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#### **BOSTON UNIVERSITY**

# SARGENT COLLEGE OF HEALTH AND REHABILITATION SCIENCES

# **Doctoral Project**

# NEURODEVELOPMENTAL SUPPORTIVE CARE AND THE ROLE OF OCCUPATIONAL THERAPY IN GREEK NEONATAL INTENSIVE CARE UNITS NEOGNO: A HEALTH AWARENESS PROGRAM

by

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Submitted in partial fulfillment of the requirements for the degree of Doctor of Occupational Therapy

# Approved by

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My parents, for teaching me perseverance.

# NEURODEVELOPMENTAL SUPPORTIVE CARE AND THE ROLE OF OCCUPATIONAL THERAPY IN GREEK NEONATAL INTENSIVE CARE UNITS

NEOGNO: A HEALTH AWARENESS PROGRAM

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ABSTRACT

The Neonatal Intensive Care Unit (NICU) environment exposes infants to a constant barrage of negative stimuli that impact the long-term development of the neonatal brain. Neurodevelopmental Supportive Care (NDSC) are specific applications to protect neonatal brain development and foster family support care. Neonatal occupational therapists (NT OT) are vital members of the NICU team and integral to the implementation of NDSC.

Premature births in Greece have increased from 9.62% in 2008 to 11.18% in 2010, to an estimated rate of 20% in 2019, creating dramatic need for preventive interventions. Appropriate neuroprotective care for these infants is of critical importance. However, there is a void of data on NDSC applications and NT OT staffing in Greek NICUs. To facilitate implementation of these practices in Greece, it is important to first raise awareness of NDSC and OT NT to the NICU personnel, medical and other healthcare disciplines, government agencies, and the general public.

The author's "NEOGNO" online program is an innovative health awareness

program in Greece aimed at promoting NDSC and NT OT in all NICUs, endorsing future NDSC and NT OT research, and establishing strong advocacy for newborn neuroprotection. The program is guided by the Health Belief Model (HBM) which targets the awareness, attitudes, perceptions, and beliefs of the health care professional community that impact the application of NDSC and neonatal OT in NICUs.

NEOGNO's platform offers a plethora of evidence-based information at different levels of complexity to address the diversity of participants' interests. The platform also includes a participant program evaluation questionnaire, and an exploratory survey for data collection for an upcoming first exploratory research on NDSC in Greece by the same author. A program evaluation research checklist will assist in the assessment of NEOGNO by stakeholders before, during and after the launching of the program.

Dissemination efforts will continue using electronic media and expanding beyond the borders of Greece. Funding of NEOGNO will initially derive from the author's private practice until other public and private sources are located.

NEOGNO is the first of its kind health awareness program in Greece, and a launching point for future change in current practices in Greek NICUs, OT, public and private funding of neonatal neuroprotection, and for the inauguration of NDSC and NT OT research. Most importantly, NEOGNO will become a strong voice for the fragile infants and their families.

#### **PREFACE**

"Then Hera darted swiftly from high Olympus to Argos in Achaea where she knew that Nicippe, noble wife of Sthenelus, Perseus' son, was seven months pregnant with a boy-child. Hera induced the child **prematurely**, while restraining the Eileithyiae, and delaying Alcmene's labour".

Homer. (8th century BCE). Iliad, Book 19, line 114-124

"Ήρη δ' ἀΐξασα λίπεν ῥίον Οὐλύμποιο, καρπαλίμως δ' ἵκετ' Ἄργος Ἀχαιικόν, ἔνθ' ἄρα ἤδη ἰφθίμην ἄλοχον Σθενέλου Περσηϊάδαο. ἣ δ' ἐκύει φίλον υἱόν, ὃ δ' ἔβδομος ἑστήκει μείς ἐκ δ' ἄγαγε πρὸ φόως δὲ καὶ ἤλιτόμηνον ἐόντα, Ἀλκμήνης δ' ἀπέπαυσε τόκον, σχέθε δ' Εἰλειθυίας".

Όμηρος (8°ς αιώνας Π.Χ.). Ιλιάδα, xix, 114-124

ήλιτόμηνον (ilitominon) prop, missing the right month; born too soon

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# LIST OF ABBREVIATIONS

AOTA
BSID Bayley Scale of Infant Development
BU
CANN
CAPWHNCanadian Association of Perinatal and Women's Health Nurses
CI
CINAHL
CITI
CNS Central Nervous System
CNT
COINN
COTECCouncil of Occupational Therapists for European Countries
dBDecibe
DC
EEG
EFCNIEuropean Foundation for the Care of Newborn Infants
EKPA
ENOTHE European Network of Occupational Therapy in Higher Education
EU European Union
FCCFamily-centered care
FNI

GAGestational Age
GLANCE
HBMHealth Belief Model
HTTPS
IBAIP Infant Behavioral Assessment and Intervention Program
IHDC
IRB Institutional Review Board
IQ
IT
KC
LBWLow Birth Weight
MIP
MITP
NANN
NANT
n.d
NDSC
NDT
NICU
NIDCAP Newborn Individualized Developmental Care and Assessment Program
NNS
NT

NTCB
NTNCB
NTNTB
OT
PBPreterm Birth
PBPPotentially Better Practices
PMNCHPartnership for Maternal, Newborn & Child Health
PSE
PTPhysical Therapy
RCTs
SLP
SSL
TVTelevision
UNESCO United Nations Educational, Scientific and Cultural Organization
USA
WFOT
WHOWorld Health Organization

#### **CHAPTER ONE – Introduction**

#### Chapter One: Introduction to NICU, NDSC, and NT OT

Every year worldwide, 30 million newborns are at risk including 15 million who are preterm. Approximately 10.6% of neonates are premature (Pinto et al., 2019).

Because of complex medical and rehabilitative needs, preterm and at-risk infants require hospitalization in Neonatal Intensive Care Units (NICUs). Although NICUs offer advanced medical technology, the incidence of disability and neurodevelopmental disorders among neonatal intensive care survivors remains high and problematic because of harming sensory motor stimulation (Vandenberg, 2007).

Studies increasingly document that the NICU environment itself exposes infants, parents, and staff to a constant barrage of negative, variable, non-contingent stimuli, and impacts on the long-term development of the neonatal brain (Blackburn, 2008; Hunt, 2011). To support the neonatal brain or to facilitate brain development after a neuronal injury, specific strategies and interventions were developed, coined "neuroprotection" (Altimier & Philips, 2018).

Neuroprotection has been adopted by several NICU programs, including the Neurodevelopmental Supportive Care (NDSC) program, which is implemented to minimize the NICU milieu's adverse effects on fragile newborns (Carey, 2018; Rheeder et al., 2017). Evidence-based research indicates that NDSC prevents or lessens the possibility of neurodevelopmental disorders such as autism and cerebral palsy, and establishes a better quality of life for the children and their families (Milette et al., 2017).

An essential component of a comprehensive preventive model of family-centered

NDSC services is the inclusion of occupational therapists (OTs) as neonatal therapists (NTs) as vital members of the NICU teams (American Academy of Pediatrics, 2017; Craig & Smith, 2020). The NT OT recognizes the infant as an occupational being who performs activities and is an active coparticipant in action patterns that emerge from the child's interaction with the environment.

Despite NDSC's popularity (Als, 2017), there is no empirical evidence if and how many NICUs are aligned with NDSC standards, including NT OT services, in Greece. Furthermore, although neonatal OT's role in NDSC practices has been long established internationally (AOTA, 2018; Hunter, 2009; Royal College of Occupational Therapists, 2017; Vergara et al., 2006), it is uncertain if and how OT NT plays an interdisciplinary role in NDSC planning and practice in Greek hospitals. Since the number of premature births demanding immediate specialized early intervention is rising in Greece (Vlachadis et al., 2014), the identification of NDSC applications in Greek NICUs is of utmost necessity.

Raising awareness of NDSC and NT OT to the Greek general public and the health care community is the core of the author's proposed program based on the Health Belief Model (HBM) (Rollins et al., 2018). The author's proposed multimedia, online educational program "NEOGNO" aims at (a) increasing community awareness of Neurodevelopmental Supportive Care (NDSC) and neonatal OT, and (b) collecting data to launch the first exploratory research about NDSC in Greece. It is expected that raising awareness in this health area will result in the establishment and advancement of better neuroprotective practices and NT OT intervention in Greek NICUs.

# **Background**

## Prematurity and Low Birth Weight

Preterm birth (PB) is defined as birth before 37 weeks of gestational age (GA), and is the single most significant cause of newborn death, the second leading cause of all child deaths after pneumonia, and a significant cause of neurodevelopmental disabilities (World Health Organization, 2021). Low birth weight (LBW) is defined as < 2,500 gr and can occur due to restricted fetal growth or PB. It is estimated that the proportion of LBW infants has increased over the past two decades mainly due to increase in PBs, and that 15–20% of all births worldwide are LBW (Organization for Economic Co-operation and Development, 2021; Vandenberg, 2007).

Several factors associated with low-birth-weight outcomes include but not limited to, severity of illness, chronic lung disease, bronchopulmonary dysplasia, brain injury and cerebral palsy, and retinopathy of prematurity, conditions that are associated with poor neurodevelopment outcomes. It is estimated that by the age of 8 years, over 50% of very low birth weight (< 1,500 gr) preterm children require special education services, and 15% have repeated at least one grade in school (Vandenberg, 2007).

Preterm birth consequences are inversely related to neurodevelopmental, sensory, cognitive, and physical health disturbances and lifelong support challenges to the responsiveness of health services and community systems (Pinto et al., 2019) discussed next.

### The NICU Environment, and Neurodevelopmental Disorders

Most infants admitted to the NICU are preterm or have a health condition that needs special care (Stanford children's health, 2021). The newborn infant in the NICU is provided with highly advanced medical and nursing support which has demonstrated remarkably effective success in treating high-risk infants and premature illness (Vandenberg, 2007). Preterm birth interrupts the natural process of fetal maturation in utero, and forces crucial neurologic growth to continue within the foreign environment of the NICU.

Although the intrauterine environment provides positive sensory experiences and protection for normal growth and development NICUs environment is favorable of harsh and negative stimuli. Preterm infants are exposed to pain such as heel lance procedures, long intubation periods, poor positioning, intense light and sound exposures, disruption of sleep-awake cycles, and deprivation of frequent caregiver physical and emotional contact. These NICU attributes have raised concerns for the impact of the NICU experience on the developing brain.

Hence, during a period of neurodevelopmental vulnerability and fragility, altered sensory experiences via physical, chemical, sensory, and social/emotional environments influence brain architecture (Fox et al., 2010) and the development of lower-level neural circuits upon which higher-level circuits will build more sophisticated mental functions (McCain et al., 2011; Shonkoff & Philips, n.d.). Harmful sensory experiences in early life can affect infants' cognitive, physical, social, and emotional development and impact how they will respond to their environments and participate in occupations later in life

(Bar-Shalita et al., 2008; Bart et al., 2011; Shayevits et al., 2011).

Neurodevelopmental disorders (i.e., autism, mental retardation, cerebral palsy, attention deficit disorders, learning disabilities, schizophrenia, and sensory processing disorders) appear to occur as a result of both the premature infants' immature neurological and biological systems and the NICU environment, which is unable to meet their sensory needs (Institute of Medicine, 2007).

#### **Neurodevelopmental Supportive Care (NDSC)**

Developmental support consists of a variety of intervention strategies in addition to medical care, to protect and promote the growth and development of an infant (EFCNI, 2018). Developmental care (DC) is an approach to individualized care of infants to maximize neurological development and reduce long-term cognitive and behavioral problems. DC was established by Als (2017), has been linked to a variety of positive clinical outcomes, and has evolved into a professional practice, education and research for the NICU staff and the early intervention health care community.

