relationships and community resources which can provide longer-lasting and deeper impact on its members. The name *Circle of Hope* was chosen to stand for the vision of a compassionate and inclusive community living with active hope—that is, making hope a reality in the present through mutual support and collective action. Initially, the COH-PGH program was conceived with these key intervention principles:

- A **Community Mental Health Approach** provides an overarching model for working towards strengthening the entire caregiving community surrounding the teens; tapping into the natural resources of faith, compassion, and a sense of solidarity and common humanity in suffering.
- *Mindfulness-Based Intervention* gives direction for competent clinical care of individuals with serious illness. Many compelling research studies have pointed to the benefits of Mindfulness-Based Stress Reduction (MBSR) in alleviating stress and negative emotions for patients with chronic pain and illness. Pioneered by Jon Kabat-Zinn, PhD, who established the Stress Reduction Clinic under the auspices of the University of Massachusetts Medical Center in 1979, MBSR has become a standard clinical intervention and community offering. At the core of mindfulness practice is the radical acceptance of the present reality ("what is"). It allows individuals to become unstuck from the grip of suffering, pain, and despair; and consequently make life-nurturing choices. Research studies of patients with chronic pain and illness showed that engaging in mindfulness practices significantly decreased stress, anxiety, pain, depression, physical symptoms, anger, and use of medication. There has also been evidence that those who practice mindfulness felt their lives were more meaningful and fulfilling.

Support groups became the centerpiece of the COH-PGH program. When it started in August 2015, Dr. Penalosa, then Program Coordinator, set out to identify teen leaders who eventually recruited other teen patients to form Teen *Barkada* (group of friends). Held weekly on Friday mornings, Teen Barkada became the gathering space for teen cancer patients to share their journeys and forge stronger relationships with one another, guided by *ates* and *kuyas* (Filipino term referring to elder siblings) who comprised the COH-PGH mental health team. In these weekly sessions, teens were provided a safe and accepting environment to share their experiences and struggles. At the same time, skillbuilding activities were facilitated to help cultivate mindfulness, emotional awareness, healthy coping strategies, and interpersonal support. In October 2016, a parallel group was conceived for parents, with the goal of widening the circle to the larger community. In addition to running teen and parent support groups, the COH-PGH Program includes these other service components: mental health screening for teens, bedside visitation, individual/family counseling, grief



support, and care coordination with hospital staff. Services are conducted by MA/PhD level psychologists and graduatelevel psychology interns under close clinical supervision. A Mentoring Group was formed in 2018 for patients who have "graduated" from treatment to assist with their reintegration process back into school and community life.

Teens and parents responded warmly and enthusiastically to the program. As COH-PGH grew, staff members realized that there was an opportunity to run a more sustainable organization and to provide community mental health services to other under-served populations. COH formally registered as a non-profit agency with the Philippine SEC, becoming Circle of Hope Community Services, Inc. In its first strategic planning session as an SECapproved organization, COHCS recognized its purpose of providing services and education in the field of mental health and disabilities in order to promote wellbeing among marginalized sectors in the Philippines.

### **Board of Trustees**

President Chairperson	Carlos Pizarro, DMD, MA Cand (COH Co-Founder, Mental Health Specialist at MedMom) Lourdes Tanchanco, MD (MedMom Founder, Developmental-Behavioral Pediatrician)
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Executive Director	Joanna Herrera, PsyD, RPsy (COH Co-Founder, MedMom Head of Psychological Services)

### **Vision-Mission**

In November 2018 founding staff and board members gathered for the first strategic planning for COHCS as an SEC-registered non-profit organization. From this 3-year strategic planning session, the following Vision-Mission statements were formulated:

### Vision

# To be a compassionate community that brings out hope and transformation to marginalized sectors.

COHCS is dedicated to serving the needs of economically and socio-culturally marginalized sectors. It values inclusivity and compassion, which is expressed in privileging those who have been excluded and disadvantaged. COHCS believes in the inherent dignity and value of every person, and that each human being deserves the opportunity to reach their fullest potential. Cultivating compassion is the main vehicle for bringing about hope and transformation in those who are suffering and marginalized in society. Through compassion we connect with the suffering of others, realize our deep interdependence, and work to alleviate the suffering. Hope and transformation become possible when people come to experience the compassionate presence of others who seek their upliftment and empowerment. True compassion allows for everyone to discover and experience their strengths and capacities, and to make a contribution to the larger whole whatever their circumstances are in life. It also acknowledges that the power associated with traditional "helping roles" need to be challenged in ways that make room for compassion to flow in all directions, thereby enabling all who are part of the community to receive the gifts of interconnection.



# Mission To improve access to services and education in the field of mental health and disabilities for marginalized sectors.

As the non-profit arm of MedMom Institute of Human Development, COHCS is focused on addressing needs related to mental health and disabilities. COHCS aims to pave the way for services and education to become more accessible to underserved populations. We seek to be effective and efficient in developing programs and services by ensuring that evaluation and feedback mechanisms are in place to measure the impact of our work in communities. We are committed to continuously learning and growing in order to better serve the community.

# Key Principles (Loob-Kapwa-Diwa)

From its inception, COHCS has sought to ascribe to a community-based service delivery model based on principles that are culturally-meaningful to the Filipino experience, at the same time in dialogue with the developments and insights in the science of wellbeing, particularly on the well-established benefits of mindfulness practice and compassion cultivation. This model is founded on the interrelation amongst *loob, kapwa*, and *diwa*, which underscores core Filipino values that give shape and direction to the goals of COHCS and the transformative nature of its work with communities. These inter-related values and principles emerged from shared reflection and practice in the journey towards forming the COHCS community at PGH.

Loob (interiority or inner core) is seen as the root of community wellbeing. Loob can be understood as the inner reality of who we are that goes beyond the external conditions and roles that define our identity. It also describes the action and process through which we connect with, dwell in, and nurture our inner core. Mental health and wellbeing arise from a capacity to know ourselves deeply, to see ourselves with truth and objectivity, and to live the fullness of who we are. Entering and dwelling in *loob* requires mindful and open-hearted awareness, a discipline of keen, nonjudgmental, and loving attentiveness to all that is happening inside and outside of ourselves. Through the power of awareness, we can consciously nurture wisdom that enables us to decrease maladaptive thoughts and beliefs, and disposes us to meet our suffering and difficulties with equanimity. Tending to the *loob* involves honoring, deep listening, and acceptance of our internal experiences. *Pakikinig* (listening), *pakikiramdam* (sensitivity), and *pagtanggap* (acceptance) are the ways in which we develop a relationship with the *loob*. It is through habits of awareness that we come to know our true selves, our *loob*. This becomes the source of deep empowerment and resilience, but also of compassion for others. By nurturing our own wellbeing, our presence becomes refreshing and life-giving to others and the entire community.

Loob leads to Kapwa ("neighbor"). Kapwa involves the awakening to the other as myself. Experiencing our innermost core opens into an awareness that we are not alone, we are not separate from other human beings and the whole of creation. Therefore, receiving others with openness and compassion brings a sense of wholeness in our experience of who we are. Kapwa represents an awakening to interbeing and interconnection. We can heal conflicts and division through honest communication, perspective taking, and seeing our responsibility for the suffering we cause in others. In this process, we invite the other (Kapwa) to experience who we really are (Loob). We also open ourselves (Loob) to see the other (Kapwa) through the eyes of understanding and compassion.



*Diwa* refers to the collective energy or consciousness that develops in community when individuals hone their practice of awareness and compassion. Each person has something to contribute to building a healthy and wholesome culture. We need to consciously cultivate a community in which the culture that permeates through it has the power to inspire, heal, and empower. *Diwa* also involves harnessing the strength of the community to stand against unhealthy, hurtful, and unjust forces that trample on life and truth. It recognizes the courage and integrity in compassion that empowers us to say no to actions and forces that damage community. Ethics is therefore grounded in becoming keenly aware of the effects of our unskillful words and actions to the larger whole.

### Results

COH-PGH support groups are conducted weekly on Friday mornings. Attendance to Teen Barkada averages at 10-15 participants per session. Since 2015, about 70 teen patients have participated in Teen Barkada. Parent Support Group attendance ranges from 15-20 per session. A total of 24 parents have participated in the support group. While the number of parents has not expanded significantly, attendance has been very consistent for those who take part in the group. Parents who have participated in the support group have also been providing informal mentoring to other parents in the Pedia Hema-Onco Department who are unable to attend group sessions.

The following outcomes were sought for the COH-PGH program:

- Decrease incidence of depression and other related mental health problems among youth cancer patients.
- Increase awareness and utilization of tools and practices that promote psychological wellness, adaptation to life changes, and coping with stressors related to cancer treatment.
- Strengthen community support for young cancer patients by helping parents and professional care providers manage stressors related to caring for these young patients.
- Strengthen the patient's and family's capacity to cope with significant transitions in the diagnosis and treatment process.

A qualitative study was conducted from June to August 2018, exploring the phenomenological experience of the stakeholders in their participation in Circle of Hope, specifically, the COH staff, adolescents, and the parents. This study was also used to evaluate the effectiveness of the program, if the model of care has been able to result in the desired outcomes for its clients. Focus group discussions (FGD's) were held separately with COH staff members, teens, and parents. The evaluation of each goal was expounded through themes and narratives shared by the participants as summarized below:

# Life Changing

"Life changing" was a description that COH staff shared about their experience with the program. Both teen and parent groups also noted that they noticed changes within themselves, as well as their relationship with their family and community, as they got more involved with the program. Overall, the experience with COH was described as positive by all groups, comprising of the following themes:

# Makulay at Masaya (Colorful and Fun)

According to the teen groups, because of COH, they now look forward to going to the hospital for their treatment and check-ups. They look forward to attending the group therapy sessions and COH has made them feel that



the hospital has become a safe haven for them, emotionally. The parents group describe themselves as *"iyak-tawa"*, meaning that despite some sharing that they find joy in each other, despite having to share some problems that may elicit negative feelings. Through COH, participants from all groups have also shared that they have become more nurturing and willing to relate with others because of COH. They have learned ways to communicate more effectively such as saying good morning to family members as well as changing the tone of voice during arguments. It is also through COH that they have found people going through the same experience. According to the teens group, they felt a profound loneliness since being diagnosed with cancer as other people their age may have different experiences and problems. Having shared experiences with a group has made them feel that there are people who are going through the same challenges. They shared that the openness and non-judgmental approach of the staff during group sessions helped them share their stories to their peers. The trust that has been developed within the groups has also created a safe space for the participants to share their problems and difficulties, not only with dealing with the cancer, but more so, in managing their other relationships at home.

# Mahirap at Makahulogan (Challenging and Meaningful)

According to COH staff, being part of the program has also been a very challenging task. For the program staff, the challenges were mostly due to a lack in resources in terms of finances as well as overall support from other involved stakeholders. On a personal level, being part of COH has also become an opportunity to confront themselves, meaning that they also have to be able to find meaning in loss and suffering as they deal with their patients. Several losses have also occurred in the recent years. According to the teens, instead of looking at death as a loss, they have started to find meaning in these losses, and instead, look towards to celebrating the life of the friend that was lost. Being able to repair their own relationships at home and within themselves have helped them give more meaning to their lives. More so, their identity has gone beyond being a cancer patient, and recognizing themselves as individuals who experience life, love, and loss in the same way that other people would. The parents' group have shared that it is also through COH that they started to recognize that a child or teenager with cancer, is still a teenager at his or her core. Because of this, they have learned to balance between caring for them and giving them their independence.

# Magaan ngunit Malalim (Ease and Depth)

Although themes of death and loss are part of the program, the participants shared that they still find the group as having a very jovial atmosphere during group sessions. When asked about their favorite topic, the teens group shared that they are most interested when the topic is about romantic relationships. Even though this subject comes off as a typical topic, the group is able to deepen the conversation because of the lessons derived from it. Particularly for this topic, the teens were able to apply what they learned to other kinds of relationships in their lives. They have also shared that both parents and teens have become more cheerful and talkative during group sessions. Through COH, both parents and teens have found meaning in their life situations, thereby giving them hope that all these challenges may be worth something in the end. It is also through COH that they found that their spirituality has been developing. Faith in God was identified as a way in which COH participants are able to connect. In difficult times, each one shows their support by praying for one another. The experience is described as "malalim" as it has evinced change in all the groups at different levels, from the self, family, and towards the community.



### Goals for 2019-2021

In establishing itself as a nonprofit organization, COHCS aims to expand its capacity to serve the needs of marginalized sectors in the area of mental health and disabilities. From the 3-year strategic planning process participated in by board and staff members, the following broad goals were identified:

- 1. To provide mental health and developmental services
- 2. To improve and widen access to services and education
- 3. To leverage the benefits of collaboration through effective partnerships with communities and stakeholders
- 4. To inform and educate the general public on issues pertaining to mental health and developmental disabilities
- 5. To provide training that enhances professional competencies in delivering mental health and developmental services
- 6. To develop leaders who will foster the advancement of mental health and developmental services in the Philippines

#### Key Initiatives for 2019-2021

#### 1. Community Mental Health

COHCS will continue to run the community mental health program serving pediatric cancer patients and families at The Philippine General Hospital. Within the next 3 years, there will be a focus on developing structures and tools that will enable community members to feel empowered and equipped to take on a more active role in carrying out program activities. This would involve: (a) conducting training programs for mentors and group facilitators, (b) developing modules and resource materials on the Loob-Kapwa-Diwa (LKD) community mental health model, and (c) working to deepen the awareness and education among hospital staff about the interconnectedness of mental and physical health. An overarching goal is to make the Loob-Kapwa-Diwa framework and practice available for replication in other community settings.

### 2. Early Childhood Development

A new initiative being developed is the Birth to Five Mobile Resource Center. Through this project, COHCS will be delivering parent and caregiver training to low-income communities focusing on the critical early childhood years. Because brain growth is at its peak in the first few years of life, these early years offer the best opportunity to shape a child's developmental outcomes and success in life. An interdisciplinary team of early childhood specialists will be formed to design a 0-5 Parent and Caregiver Training Curriculum. This curriculum will integrate Loob-Kapwa-Diwa principles and practices to foster community wellbeing, which in turn enriches the interpersonal matrix for caregiving. Pilot community for this initiative is Tondo, a densely populated urban poor neighborhood with the highest crime rate in Manila.

#### 3. Access to Interventions

Capacity-building efforts will also be directed towards increasing clients served under Project CARE (Community Access to Resource and Education). Project CARE is a program that provides low-fee mental health and developmental services to individuals who cannot access these services due to lack of financial resources.