DC has evolved over the course of forty years. Neuroprotection strategies and family-centered care (FC) have enriched DC and further evolved various neurodevelopmental care programs known as the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) (Als, 2017), Neonatal Integrative Developmental Care Model (IDC) (Altimier & Phillips, 2013), Wee Care Neuroprotective NICU program (Altimier et al., 2015), Modified-Mother-Infant Transaction Program (MITP), PremieStart, Cues Intervention, In-Hospital Developmental Care, Family Nurture Intervention, the Multisensory Intervention Program, and Kangaroo

Mother Care (KMC), among others. This awareness program will address evidence-based principles that define DC, neuroprotection and FC using the term Neurodevelopmental Support Care (NDSC) as per Jacobs (2018), Rheeder et al (2017), and Sidney Children's Hospital Network (SCHN, 2021).

NDSC can alter the developing brain's structure and function, nurtures preemies' neuroprotection, and if more broadly implemented, NDSC might save a considerable amount of rehabilitation and special schooling efforts and expense (Als & McAnulty, 2011). NDSC includes specific guidelines, handling techniques, sensory considerations of the environment where infants are being taken care of, parent training and support, protocol making, and efficient NICU multi-disciplinary communication. NDSC has become the golden standard of NICU care worldwide, and there have been ongoing research efforts to validate its efficacy (Aita et al., 2020; Als, 2017; Burke, 2018; Hasanpour et al., 2017; Lubbe et al., 2020; Sheldon, 2017; Soleimani et al., 2020).

#### Domain of Occupational Therapy

Neonatal healthcare professionals (NT), including OTs involved in neonatal and infant care, have an essential role in supporting infants' appropriate neurodevelopment (Research Review, 2015). The occupational therapy professionals contribute to the flexibility and integrity in the management of the premature infant (Rubio-Grillo, 2019).

NT OTs apply NDSC practices through infant's activities (sensory, feeding, sleep, and rest activities), infant's sensory-motor integration factors (self-regulation, neuromuscular and postural factors, muscle strength and resistance, oral-motor control, alertness, awareness, state transitions, and developmental skills), and contextual factors

(physical, social and temporal).

The OT in neonatology follows the standards described in the Occupational Therapy Practice Framework: Domain and Process (AOTA, 2020). Moreover, the Neonatal Therapy National Certification Board (NTNCB) (2019) and the National Association of Neonatal Therapists (NANT) (2020) have set specific requirements and training for occupational therapists to become neonatal professionals, including extensive continuing education and closely graded, supervised, and mentored practice (AOTA, 2018). NT OT can be a decisive and an irreplaceable partner in prematurity neuroprotection, providing evidence-based practices in the NICU and reducing modifiable risk factors for the fragile infants (Pinto et al., 2019).

#### **Identified Problem**

The preterm birth rate in Greece has increased fourfold in the past two decades and more than doubled in the latest seven years (2003–2010). This rise is considered a significant health issue and places dramatic challenges for public health and the need for preventive interventions (Vlachadis et al., 2014; Baroutis et al., 2013). Despite the growing number of premature births, Greece has never participated in any extensive NICU research projects and lacks empirical data regarding newborns' intensive care (Daglas & Petousi, 2018). Specifically, there is no data regarding; (a) if, where, and how NICUs align with NDSC standards for newborn and premature infants, (b) measured outcomes (qualitative and quantitative) of infants graduating from NDSC supported NICUs in the first and later years of life, and (c) if, where, and how OTs as neonatal specialists are involved in NDSC applications.

Lack of such information is of great importance considering the impact of the social, emotional, physical, and sensory properties of the NICU environments (Kuhn et al., 2018) and the significance of NT OT in NDSC practices (Ross et al., 2017; Rubio-Grillo, 2019).

#### **Awareness Program Overview**

Based on the previous discussion, raising public and health community awareness regarding NDSC and NT OT significance is of utmost importance in order to develop such practices in Greece.

The proposed online awareness program is based on the Health Belief Model (HBM) and targets NICU staff and administration, health care professionals including OTs, the medical community, and the general public for becoming advocates for NDSC and NT OT in all NICUs in Greece. This is the first program of its kind in the country and in the OT profession. The program includes evidence-based information for NICU, NDSC and NT OT practices, access to free downloads of brochures and newsletters, videos and podcasts from NICUs implementing NDSC and demonstrating NT OT, links to NDSC agencies, program quality questionnaires, and a research survey. The latter will collect data for the first exploratory research in Greece concerning the areas discussed previously in the Identified Problem section. It is intended that this first exploratory research based on the awareness program will serve as a platform for further investigation of the long-term consequences of non NDSC applications in the NICU, and possible public health measures to tackle them.

In the following chapters, a detailed overview of the problem, questions and

evidence-based answers, the theoretical grounding and structure of NEOGNO awareness program, program evaluation, dissemination and funding will be discussed. In the appendices, pre- and post- explanatory visual models, short and long logic models, materials posted on the program's website, and several surveys including the exploratory research survey will provide a clear perspective of the content of NEOGNO awareness program.

# **CHAPTER TWO – Program Theoretical and Evidence Base**

#### Introduction

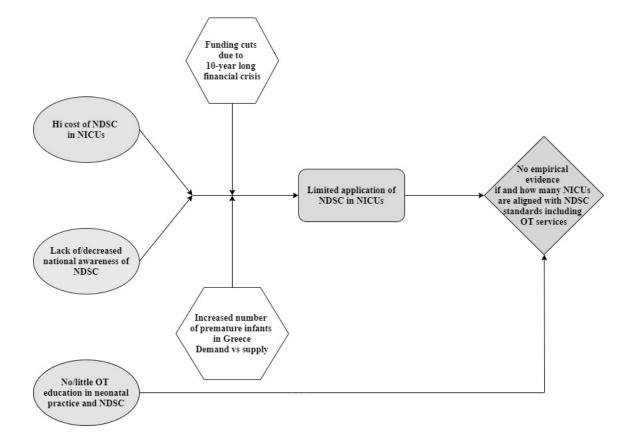
Increasing premature birth rate constitutes a significant health issue and places dramatic challenges for public health and the need for preventive interventions (Vlachadis et al., 2014). Although the number of premature births has been increasing in Greece, very little is known about the use of NDSC and NT OT within the context of early intervention. NDSC includes various NICU environmental modifications, equipment, handling and positioning techniques, instructions to parents, creation of protocols for assessment and follow-up, and interdisciplinary communication and collaboration (Als & McAnulty, 2011). The goal of NDSC is neuroprotection of vulnerable newborns. NDSC can prevent or lessen the development of neurological impairments, save a significant amount of hospital expenses for neonatal care, and later in life, rehabilitation, schooling expenses, and services (Vandenberg, 2007). Occupational therapists (OTs) involved in neonatal and infant care (NT) have an essential role to play in supporting appropriate sensory development in infants (Ross et al., 2017) and can significantly contribute to the flexibility and integrity in the management of the premature infant using NDSC applications (Rubio-Grillo, 2019).

This chapter investigates the empirical evidence concerning if and how Neonatal Intensive Care Units (NICUs) are aligned with standards of Neurodevelopmental Supportive Care (NDSC) for at-risk, low birth weight, and premature newborns, and if and how neonatal (NT) occupational therapy services (OT) contribute to the implementation of NDSC practices in Greece.

# Overview of the Problem - Development of a Visual Model

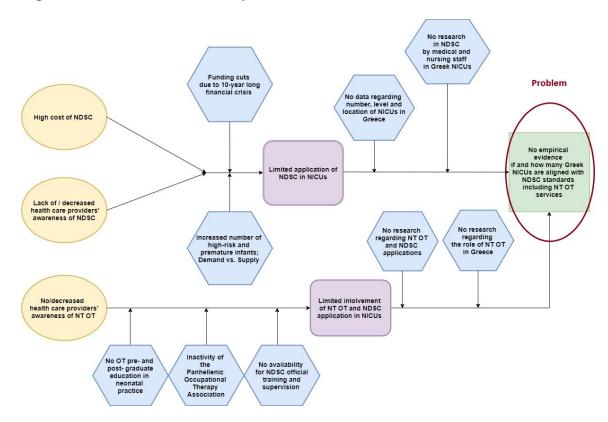
The lack of empirical research and evidence regarding if and how many NICUs are aligned with NDSC standards, including OT services, in Greece is associated with three factors: a) high cost of NDSC applications and staff training, b) lack of or decreased awareness of NDSC by health care and NICU providers, and c) lack of or decreased awareness of the role of neonatal OTs. A succession of visual models was developed to depict the sequence of factors and contributing mediators for the existing problem. The visual models presented below reflect the progression of the problem analysis and evidence-based justification of main and contributing factors by the author.

Figure 2.1 Initial Visual Model of Problem Overview



As shown in Figure 2.1, the initial conception of the visual model included three primary factors and two contributing mediators leading to two moderators (i.e., limited application of NDSC in NICUs, and limited NT OT involvement in NDSC applications) and finally to the target problem.

Figure 2.2 Final Visual Problem of Problem Overview



However, further investigation through literature review of each of the main factors and their connection to the problem surfaced new mediators depicted in the revised visual model (see Figure 2.2). Furthermore, consideration of the Health Belief Model (HBM) as a guide for identifying moderators and mediators contributed to the whole, logical and justifiable flow of the final visual model. The visual model sequence in Figure 2.2 guided the author to consider the problem and the proposed program from

different angles. Any further discussion on the visual model will refer to Figure 2.2.

## **Theoretical Grounding**

## Reference to the Health Belief Model (HBM)

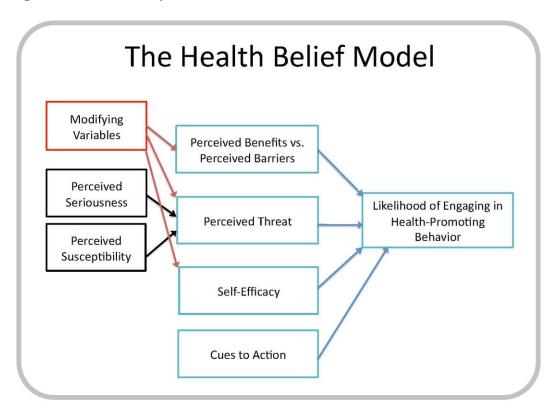
In the 2018 WFOT Congress, Jacobs (2018) presented "NDSC in South African NICUs - An Essential Change of Attitude" supporting evidence-based benefits of NDSC. Rubio-Grillo (2019) and Schnack et al. (2018) justified occupational therapy's role in NDSC practices in the NICU. All authors focused on the health threat of limited infant neuroprotection and family-centered care to short and long-term developmental outcomes of NICU infants. The health-related problem of no or insufficient NDSC practices and OT's limited role in NDSC applications in Greece will be investigated through the lens of change in awareness and perceptions, action, and self-efficiency of the health care community and the public as well.

As such, the Health Belief Model (HBM) (Conner, 2010; Rosenstock et al., 1988). will guide exploration of propositions and beliefs about NDSC and OT in NICUs. Insights from the model can increase awareness and use of NDSC and OT services by the health-related professions, the public, and government and civil society agencies. The model includes the following propositions: susceptibility, seriousness, benefits, and barriers to a behavior, cues to action, and self-efficacy.

All of the following propositions are influenced by modifying variables, which in turn affect perceptions (i.e., perceived seriousness, susceptibility, benefits, and barriers) of health-related behaviors. The HBM suggests that modifying propositions affect health-related behaviors indirectly through changes in perceived seriousness, susceptibility,

benefits, and barriers (Figure 2.3). In terms of HBM application in this program's context, the focus is on identifying the propositions of awareness, attitudes, perceptions, and beliefs of the health care professional community that impact the application of NDSC and neonatal OT involvement in NICUs (Chapters 2 and 4).

Figure 2.3 Health Belief Model



Note. Source: https://commons.wikimedia.org/wiki/File:The Health Belief Model.pdf

# Perceived Susceptibility and Perceived Severity.

Perceived Susceptibility refers to one's subjective assessment (or not) of the likelihood of developing a health problem, whereas Perceived Severity is the subjective assessment of the severity of a health problem and its potential consequences. Together, they are referred to as "perceived threat." Perceived severity and perceived susceptibility

to a given health condition depend on knowledge about the condition.

Lack of or decreased awareness of NDSC impacts the perceived susceptibility and severity of the health problem. Decreased or no perception of NDSC (threat) will cause limited application of NDSC in NICUs. Two more threats can be included here: no or little awareness of NT OT may cause limited application of NDSC by OTs in the NICUs, and the increased cost of NDSC may be considered a prohibitive reason to its implementation if one does not know how to allocate funding as a solution.

#### Perceived Benefits and Perceived Barriers.

Perceived Benefits pertain to an individual's assessment of the value or efficacy of engaging in a health-promoting behavior to decrease the risk of disease. Perceived Barriers refer to an individual's assessment of the obstacles to behavior change. The propositions discussed earlier lead to limited awareness of the benefit of NDSC and NT OT. Little or no awareness of benefits will not promote change, such as including NDSC and NT OT in NICUs. Limited Benefit perception will enhance the perception of barriers to NDSC implementation; one of them is the NDSC high cost. Parallelly, it will weaken the health motive to adopt NDSC in NICUs. The same stands for NT OT. If there is are no Perceived Benefit for NT OT (enhanced by lack of NT OT education, inactivity of the Panhellenic OT Association (PSE), and limited NDSC training), there will be no reason to engage NT OT in NDSC NICU practices.

#### Cues to Action.

The HBM posits that a cue, or trigger, is necessary for promoting engagement in health-promoting behaviors. Limited intentions, motivation, and belief in the

understanding and value of NDSC and NT OT will further behoove action taking toward awareness and application of NDSC and NT OT; furthermore, it will not promote any research in Greek NICUs. Eventually, no or little action taking will not foster self-efficacy stated below.

#### Self-Efficacy.

Refers to the person's confidence and belief in performing successfully and changing the action or behavior. Self-efficacy is built upon all previous elements of HBM. It is the end product of a chain reaction. Self-efficacy in promoting NDSC and NT OT will not happen if the public and the health care community are not aware of the threat for not investing in NDSC and NT OT, the acquired short and long term benefits (less hospital spending, better developmental predictors for the children, less expenses on special education, and better preventive medicine), the means for overcoming barriers (for example locating private funding sources for NDSC training, and establishing NT OT programs), and the action taking so that all Greek NICUs employ NDSC and have NT OT on staff. These steps and successes will build self-confidence and efficacy for continuing NDSC and NT OT, including evidence-based practice.

#### Discussion of the Visual Model through the Lens of HBM

The following discussion is based on published research. The databases used to gather literature were MEDLINE via PubMed and Ovid, CINAHL Complete via Ebsco, Cochrane Database of Systematic Reviews via Ovid, PsycInfo, CanChild, AOTA, Embase, Pediatric Academic Societies' Abstracts and Web of Science, Google Scholar, and ClinicalTrials.gov.

The search terms included neonatal occupational therapy, neonatal intensive care, developmental neuroprotection, Newborn Individualized Developmental Care and Assessment Program (NIDCAP), Neurodevelopmental Supportive Care (NDSC), Greek neonatal care, Greek NICUs, Greece, NICU cost, Greek health care, financial crisis, OT education, and evidence-based practice. The following discussion will address each factor through a question-and-answer fashion. Effort will be placed in using evidence-based information to support each answer. In total, there are three answered questions that include discussion of five contributing moderators and nine mediators.

## Question 1

Is there evidence high cost of NDSC in NICUs limits the NDSC application in Greece?

NICUs' cost is high, averaging approximately \$114,000.00 for each surviving ventilated infant in the USA (Meadow et al., 2012). According to Geitona et al. (2007), "neonatal intensive care in Greece is associated with significant costs that exceed reimbursement from social funds. Reimbursement should be adjusted to make neonatal intensive care economically viable to private hospitals and thus, increase the capacity of the services provided" (p. 1). Furthermore, the cost of NDSC in NICUs such as NIDCAP is high, averaging approximately \$30,000.00 per person (Newborn Individualized Developmental Care and Assessment Program, 2021; Westrup, 2007), excluding the cost for NICU space modifications and equipment. Consequently, the expense of NICUs and the NDSC is exceptionally high for hospitals and the national health care budget, as mentioned next.

## **Contributing Mediators.**

### Funding cuts for and to NICUs due to a 10-year long financial crisis in Greece.

The consequences of a 10-year long (2009-2018) severe financial crisis to the Greek health care system have been documented (Keramidou & Triantafyllopoulos, 2018; World Health Organization, 2018). A systematic review by Simou and Koutsogeorgou (2014) on the effects of the economic crisis on healthcare in Greece from 2009 to 2013 reported that the Greek health care system has been suffering severe financial burdens, insufficient long-term health care planning, corruption, medical staff, and supplies cuts, allocation of funds from vulnerable age groups such as early intervention, and lack of accurate documentation of where funding is provided. Although there is no direct reference to financial cuts for NDSC, one may assume that the severe reductions in the Greek health care system will impact any costly NICU innovations, including NDSC.

## Increased number of high-risk and premature infants; Demand versus Supply.

Preterm birth rates in Greece have increased almost twofold in the past three decades, accounting for 9.62% of live births by 2008 (Baroutis et al., 2013). The 2010 preterm birth rate (PBR) of 11.18 in Greece poses dramatic challenges for public health and emphasizes the need for preventive interventions to be implemented (Vlachadis et al., 2014). More premature births demand more NICU availability. Geitona et al (2007) mentioned that rural areas' continuing urbanization and depopulation shifted the health services demand to Greece's urban areas. The result is large socio-economic and geographical inequalities in the health services' provision and an inadequate supply and

unequal distribution of the NICUs beds in the various geographical regions. The above statements imply that the demand for NICU and NDSC services may be greater than the supply. Consequently, the increasing number of premature births may constitute a moderator for the limited application of NDSC in NICUs and apparently for related research of NDSC in Greek NICUs.

#### Question 2

Is there evidence lack of or decreased health care providers' awareness of NDSC limits the NDSC application in Greece?

A search for NDSC awareness by health care professionals in Greece revealed no specific results. Galanis et al. (2016) bore some indirect relevance to NDSC practices. He mentions that "nurses could play a key role in creating an educational process in which they share knowledge and teach appropriate techniques to parents to allow them to effectively meet their infant's needs" (p. 8). Since NDSC applications include parent education, one may assume that NDSC practices to parents by NICU personnel in Greece are little or insufficient. Daglas and Petousi (2018) reported that Greek NICU health care professionals appear to concentrate more on quantity of life (vitalistic approach) instead of quality of life. NDSC focuses solely on the quality of life. Combining the views from both articles, it appears that the majority of health care providers are not familiar with the nature and scope of NDSC.

# **Contributing Mediators.**

Funding cuts for and to NICUs due to a 10-year long financial crisis in Greece and increased number of high-risk and premature infants; Demand versus Supply.

These two mediators were described previously. It is logical to assume that limited or no applications of NDSC due to financial strains, and insufficient NICU capacity affect NDSC practices nationwide.

## Question 3

Is there evidence that lack of or decreased healthcare providers' awareness of neonatal OT results in limited OT and NDSC application in NCUs and NICUs in Greece?

Occupational therapy (OT) is a member of a multidisciplinary team approach that enables participation in meaningful occupations as an essential healthcare element (Atwal et al., 2006; College of Occupational Therapists, 2015). Jackman and Stagnitti (2007) and Jamnadas et al. (2009) have documented that the limited understanding and awareness of OT among the general public as well as healthcare professionals specifically can hinder the delivery of comprehensive, holistic, and quality care OT services. Carrier et al. (2013) and Kristensen et al. (2012) also mentioned that the therapists' cultural knowledge and how culture influences healthcare practices influence decision-making for implementing evidence-based practices. Systematic literature review in Greece from a scientific and cultural perspective did not reveal any results regarding health care professionals' awareness of NT OT. Instead, two contributing mediators intercept NT OT awareness as described next.

# **Contributing Mediators.**

#### No OT Pre- and Post- Graduate Education in Neonatal Practice.

Literature searches did not reveal any neonatal OT education at entry-level OT programs, nor guidelines and requirements for occupational therapy practitioners working in NICUs in Greece by the Panhellenic Occupational Therapy Association (PSE). Kyriaki Keramiotou, president of the PSE, confirmed that there is no OT entry-level, post-graduate education, or specialized training to become a neonatal therapist in Greece (personal communication, October 7, 2019). She also confirmed that no empirical research about the OTs' role in implementing NDSC in Greek NICUs had been conducted. If there is no background for the development of NT OT, this specialization will inevitably not be known or used in a NICU milieu.

## Inactivity of the Panhellenic Occupational Therapy Association.

Throughout the history of the former Hellenic Association of Ergotherapists (February 13, 2021) and the newly founded PanHellenic Association of Occupational Therapists (February 13, 2021), no information on neonatal OT was found. Retrieval of all OT conferences and publications by the two associations did not surface any means to promoting awareness, education, and support to neonatal OTs. If the professional association does not acknowledge neonatal OT's role, there will be no validation of NT OT involvement in NDSC and inevitably no empirical evidence of how many NICUs include NT OT services. Consequently, the OTs' role as neonatal specialists and members of a multidisciplinary NICU team is ambiguous.

# **Synopsis**

The discussion of the three main factors reinforced by five contributing mediators as seen on the left of the visual model indicates no support for establishing and developing systematic NDSC practices in the Greek NICUs and NT OTs field. If there is limited application of NDSC and NT OT involvement, there will be little incentive to research these areas (two moderators and contributing mediators seen in the center and right of the visual model). Consequently, no empirical evidence is accumulated regarding if and how many NICUs are aligned with NDSC standards, including OT services (right on the visual model).

#### **Summary and Conclusion**

In this chapter, the origins of the proposed problem were addressed. The visual model indicates three primary factors that have generated the problem and a sequence of nine mediators and two moderators. A series of questions for evidence-based answers were presented. Some answers were more compelling than others depending on the volume of the appointed supportive evidence. Yet, the summation of this evidence supports that there is an actual problem in Greece concerning lack of empirical evidence of if, where, and how Neonatal Intensive Care Units (NICUs) are aligned with standards of Neurodevelopmental Supportive Care (NDSC) for at-risk, low birth weight, and premature newborns, and the role of NT OT in NDSC applications.

# CHAPTER THREE – Overview of Current Approaches and Methods Introduction

This OTD project investigates if, where, and how many Greek NICUs implement Neurodevelopmental Supportive Care (NDSC) for premature infants according to the standards by the Canadian Association of Neonatal Nurses (CANN), the Canadian Association of Perinatal and Women's Health Nurses (CAPWHN), the Council of International Neonatal Nurses (COINN), and the National Association of Neonatal Nurses (NANN) (Milette et al., 2017), and the role of OT in this process.

Neurodevelopmental Supportive Care (NDSC) is an approach that combines specific environmental, handling, educational, family centered care, and administrative applications that support the neuroprotection of premature infants while in the NICU (Byers, 2003). NDSC can prevent or lessen the occurrence of neurodevelopmental disorders such as autism, cerebral palsy, and mental retardation (Kiechl-Kohlendorfer et al., 2015). NDSC has become the golden standard of NICU care worldwide (Als, 2017) and is carried out primarily by nurses and occupational therapists. In recent years, there have been efforts to establish universal guidelines by CANN, CAPWHN, NANN, and COINN (Milette et al., 2017) so that NDSC clinical applications and, eventually, research is consistent.

A particular problem of NDSC applications concerns Greek NICUs. Greece has one of the highest indices in premature births globally (Vlachadis et al., 2014) yet has never participated in any extensive NICU research projects, lacking empirical research regarding intensive care of newborns (Daglas & Petousi, 2018). Moreover, there is no

evidence regarding the role of neonatal OT in NDSC practices.

Consequently, several questions arise in need of support by literature review. In the next section seven questions are discussed based on evidence-based information located in CINAHL, PubMed, Web of Science, and Google Scholar data bases using MeSH/Thesaurus terms for relevant studies. Questions are listed as follows:

#### Question 1

What NDSC interventions exist for achieving neurodevelopment for premature infants in the NICU, and what is the evidence of their effectiveness?

#### Question 2

What is the evidence about applying NDSC interventions to the three types of prematurity (less than 28 weeks, 29-32 weeks, 34-37 weeks gestation)?

#### **Question 3**

What is the evidence about how NDSC is applied at all levels (I, II, III, and IV) of the NICU?

#### Question 4

What is the evidence of the role of neonatal occupational therapy in the implementation of NDSC in NICUs?

#### Question 5

What is the evidence of the qualifications for an OT to work in the NICU?

## Question 6

What is the evidence of how OT and other NICU staff collaborate for NDSC applications?

## Question 7

What is the evidence of the effectiveness of NDSC and its features?

#### Discussion

#### Question 1

What NDSC interventions exist for achieving neurodevelopment for premature infants in the NICU, and what is the evidence of their effectiveness?

A systematic literature review of NDSC interventions since 2006 by Burke (2018) showed that there are several NICU neurodevelopmental care applications. These include: (1) the Modified-Mother-Infant Transaction Program (MITP), (2) PremieStart, (3) NIDCAP, (4) Cues Intervention, (5) Massage, (6) Infant Behavioral Assessment and Intervention Program (IBAIP), (7) In-Hospital Developmental Care, (8) Family Nurture Intervention, (9) the Multisensory Intervention Program, and (10) Kangaroo Care.

The above applications focus – at a greater or lesser degree – on distinctly different areas, such as parent support, child development support, and parent education, or on the combination of all three. Burke (2018) described their treatment efficacy using 19 outcome measures, including behavioral observations, standardized assessments, and whenever appropriate, neuroimaging. He further concluded that from all neurodevelopmental approaches NIDCAP was the most commonly studied intervention. Many outcomes were significant but mixed as they were measured differently using various developmental assessment tools, IQ tests, school achievements, executive function tests, and EEG spectral coherence measures.

IBAIP studies that used the Bayley Scale of Infant Development (BSID) resulted

in significant differences in total BSID scores at six months of age, at 24 months only on motor skills, with no changes at 44 months, and mixed results at 5.5 years. Moreover, there were no significant longitudinal intervention effects on cognitive development. In regard to the Family Nurture Intervention (FNI), there was significantly increased frontal brain activity during sleep, lower EEG coherence within and between frontal regions of the brain near-term age, significantly higher cognitive and language scores on the BSID-III, and fewer attention problems on the Child Behavior Checklist at 18 months of age. The modified version of the MITP showed no significant difference at two or three years of age but a significant difference in full-scale IQ and performance IQ at five years of age. The PremieStart showed significant difference in communication and symbolic behavior at six months of age. The Cues Intervention presented no difference between the experimental and control groups at six months of age, whereas Massage showed significant difference only on the mental subscale of the BSID at 12 months. The Multisensory Intervention had significant differences in the language and motor domains of the BSID-III at two to three years of age. The Kangaroo Care resulted in significant difference in EEG complexity between the experimental and standard care at term.

Burke (2018) concludes that the outcomes regarding NDSC effectiveness are promising. Nevertheless, NDSC efficacy requires further research, including behavioral observations and EEG data. Additionally, NDSC components need to be reliably operationalized, and emphasis should be placed on treatment fidelity.

## Question 2

What is the evidence about applying NDSC interventions to the three types of prematurity (less than 28 weeks, 29–32 weeks, 34–37 weeks gestation)?

Liu et al (2007) mentions that there is a recognized need to systematically address NDSC practices in the NICU so as to match the rapidly evolving body of evidence in medical and nursing literature and neuroscience, neurobiology, neurophysiology, developmental psychology, and developmental psychobiology. Liu (2007) conducted a systematic review and identified sixteen developmental "potentially better practices" (PBP) developmental care practices applied in premature infants according to their age and based on the level of evidence using the Gray-Muir classification system (Gray-Muir, 1997). PBPs are grouped into two major gestational age consortiums: (1) 11 practices with recommended implementation starting at 23 weeks and continued to term, and (2) 5 PBPs with implementation at 31 to 32 weeks and continued to term and beyond in some cases.

The eleven practices which can be introduced at 23 weeks gestation age include: containment and body flexion, non-nutritive suck, gentle touch, decrease painful/negative stimulation, exposure to mother's scent, minimizing of exposure to noxious odors, noise abatement, minimizing ambient light exposure, avoiding light exposure, promotion of sleep cycles, family involvement, and minimizing exposure to narcotics and other medication that may disrupt sleep cycles.

For all NICU admissions beginning by 31-32 weeks and on, full implementation of the aforementioned is recommended as well as infant massage/diurnal implementation,

skin to skin care, exposure to audible maternal voice/diurnal implementation, cycled lighting of minimum 1–2 hours, and provision of complex visual stimulation.

Liu et al. (2007) highlights that the sixteen PBPs potentially support neurodevelopment, but continued research is needed. Only skin to skin care and oral stimulation/non-nutritive suck practices have a Level 1 of evidence supporting short-term benefits. Liu further indicates that NDSC is an emerging field of practice and its results are based primarily on incidental experience, rather than clinical or theoretical evidence. Advances in electrophysiology and neuro-imaging technology may increase the understanding and evidence of NDSC practices' correlation to brain structure and function and, consequently, to short and long-term effects on infant development and function.

#### **Question 3**

What is the evidence about how NDSC is applied at all levels (I, II, III, and IV) of the NICU?

A NICU is an intensive care unit where high-risk babies require and receive a higher level of care than in a typical hospital nursery. Infants at high-risk are considered premature or post-term, with inappropriate weight for gestational age, systemic illnesses, metabolic abnormalities, and congenital malformations (Raju, 2012). All NICUs provide assessment and intervention for babies at high-risk. However, there are four NICU levels and developmental care provision levels can vary between hospitals (Vandermeer, 2018).

Level I (Basic Newborn Care or Well Newborn Nursery) offer assessment and routine care to infants 35 weeks or older, and are equipped to stabilize babies when

transported to a higher-level NICU. Level II (IIA and IIB; Special Newborn Care) treats babies born greater than 32 weeks or those that are full-term and require close monitoring of problems that are expected to resolve soon. Level III (IIIA and IIIB; Subspecialty Newborn Care) have a wide variety of staff available 24 hours a day and are equipped to provide continuous life support and critical medical and surgical care to tiny and very sick newborns. Level IV (Regional NICU; sometimes called Level IIIC) is the highest NICU care level and is often a regional facility with on-site surgical capabilities for the most severe medical conditions. They care for babies at the lowest age of viability or micro-preemies.

Literature review did not reveal specific information on the methods and effectiveness of NDSC according to NICU Levels. Yet, one may assume that NDSC may be applied to all NICU levels since research refers to application of NDSC in NICUs in general terms.

#### Ouestion 4

What is the evidence of the role of neonatal occupational therapy in the implementation of NDSC in NICUs?

To date, there is limited evidence regarding NDSC-based occupational therapy. Most research has been directed to preterm infants, and neurodevelopmental care and systematic reviews have shown positive results and short-term effects of NDSC (Liu et al., 2007). Nevertheless, these studies have several limitations due to small sample sizes and low-level evidence (Blauw-Hospers & Hadders-Algra, 2005; Case-Smith et al., 2013; Symington & Pinelli, 2006). A study by Schnack et al. (2018) investigated OT's outcome

in premature infants born at 23-28 weeks, using systematic sensory-based interventions with promising results. The authors also recommended further research and evidence-based OT practices in the NICU, including NDSC applications. Consequently, the area of neonatal OT in NDSC practices has not been adequately investigated.

## Question 5

What is the evidence of the qualifications for an OT to work in the NICU? Although the need for occupational therapy in the NICU has been documented (Craig & Smith, 2020; Rubio-Grillo, 2019; Vergara et al., 2006), an OT-specific neonatal certification process is still in progress. In 2006 the American Occupational Therapy Association (AOTA) outlined the specialized knowledge and skills needed for occupational therapists practicing in the NICU (Vergara et al., 2006). In 2018 the AOTA Practice Council published the role of the neonatal OT (Craig et al., 2018). Most importantly, a national independently governed multidisciplinary board was established in 2015 to evaluate, establish, and validate the development and administration of a neonatal therapy (NT) certification process in the United States (NTNCB, 2015). The board grants Certified Neonatal Therapist (CNT) certification to licensed OTs, who have completed all competencies necessary for CNT certification (NTNCB, 2015). Yet, despite all efforts mentioned above, researchers need to further investigate the evidence of neonatal OT qualifications.

## Question 6

What is the evidence of how OT and other NICU staff collaborate for NDSC applications?

Sturdivant (2013) mentions that in 2009 the Neonatal Therapy National Certification Board (NTNTB) founded the National Association of Neonatal Therapists (NANT). NANT was specifically created to support neonatal occupational therapists (OTs), physical therapists (PTs), and speech language pathologists SLPs in order to advance the field of neonatal practice on a national level. In 2012, NANT formed the NANT Professional Collaborative (NPC), a multidisciplinary group of neonatal therapists that helps define, create, and review emerging standards, practices, and guidelines for NANT. Neonatal therapists play a vital role in the NICU, offer advanced skills and knowledge with unique attributes and characteristics beneficial to the growth and development of the fragile or premature infant, and provide support for the infant-family dyad. As neonatal therapy is defined, new and many additional questions arise. NANT plans to address these questions to create further and review emerging standards, practices, and guidelines (Sturdivant, 2013). Several other descriptive studies focused on the role of neonatal therapists and the onset, type, frequency, and overlap of developmental care services among disciplines (Ross et al., 2017; Barbosa, 2013; Sturdivant, 2013). Nevertheless, no studies of evidence-based neonatal staff collaborative NDSC practices were located.

## Question 7

What is the evidence of the effectiveness of NDSC and its features?

According to Pressler et al. (2010), NDSC applications include five core developmentally supportive areas: developmentally supportive daily living activities, the healing environment, protected sleep, pain management, and family-centered care.

Developmentally supportive daily living activities include (1) optimized infant-driven feeding to human milk (breastfeeding), and (2) infant positioning.

Optimized infant-driven feeding to human milk (breastfeeding) is a new area of NDSC intervention. For the past decade, research results have supported breast milk's beneficial effects on preterm infant feeding, such as facilitation of digestion, better adaption to preterm infant's nutritional needs (Schanler et al., 1999), strengthening of their immune system, and protection against gastrointestinal diseases (Koo et al., 2014; Lechner & Vohr, 2017). Moreover, there is mounting evidence that human milk consumption during NICU hospitalization facilitates preterm infants' neurodevelopment during infancy, childhood, adolescence, and adulthood (Belfort et al., 2016b; Bier et al., 2002; Gibertoni et al., 2015; Isaacs et al., 2010; Johnson et al., 2011; O'Connor et al., 2003; Roze et al., 2012; Sammallahti et al., 2017; Tanaka et al., 2009; Vohr et al., 2006).

Infant positioning that mimics the position in the intrauterine environment enhances neurodevelopment by eliminating stress, prolonging sleep (King and Norton, 2017; Lavallée et al., 2018) and improving oxygen saturation (Ballout et al., 2017; Rivas-Fernandez et al., 2016). Poor positioning is associated with severe complications for the motor system (Waitzman, 2007) and neurobehavioral complications in the first year (Sizun et al., 2014).

The Healing Environment refers to practices for controlling the NICU sensory

environment, particularly light and noise levels. Environmental modifications are central to reducing preterm infants' stress (Lebel et al., 2017; Symington and Pinelli, 2006), enhancing their autonomic stability (Altimier et al., 2015; Santos et al., 2015) and prolonging uninterrupted sleep (Calciolari & Montirosso, 2011).

There is consistent research agreement on the positive outcomes of modifying lighting in premature infants, such as weight gain, reduction of retinopathy, decrease in crying time (Morag & Ohlsson, 2016), improved oxygen saturation, increased weight gain, and shorter length of hospitalization (Vasquez-Ruiz et al., 2014). NICU noise has been documented to cause stress responses such as bradycardia or tachycardia, increased systolic and diastolic blood pressure, apnea, hypoxemia, alteration in oxygen saturation, and increased oxygen consumption, and increase in intracranial pressure (Wachman & Lahav, 2011). These stressors may increase the risk of physiological and neurodevelopmental disorders (Almadhoob & Ohlsson, 2020).

Despite the popularity of NICU noise reduction, there are no large well designed, conducted, and reported randomized controlled trials (RCTs) studying specific variables (dB, Hertz, use of earplugs or earphones, among others). NDSC recommends a noise reduction to below 45 dB; however, this has not been achieved in most neonatal intensive care units (NICUs) (Almadhoob and Ohlsson, pg. 12, 2020).

Protected (uninterrupted) sleep has been well documented to be directly associated with early infant neurodevelopment (Arditi-Babchuk et al.; 2009; Liaw et al., 2012; Pereira et al., 2013; Vandenberg, 2007). The NICU environment is harmful to the neonatal sleep, given the intense visual, auditory, handling, and painful procedures all of

which are stressing factors and disturb sleep. Sleep deprivation in newborns has a negative impact on neuroplasticity, can result in neurological damage, and can cause negative effects in growth and development, health recovery, and behavioral changes in adulthood (Correia & Lourenço, 2019).

NICU infants undergo numerous painful procedures. Pain causes hyperactivity of the central nervous system (CNS) and changes brain plasticity (Brummelte et al., 2012) with long term effects such as pain hypersensitivity (Crozier et al., 2016; Valeri et al., 2016) and lower motor and intellectual development indices (Grunau et al., 2009). Pain management as an NDSC practice is still under investigation (Pillai Riddell et al., 2015) because painful procedures are accompanied by non-pharmacological intervention (skinto-skin contact/Kangaroo Care, sucrose administration associated with non-nutritive sucking (NNS), and swaddling or tucking) only 50% of the time (Johnston et al., 2011).

Family-centered care (FCC) is vital to NDSC. It includes nine areas: a) involvement of family in the infant's life starting from the NICU, b) collaboration of NICU staff with parents regarding infant's health care, c) racial, ethnic, cultural, and socio-economic conditions, d) enhancement of families' strengths and coping methods, e) providing families with complete information, f) understanding families' need of support and networking, g) child and family developmental needs as part of healthcare practices, h) emotional and financial support; and i) healthcare that is flexible, culturally competent and responsive to family needs (Shields et al., 2012). There is extensive NICU research on the positive results of the FCC. FCC promotes neurodevelopment (Vanderveen et al., 2009), parental participation (Lavallée et al., 2017), and parental sensitivity. FCC has

shown general neurodevelopmental, neurobehavioral, and functional maturation due to decreased stress and improved cortex development necessary (Calciolari & Montirosso, 2011; Cooper et al., 2007; Myers et al., 2015; O'Brien et al., 2013; Reynolds et al., 2013; Teti et al., 2009; Welch et al., 2017; Yu et al., 2017). Moreover, FCC has benefits for parents, such as reducing fear and stress and increasing parental confidence (Cocroft, 2012).

All of the above are considered neurodevelopmental outcomes in preterm infants. Aita et al. (2020) conducted an extensive systematic review and meta-analyses of studies from 2002 to 2020 regarding NICU interventions' effectiveness to infants aged 24-36 weeks. This research included 12 studies and 901 infants. The study concluded that reports of NDSC practices' effectiveness were either conflicting or partial, due to the investigated research quality. Specifically, the research quality was rated low to very low due to: a) high to unclear risk of bias, b) small sample sizes, and c) heterogeneity. Nevertheless, Aida et al (2020) recommended the Newborn Individualized Developmental Care and Assessment Program (NIDCAP), which includes many areas of NDSC, be used in NICU clinical practice, whereas other areas of NDSC, such as parental participation programs, be further investigated.

#### Summary

NDSC is a widely recognized set of practices for the neuroprotection and neurodevelopment of high-risk infants with a history spanning since the 1980s. Most of the research supports that NDSC is promising. Despite its popularity, research on NDSC's effectiveness is still contradictory due to low research quality, small and

heterogenous group samples, non-reliably operationalized NDSC components, insufficient behavioral observations and EEG data, and scarce investigation on treatment fidelity. Investigation of NDSC applicability and treatment effectiveness research in Greece did not reveal any results. Furthermore, there is no substantial evidence of the role of OT and its NT training for implementing NDSC practices in Greek NICUs.

The discussion in chapter three is the cornerstone on which the author's awareness program was built. In the next chapter, the awareness program will be discussed in detail including the following sections: basis of the proposed program, explanatory and full logic models, program content, participants, materials and sources, program outcomes, and perceived barriers and challenges.

## **CHAPTER FOUR – Description of the Proposed Program**

#### **Basis of the Proposed Program**

Developmental Care (DC) refers to a range of programs and strategies designed to modify the neonatal intensive care unit (NICU) environment to reduce stressors on the developing brain (Als & McAnulty, 2011). Neurodevelopmental Supportive Care (NDSC) is a DC program that emphasizes infant neuroprotection through NICU environmental modifications and equipment, infant handling and positioning techniques, family-centered practices, and specialized NICU staff training. Evidence-based research indicates that NDSC improves premature infants' ability to move, learn, and think; may prevent or lessen the possibility of neurodevelopmental disorders such as autism and cerebral palsy; and establishes a better quality of life for children and their families (Milette et al., 2017).

Inclusion of Occupational Therapists (OTs) as neonatal therapists (NTs) is an essential component of a comprehensive preventive model of family-centered neuroprotective care services to infants at increased risk for developmental compromise and their families (Craig & Smith, 2020). NT OTs contribute to the provision of care in each of the four levels of nurseries and are important members of the NICU teams (American Academy of Pediatrics, 2017).

NDSC applications and neonatal OT contributions in developmental care practices are at an incipient stage in Greece (see analysis in Chapter 2). Since the number of premature births demanding immediate specialized early intervention is rising, the implementation of NDSC in every Greek NICU is of utmost necessity.

This chapter describes an innovative, multimedia, online educational program aimed at establishing and increasing community awareness of Neurodevelopmental Supportive Care (NDSC) applications in Greek Neonatal Intensive Care Units (NICUs) and the role of neonatal occupational therapists (NT OT) in this process. Program participants will become familiar with the neurodevelopment of prematurity, the external factors that may hinder neurological maturity and adverse outcomes in later life, the role and components of NDSC applications, and NDSC educational resources. Participants will learn about the qualifications and training that NICU therapists and OTs must acquire to design and implement NDSC practices.

In order to accommodate the educational needs of different participant groups, the program offers three tracks: Track one will provide general information of NDSC in NICUs and neonatal OT for the general public; Track two will offer specific information and resources for the medical, nursing, therapeutic, and NICU community; and Track three will include specialized information for the medical, nursing, therapeutic, and NICU community along with a collection of data for the launch of the first NDSC research on a large scale in Greece in 2021. Health professionals may participate in either track two or three, or both two and three, depending on their competency with NDSC terminology, NICU work experience, and the level of awareness they need or wish. Each track's participants will be requested to complete a corresponding program evaluation questionnaire.

This is an ambitious, viable, and exciting program that will boost the NICU and OT community to build upon their existing knowledge and promote clinical, educational,

administrative, social, and economic changes in the area of preventive medicine and early intervention. It will foster consideration and implementation of NDSC practices and neonatal OT in every NICU in Greece according to universal standards and the most current evidence-based practice. Clinical changes will establish a foundation for further research on NDSC efficacy in neonatal care and investigate NDSC practices' outcomes in premature infants' well-being later in life. Moreover, this program may pave the way for Greece to strengthen its position in the universal world of early intervention neuroprotective medicine.

## **Issues and Explanatory Model**

Updated research data regarding premature birth and low birth weight rates in Greece are sparce. According to Vlachadis et al (2014) preterm birth rate in Greece from the 1980s to 2010 has increased fourfold, and more than doubled from 2003 to 2010. The same author also mentioned that the 2010 preterm birth rate (PBR) of 11.18 in Greece poses dramatic challenges for public health and emphasizes the need for preventive interventions to be implemented. A study by Chalkia et al (2015) and OECD-Health at a Glance (2014) showed that births of underweight infants (less than 2500 grams), and premature births are constantly increasing in Greece. A most recent study by Zografaki et al (2018) indicated that the financial crisis in Greece contributed to an increase in low birth weight and preterm deliveries.

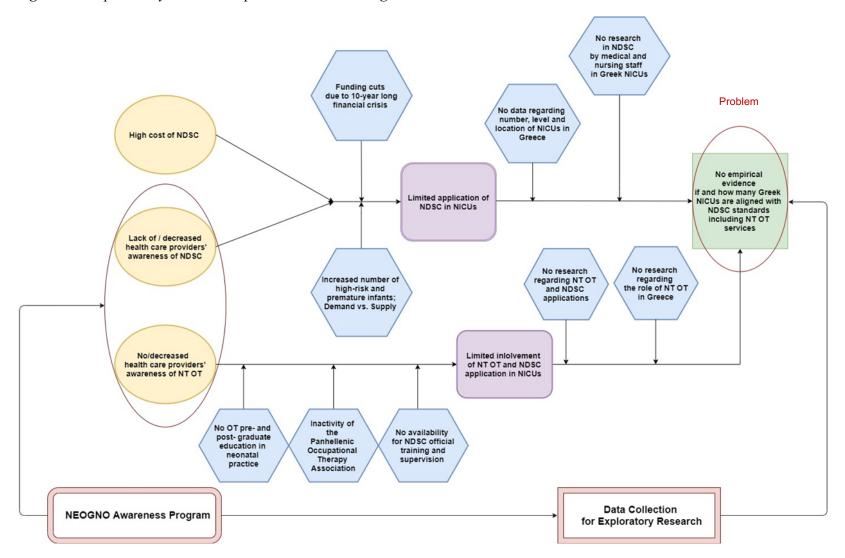
Despite the growing number of premature births, Greece has never participated in any extensive NICU research projects and is lacking empirical data regarding the following areas; (a) if, where, and how intensive care of newborns is based on NDSC

practices, (b) measured outcomes (qualitative and quantitative) of infants graduating from NDSC-supported NICUs in the first year of life and later years, and (c) if, where, and how OTs as neonatal specialists are involved in NDSC applications.

# **Explanatory Model**

The following explanatory model (Figure 4.1) depicts the Problem, Main Factors, and the Proposed NEOGNO Program.

Figure 4.1 Explanatory Model: Proposed NEOGNO Program



There are three main factors that contribute to the lack of empirical evidence concerning NDSC in NICUs and neonatal OT: (a) high cost of NDSC, (b) deficient or decreased awareness of NDSC by health care providers, and (c) deficient or decreased awareness of the role of neonatal OTs. The factors derived from the literature review (see Chapter 2) and testimonials of parents of premature infants who required NICU support.

The first factor concerns the cost of NDSC in NICUs. NICUs' expenditure is high, averaging approximately \$114,000.00 for each surviving ventilated infant in the USA (Meadow et al., 2012), and Greece is no exception (Geitona et al., 2007). Compounding factors are the costly NDSC training and implementation (NIDCAP, 2006; Soleimani et al., 2020) and the 2012-2019 financial crisis in Greece that had a profound reduction in health care services and reimbursement (Keramidou & Triantafyllopoulos, 2018; World Health Organization, 2018).

The second factor is the limited NDSC awareness by health care professionals. Scholastic literature review surfaced only two Greek NICU articles with partial references to elements of NDSC: (a) NICU nurses' need for family-care practice (Galanis et al., 2016), and (b) Greek NICU's staff focus on quantity of life versus quality of life (Daglas & Petousi, 2018). Limited research findings of NDSC and neonatal OT may reflect no or little awareness of DC and NICU OT by the health care community.

The explanatory model's third factor is the decreased awareness of occupational therapy's role in the NICU and NDSC applications. Neonatal OT is a highly specialized and expanding field that requires advanced education, mentorship, and clinical skills (AOTA, 2018). NT OTs role is to conduct assessment and treatment of the high-risk

neonate on an individualized, developmental approach based on the synactive theory of development considering their influence on short- and long-term outcomes of the child and family that support life roles and occupations (AOTA, 2018; Hunter, 2009; Vergara et al., 2006). NT OTs make a unique contribution to the neonatal team, offering the clinical expertise to assess and treat the family and infant's occupational skills from delivery to discharge in the hospital environment (Royal College of Occupational Therapists, 2017).

NT OT is a new discipline in Greece. There are no NT OT graduate, postgraduate or certification programs. It is unknown if OTs are trained in NDSC and their role in Greek NICUs. No NT OT NDSC publications were located and there is no reference to this specialty on the website of the Hellenic Occupational Therapy Association (PSE, n.d.). Contributing elements to the lack of professional, parental, and public awareness of NICU OT are lack of focus on early intervention and neonatology in OT entry-level education, limited or no OT neonatal training and mentorship, no postgraduate neonatal OT programs, no guidelines nor requirements for working in NICUs, and no support by the Hellenic Occupational Therapy Association. The few OTs working in Greek NICUs have acquired their training from abroad on their own time and expense hence missing collective recognition by their profession, other health care professions, and public bodies. If education and training of OTs in neonatal and NDSC practices are inadequate, OT may not be expected to implement NDSC in NICU environments or be recognized as a team contributor. Subsequently, there has been no empirical research conducted to date in this area in Greece.

The author's awareness program will target two of the three previously discussed areas (i.e., awareness of NDSC and the role of NT OT in NICUs in Greece), which are circled on the left side of Figure 4.1. The circled areas on the right will be addressed by the data collected through the awareness program and launch of the first exploratory research of NDSC in Greece in 2021. Research results will then be used to further design training programs, raise evidence-based support of NDSC and NICU OT, and promote more research in neuroprotective practices for high-risk neonates.

## **Theoretical Grounding**

The awareness program's selected theory is the Health Belief Model (HBM) (Conner, 2010; Rosenstock et al., 1988). The HBM aims at people's perception of health, health problems, and prevention of health problems through self-awareness, critical thinking, beliefs, willingness, and action-taking. Moreover, the HBM model focuses on what health behaviors are and how, why, when, and if these behaviors can be predicted. In terms of HBM application in the context of this program, the focus is on identifying the parameters of awareness, attitudes, perceptions, and beliefs of the health care professional community that impact the application of NDSC and neonatal OT in NICUs.

Although in the past the HBM was used primarily at intrapersonal (micro) and interpersonal (meso) levels, it has expanded its theoretical and clinical applications to the community (macro) level as well (Amraei et al., 2020; Hendricks-Muñoz & Prendergast, 2007; Rollins et al., 2018). As with other community educational programs rooted in HBM, it is anticipated that the author's program will depict a change in the perception of NDSC and NICU OT in Greece at all levels: micro (individual NICU practitioners), meso

(the NICU and health care community) and macro (Department of Health and legislation for early intervention).

A common cause for limited applications of NDSC in Greek NICUs may be the perception that neurodevelopmental intervention is not equal to medical practices (medication or surgery) and, hence, not always necessary (perceived susceptibility). It is also a common perception that as long as neonates survive, there is a probability of developing neurodevelopmental disorders; however, there is little consideration for preventing or reducing such outcomes through NDSC (perceived severity).

Consequently, the benefits of NDSC in early life are not appreciated as highly as they should be (perceived benefits), and particular action taking (establishing NDSC programs in all NICUs) may not be taken. Furthermore, factors such as high cost, decreased societal and political awareness, and inadequate support of NDSC by the medical and OT community appear as significant barriers to NDSC implementation (perceived barriers) and unnecessary to reduce perceived threat (health motive).

In terms of intervention, HBM is a guiding theory to discover how many, where, if, and which NICUs (target population) are keen on NDSC applications, NDSC educational guidelines, neonatal OT in NDSC practices, and NDSC and NICU OT research for future program planning. The awareness program will provide the necessary information for health care professionals to feel competent (self-efficacy) to take action and to reinforce behavior change (e.g., implementation of NDSC practices in all NICUs). Table 4.1 depicts how the awareness program will address HBM constructs to understand the problem and guide the program design.

 Table 4.1 The Health Belief Model and Applications to the Awareness Program

Inter- and Intra- Levels	
HBM Construct that supports	Program Content
<b>Perceived susceptibility</b> : one's subjective perception of a health problem	Raise NICU staff awareness of the importance of NDSC applications in the NICU
<b>Perceived severity</b> : one's subjective perception of the seriousness of a health problem	Raise NICU staff awareness of the possible consequences of non-NDSC applications (e.g., neurodevelopmental disorders)
<b>Perceived benefits:</b> one's subjective perception to act or not on a health problem; greatly depends on one's values and beliefs	Raise NICU staff awareness of the benefit of supporting and implementing NDSC in terms of financial and societal gains (e.g., NDSC practices reduce the need for early intervention and school-based services, as well as decrease the levels of domestic violence)
<b>Perceived barriers:</b> one's subjective perception of what obstacles may prevent or interfere with action taking for a health problem	Raise NICU staff awareness of the barriers for NDSC applications and the solutions concerning NDSC certification, NICU equipment, protocol making, etc.
Cues to action: refers to prompts (reminders, how-to charting, media, financial incentives, etc.) needed to move the person into the state where they are ready to take the prescribed action	Raise awareness about NDSC significance through media, reading material, conferences, lectures, and research to specific groups such as health-related professionals and organizations, medical associations, schools of health-related professions (i.e., OT school), and hospitals. Begin NDSC certification training. Positive reinforcement is central to this phase
Self-efficacy: This refers to the person's confidence and belief in their ability to take the given action. Self-efficacy is interdependent with self-belief and self-empowerment. Encouragement, training, and other support foster self-efficacy	NICU professionals are empowered to implement NDSC in their hospitals. Reinforce networking among NDSC trained personnel and non-trained personnel of other hospitals to enhance self- empowerment and leadership

Community Level	
HBM Construct that supports	Program Content
Perceived susceptibility: one's subjective	Raise community awareness of the importance of
perception of a health problem	NDSC applications in the NICU
Perceived severity: one's subjective perception	Raise community awareness of the severity of non-
of the seriousness of a health problem	NDSC applications in the NICU for future
	development and severity of neurodevelopmental
	disorders, such as autism
Perceived benefits: one's subjective perception	Raise community awareness of the benefit of
to act or not about a health problem; greatly	supporting and implementing NDSC in NICUs in
depends on one's values and beliefs	terms of financial and societal gains (e.g., NDSC
	practices reduce the need for early intervention and
	school-based services)
Perceived barriers: one's subjective perception	Raise community awareness of the barriers for
of what obstacles may prevent or interfere with	NDSC applications and the solutions that exist (e.g.,
action taking for a health problem	educational, financial, physical, social, medical, etc.)
Cues to action: refers to prompts (reminders,	Raise community awareness about NDSC
how-to charting, media, financial incentives, etc.)	Raise community awareness about NDSC significance through media, reading material,
	•
how-to charting, media, financial incentives, etc.)	significance through media, reading material,
how-to charting, media, financial incentives, etc.) needed to move the person into the state where they	significance through media, reading material, conferences, and lectures. Invite NDSC professionals
how-to charting, media, financial incentives, etc.) needed to move the person into the state where they are ready to take the prescribed action	significance through media, reading material, conferences, and lectures. Invite NDSC professionals from other countries to present NDSC on TV and the Ministry of Health
how-to charting, media, financial incentives, etc.) needed to move the person into the state where they are ready to take the prescribed action  Self-efficacy: This refers to the person's	significance through media, reading material, conferences, and lectures. Invite NDSC professionals from other countries to present NDSC on TV and the Ministry of Health  Hospital administrators and officials from the
how-to charting, media, financial incentives, etc.) needed to move the person into the state where they are ready to take the prescribed action  Self-efficacy: This refers to the person's confidence and belief in their ability to take the	significance through media, reading material, conferences, and lectures. Invite NDSC professionals from other countries to present NDSC on TV and the Ministry of Health  Hospital administrators and officials from the Ministry of Health are empowered to implement
how-to charting, media, financial incentives, etc.) needed to move the person into the state where they are ready to take the prescribed action  Self-efficacy: This refers to the person's confidence and belief in their ability to take the given action. Self-efficacy is interdependent with	significance through media, reading material, conferences, and lectures. Invite NDSC professionals from other countries to present NDSC on TV and the Ministry of Health  Hospital administrators and officials from the Ministry of Health are empowered to implement NDSC in Greek hospitals. Reinforce networking
how-to charting, media, financial incentives, etc.) needed to move the person into the state where they are ready to take the prescribed action  Self-efficacy: This refers to the person's confidence and belief in their ability to take the given action. Self-efficacy is interdependent with self-belief and self-empowerment. Encouragement,	significance through media, reading material, conferences, and lectures. Invite NDSC professionals from other countries to present NDSC on TV and the Ministry of Health  Hospital administrators and officials from the Ministry of Health are empowered to implement NDSC in Greek hospitals. Reinforce networking among these parties with NDSC experts and
how-to charting, media, financial incentives, etc.) needed to move the person into the state where they are ready to take the prescribed action  Self-efficacy: This refers to the person's confidence and belief in their ability to take the given action. Self-efficacy is interdependent with	significance through media, reading material, conferences, and lectures. Invite NDSC professionals from other countries to present NDSC on TV and the Ministry of Health  Hospital administrators and officials from the Ministry of Health are empowered to implement NDSC in Greek hospitals. Reinforce networking

## **Engagement of Program Stakeholders**

The awareness program targets three groups of stakeholders: (a) non-healthcare professionals, (b) non-NICU health care professionals, and (c) NICU health care professionals. The first is a community group that may include the general public, students, parents, politicians and public servants, funding organizations, and hospital administrators. The second group addresses health care providers not necessarily associated with NICU practices, including physicians, nurses, occupational therapy professionals, other therapists, medical researchers, physician-hospital administrators, and health care professional students and associations. The third group encompasses NICU professionals, including therapists, health care students, NICU societies and associations, and NICU parents. The distinction among groups will allow stakeholders to participate in the most relevant level of the awareness program, according to their need, desire, expertise, and time availability. Furthermore, level selection will designate the appropriate candidates for the exploratory research survey completion.

#### Full Logic Model

The program's logic model (see Appendix G) is a graphic depiction of the shared relationships among the awareness program's underlying theory and logic, resources, activities, outputs, outcomes, impact, and its intended effects.

#### **Program Description**

This is an online awareness program about NDSC and neonatal OT for the NICU, and health care community and the general public. The following is a discussion of the program content and participants, personnel and recruitment, and intervention and

activities.

## Program Content and Participants

The online awareness program will be hosted on a custom-made website (see Appendix B). It will include the following: an introduction to the program's vision and history; information about the author; description of the philosophy, benefits, structure, education, and application of NDSC according to universal standards; definition of the role of neonatal OT; research about NDSC; links to NICU, NDSC, and neonatal OT organizations and societies; testimonials from NICU professionals and parents; and information for becoming a neonatal and NDSC trained therapist. The site will offer short videos on NDSC and neonatal occupational therapists applying NDSC practices in English with Greek subtitles. All educational materials and materials for free download are included in Appendices D and E.

The program's website will also include (a) an optional exploratory research survey (see Appendix C) for qualitative and quantitative data collection on NICU practices in Greek hospitals and (b) a program evaluation questionnaire (see Appendix G) that assesses the website's content, the educational program's usefulness, suggestions for improvement, and desired changes in program structure.

Participants will choose from three available Tracks on the awareness program's website, according to the level of awareness they need or wish.

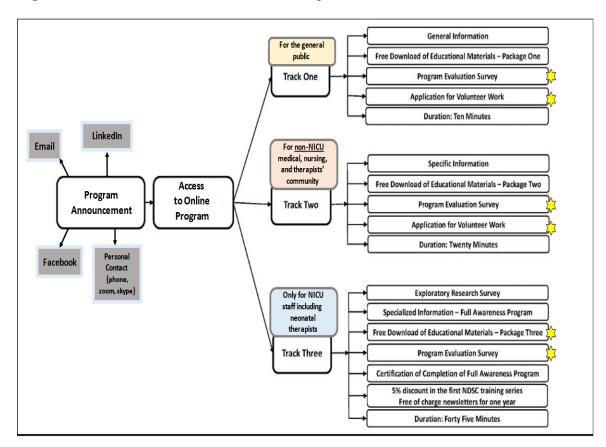


Figure 4.2 NEOGNO's Announcement, Participants, and Educational Structure

Track one will be geared toward community groups not familiar with NICU, NDSC, and neonatal OT terminology who need a quick, and clear view of the program content. Participants will have access to educational materials appropriately tailored for this level and to the evaluation questionnaire. The duration of Track one is ten minutes.

Track two will contain more specific information for NICU and non-NICU health care professionals and students. Participants need to be familiar with NICU, NDSC, and neonatal OT terminology. They will be able to download educational materials designated for this level. This Track is appropriate for health-care professionals who need more scientific and specialized resources but do not wish to participate in the data

collection process (i.e., the voluntary program evaluation questionnaire and exploratory survey about NICU practices in Greek hospitals). The duration of Track two is twenty minutes. If participants of this Track wish to obtain even more specialized information, they may choose to access Track three described below.

Track three offers specialized information for NICU and non-NICU health care professionals and students who agree to participate in the data collection process. This Track contains a detailed spectrum of educational activities specifically designed for health care professionals familiar with NICU and neonatal OT terminology.

Participants need to follow a sequence of steps starting from completing the exploratory survey about NICU practices in their hospital, then proceeding to the educational materials, and tailed by the online, multimedia awareness program evaluation questionnaire. After completion of all steps, they will receive a certificate of program awareness completion, a 5% discount in the first NDSC training series, and complimentary newsletters for one year. The duration of Track three is forty-five minutes.

All Track participants may apply for volunteer work in the program (office work, dissemination of information, public relations). Volunteers will engage in survey data collection, office work (answering messages, typing, printing, and filing), and multimedia information updating.

# **Program Intervention Activities**

The program has several intervention activities, including an announcement schedule, access and use of the online awareness platform, announcement and recruitment actions, and data collection from the two questionnaires.

 Table 4.2 Program's Announcement Time Schedule

	Announcements	Start Date	Duration	End Date	Updates
<b>A.</b>	First Announcement		One month		None
В.	Second Announcement		One month		None
C.	Third Announcement		Two months		Yes
D.	After that, every four months for two years		Four months - Three times per year		Yes
Е.	After that, twice a year		Six months – twice per year		Yes

The program's announcement will be delivered using Facebook, Instagram,

Twitter, Email, and phone calls according to the Greek public's preferred multimedia use.

A carefully planned sequence of steps for the program's launch will be followed as shown in Figure 4.2 and described in detail next. It is necessary to consider that this project's audience/participants are anticipated to be proportional to Greece's population of 10,399,955 (Worldmeter, 2020). In other words, the pool of health care providers will be analogous to a small populated country.

Regarding the first announcement, the author will publicize the program to the community by posting a brief description and the website link on multimedia on a specific date. The IT will facilitate this process by accessing a pool of 100,000 media followers selected by professional background (physicians, occupational, physical, and speech-language therapists and students, hospital administrators, nurses, social workers, private funding institutions, early intervention, and parent associations) for a monthly fee.

On the first day of the first announcement, electronic access will be granted to the online awareness program. The announcement will also be forwarded by email and personal phone calls to the author's health care professional associates and acquaintances, followed by an electronic "Thank You for Participating" note (see Appendix H). The same note will be sent by email to the Hellenic Occupational, Physical, and Speech-Language Therapy Associations, the Medical and Nursing Associations, and non-for-profit NICU groups. Finally, notes will be advanced to the Head of the maternal ward of one hundred hospitals and, if available, to the Head of their NICUs. The time frame of this step is one month. The time frame of the first and following announcements is included in Table 4.2. Additional program advertising may include publishing short articles about the awareness program in magazines that are distributed for free with the Sunday newspapers, participating in radio discussions, and being hosted by regional TV station programs.

### **Program Evaluation Questionnaire and Exploratory Research Surveys**

Two questionnaires will be available on the awareness program's webpage; a program evaluation questionnaire and a survey for exploratory research purposes. The

two-page program evaluation questionnaire (Appendix F) is optional for all Track participants. The questionnaire's purpose is to assess the website's contents in terms of importance, ease of use, hyperlinks, structure, relevance, comprehension, completeness, layout, and search options using a Likert-type scale. The results of the evaluation survey will assist in program and website modifications and upgrading. They will also serve for the planning of future surveys about online awareness programs.

The twelve-page exploratory research survey will be used for data collection regarding NICU and NDSC features in Greek hospitals (see Appendix C). Research outcomes will further assist in planning NDSC training series in Greece, advocacy, and promotion of NDSC and neonatal OT funding for NICU staff NDSC training and NICU equipment. In the exploratory research, the author will investigate if, where, how, and by whom disciplines NDSC practices are employed in Greece, OT status in NDSC practices, and compliance with NDSC international standards.

#### Personnel and Recruitment

The author will be actively involved in all aspects of program planning, delivering, and monitoring. A volunteer information technology (IT) professional and three work office secretaries from the author's business office will assist on a part-time basis until other volunteers are recruited.

The project's venue includes the author's home office, equipped with a desktop computer, two laptop computers, a copier/scanner/fax/web/printer device, stationary and mobile phones. Hardware and software for multimedia use, brochure, pamphlet, newsletter formatting, survey creation, and data collection and processing are provided.

The author will cover all project expenses if a grant is not obtained. Her home office is remotely connected with her work office, allowing access to all records and professional contacts. The author and secretaries will keep track of the announcement dates, personal contacts, invitations, follow-up calls, emails, and messages. Communication between home and work offices will be shared on a custom-made designed platform. The secretaries will assist with typing, printing, emailing, posting, phone calls, and office supplies until volunteers are located. The IT expert will undertake all the program's template designing and technical aspects, whereas the author's academic advisor will accommodate project questions.

### **Program Outputs and Outcomes**

The expected program outputs and outcomes as direct products of the program activities are depicted in the Logic Model (see Appendix G). The following is a detailed discussion of Outputs, Short-Term, Intermediate, and Long-Term Goals, aiming to understand the program's objectives.

#### **Outputs**

The anticipated program outputs include number of: (a) likes on Facebook and other multimedia per each program announcement, (b) visits to the program awareness website per each program announcement, (c) participants in each of the three Tracks, (d) program evaluation questionnaires completed, (e) completed surveys for exploratory research data collection, (f) volunteers recruited, (g) correspondence requesting promotion and educational materials, (h) requests for NDSC training series, (i) requests for evidence-based practice in NDSC and neonatal OT, (j) requests for information on

neonatal OT training, and (k) requests for information on certification process of neonatal therapists.

#### Short Term Outcomes

As per the Logic Model (see Appendix G) at two months post program's launching, it is projected that due to the increased awareness and introduction to sources for NDSC information, the health care community will initiate action. Action may take the form of proposals for NDSC application in hospitals by the NICU staff, implementation of NDSC practices, and including OT in NICUs. The first 2-hour introductory course in NDSC online is anticipated to spark further motivation to investigate NDSC in NICUs. Consequently, the primary short-term outcome is the transition from awareness to consideration and establishment of NDSC practices on a micro and meso scales. In this process, the author will be updating the website material based on program evaluation feedback and continue to announce the program to health care professionals and the general public.

#### Intermediate Outcomes

At six months post-program initiation, there will be a further increase in the awareness of all aspects of NDSC. As a result, there will be an increase in NDSC training inquiries, followed by a need for NDSC equipment and environmental modifications in NICU hospitals. Five hospitals will show interest in investigating NDSC and begin training of NICU staff. Revision of the program's content.

## Long Term Outcomes

As seen in the Logic Model, within twelve months from the program's launching, there will be a shift to macro systems for NDSC practices and neonatal OT establishment. This transition will be accomplished by hosting the first full NDSC training series in Greece and establishing preparatory courses in neonatal OT at the undergraduate level supported by the newly founded Greek NDSC Association. Furthermore, it is anticipated that ten hospitals establish NDSC, and all neonatal OTs are trained in NDSC through support by the Greek Ministry of Health. Based on the expansion of NDSC practices, it will be feasible to conduct more rigorous research and to appoint Greece to the international arena of NDSC evidence-based practice investigation.

# Synopsis

As mentioned previously, this project is the first of its kind in the country. It will inaugurate research by Greek and international educational and research institutions and collaborate with large associations such as the European Foundation for the Care of Newborn Infants (EFCNI) and The Partnership for Maternal, Newborn & Child Health (PMNCH). Most importantly, this program's outcomes will benefit premature infants and their families by rooting evidence-based practices such as NDSC early in their lives to lessen or eliminate the possibility of neurodevelopmental disorders in the future and the need for supportive services. Because of the great significance of NDSC, raising awareness through the author's program will primarily benefit NICU personnel, including medical, nursing, and OT staff. The author anticipates that hospital administrators recognize NDSC and OT's role and establish NDSC practices in their NICUs. One large

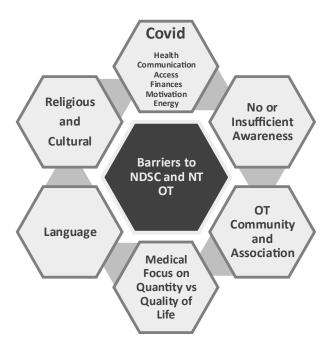
group that is expected to be affected are OTs. The program may influence OT schools to add neonatal OT and NDSC courses in the educational curriculum and the Hellenic Occupational Therapy association to support neonatal OT. This project may ultimately increase the Department of Health's interest and investment in neonatal services and the community's efforts to advocate for early intervention at the governmental level.

The bottom line is that premature infants, and their families are the primary population to benefit from the author's project. It is anticipated that the intended audience will develop greater interest and motivation for promoting NDSC practices in their local NICU. In time, every NICU in the country will endorse awareness of neonatal OT's role in NDSC apply NDSC practices according to international standards.

## **Anticipated Barriers and Challenges**

Figure 4.3 demonstrates anticipated challenges in the process of the program.

**Figure 4.3** *Anticipated Barriers in the Process of NEOGNO* 



Coronavirus Disease 2019 (COVID-19) has impacted live in-person communication, limiting the personal reciprocity factor in discussions and public relations. The pandemic has influenced people's motivation to engage in continuing education due to restrictions in transportation, accessibility, and human resources. Consequently, it may require more effort to encourage people to participate in this program.

Furthermore, public and private financial investment in NDSC practices may take secondary importance due to increased health needs. Overworked hospital personnel may be reluctant to complete surveys or to engage in NDSC training. Educational institutions have suspended on-campus operations that may delay curricula revisions to add OT neonatal courses. The hosting of a full series of NDSC training courses requires hands-on practice and inviting instructors from overseas; both of these factors will be feasible upon resolving the COVID-19 restrictions.

Religious and cultural reasons may present another challenge. Medical practices in Greek NICUs primarily focus on saving lives rather than ensuring quality of life that may bypass the effort to establish NDSC practices. The awareness program will help build on this priority by also addressing the importance of quality of life long-term for these infants and families.

NDSC applications require time, funds, structural (e.g., space), and equipment changes in hospitals, and a shift of the paradigm of neonatal care. These aspects may require more time to materialize than the preconceived time frame of the author.

Additionally, language barriers may affect the NDSC educational and training

efforts since most instructors derive from English-speaking countries. Language barriers may also impact participants' willingness to download NDSC references. Lastly, the OT community and the OT association in Greece need to refocus on the new OT practice trends and embrace neonatal OT promotion. However, the above require fundamental changes in the conception, acceptance, and implementation of new standards.

Despite the discussed anticipated barriers and challenges, there are promising facilitators, including the community of premature infants (parents and innovative health care staff), OTs who thrive on new developments in their practice, interest by large educational institutions (universities, the WHO, and ENFCI) in supporting NDSC and neonatal OT research, as well as the author's vision, faith and unlimited persistence in this project.

#### **Summary and Conclusions**

Based on the Health Belief Model, the author anticipates that this first of its kind, innovative, online, multimedia awareness program will facilitate change in perceptions of early intervention with premature infants and encourage action for establishing NDSC and NT OT in all NICUs in Greece. A great ambition is that a domino effect will occur, and changes at micro, meso, and macro levels will emerge. Greece can leave its mark on the EFCNI and WHO map in terms of promising results of NDSC practices as long as there is a starting point; the author's project. In the next chapter, details of the program evaluation research plan in reference to its necessity, structure and implementation will be discussed.

## **CHAPTER FIVE – Program Evaluation Research Plan**

## **Program Scenario and Stakeholders**

The "Neurodevelopmental Supportive Care and The Role of Occupational Therapy in Greek Neonatal Intensive Care Units - A Health Awareness Program" (NEOGNO) online awareness program is intended to increase awareness of Neurodevelopmental Supportive Care (NDSC) applications in Greek Neonatal Intensive Care Units (NICUs) and how neonatal occupational therapists (NT OT) contribute to this process (see Chapter Four for more details of the NEOGNO program). This chapter describes the evaluation research plan for NEOGNO, including program evaluation vision, stakeholder involvement, the program evaluation research design, and a plan for disseminating program evaluation research findings.

## **Vision for the Program Evaluation Research**

The research findings will demonstrate the extent to which objectives for the program and its participants were achieved. The author's short-term vision for the program outcomes includes raising awareness of NDSC and neonatal OT in the participants' group, facilitating their accessibility to NDSC and neonatal OT resources; improving the sophistication of the program by accumulating knowledge about the underlying dynamics of the program and its delivery, and optimizing program performance. The long-term vision includes organizing the first NDSC certification training in Greece, founding an NDSC non-for-profit organization, establishing NDSC practices in all Greek NICUs, and initiating specialized neonatal OT post-graduate education. Furthermore, as stated previously, a much-desired long-term goal of the author

is to orchestrate an exploratory research study.

## **Engagement of Stakeholders**

Stakeholder engagement has been identified as a key component of developing high-quality studies that investigate healthcare topics in order to better understand how research can contribute to reducing the gap between research, practice and policy. (Martinez et al., 2019). Since this program evaluation research focuses on a community awareness that benefits NICU professionals and OTs, there is a need for stakeholder engagement to ensure the program itself and the program evaluation research will contribute to raising awareness of NDSC and neonatal OT in Greece. Potential stakeholders who may be involved in planning the program and program evaluation research include: NICU professionals (physicians, nurses, OTs, other NICU health care professions, and administrators), NICU parents, developmental pediatricians, pediatric nurses, OTs, and other health care disciplines, the author, staff members of the author's educational institution, and a policy administrator from the ministry of health.

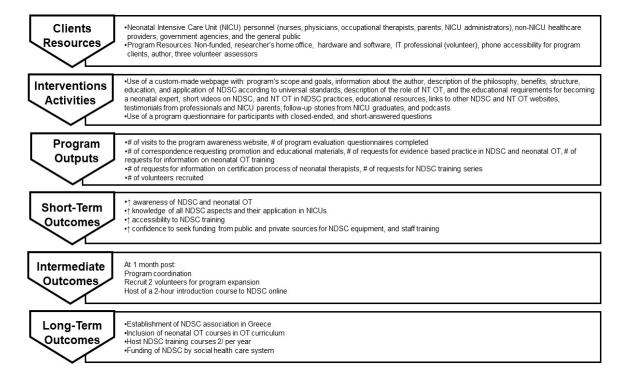
The author will contact individual stakeholders through personal phone calls, Zoom, Skype, and emails. To ensure engagement by each key stakeholder, the author will initially furnish them with a list of questions for discussion addressing "Potential reason(s) for being a stakeholder in this project," "Program areas of personal importance," "Relevance of the program to his or her practice," "Clinical evaluation questions," "Program design suggestions," "Proposed resources," "Program administration ideas," "Marketing ideas," "Willingness to contribute to the research effort," and an "Other comment box." Mutual respect, open communication, goodwill,

and enthusiasm will maintain stakeholder's interest in the program.

## Simplified Logic Model for Use with Stakeholders

Once stakeholders have agreed to be involved in helping assess and develop the program and program evaluation plans, this simplified logic model will assist them in understanding the flow of the program. (see Chapter 4 for program details)

**Figure 5.1** Simplified Logic Model for Use with Stockholders



# Preliminary Exploration and Confirmatory Process with Stakeholders

To ensure consensus and clear understanding of the program's activities, expected outcomes, and evaluation research's logistics, and to achieve and maintain stakeholder support, the following processes will be in place: The author will arrange an initial virtual group meeting with all stakeholders where they will receive information about the program, their role, means of communication, and a schedule for future meetings. A

PowerPoint presentation will orient the group to details of the program and program evaluation research plan. Stakeholders will also receive all educational materials and letters of consent and confidentiality, which they need to sign. Future meetings will be scheduled based on the program's needs and according to the stakeholders' role.

Prior to each subsequent stakeholder meeting, the author will send the discussion agenda, the schedule, and any additional meeting materials. The author will maintain archives of the meetings and make these available to stakeholders upon request. The author will encourage stakeholders to express their perspectives and values, suggestions, and constructive criticism in the meetings regarding program and program evaluation planning. Each meeting will be video and audio recorded upon the stakeholders' consent.

## Program Evaluation Research Review by Stakeholder Group

Appendix S includes a "Program Evaluation Research Checklist" with qualitative and quantitative research questions that each stakeholder or stakeholder group will follow to evaluate the NEOGNO awareness program. Stakeholders involved in planning the program evaluation research will examine and provide feedback on the "Program Evaluation Checklist" which will be completed by NEOGNO program participants. The program evaluation research design, including methods for data collection, data analysis, and dissemination of findings, will be described next.

#### **Program Evaluation Research Design**

The research design for the NEOGNO program evaluation is formative and summative. In the formative aspect, data will reflect feedback about the program's content and the usefulness of the author's method of delivering the information. Data will

also derive from participants' ratings of their experience and satisfaction following the viewing of the program. The summative aspect data will confirm if desired changes in awareness of NDSC and neonatal OT occurred due to the author's intervention.

## Qualitative Data Collection Designs

### Formative/Qualitative Designs.

For formative qualitative data collection, the author will use the administration of questionnaire with open-ended or short answer questions (see Appendices P and Q).

# **Summative/Qualitative Designs.**

For summative qualitative data collection, the author will use the administration of questionnaire with open-ended or short answer questions (see Appendices P and Q).

## Quantitative Data Collection Designs

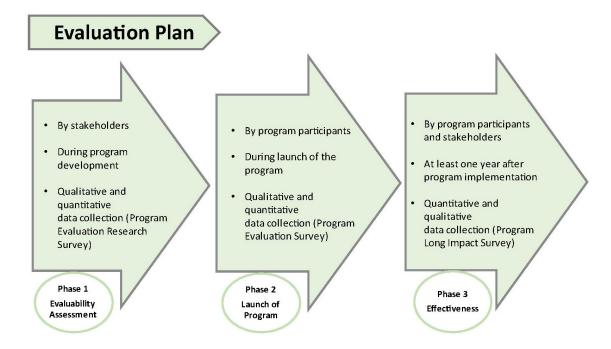
### Formative/Quantitative Designs.

For quantitative data in the formative program evaluation research, the author will include survey questions answered by Likert-type numerical rating (see Appendices P and Q).

### Summative/Quantitative Designs.

For quantitative data in the summative program evaluation research, the author will include survey questions answered by Likert-type numerical rating (see Appendices P and Q).

Figure 5.2 Program Evaluation Research Design



#### **Methods for Data Collection**

In this section, consideration is placed on information that applies to both formative and summative research designs. The information includes how confidentiality will be ensured to create a preliminary plan for obtaining Institutional Review Board IRB approval before data collection. Research methods for data collection will be further discussed.

The first step toward data collection is the acquisition of approval by the Institutional Review Board (IRB). The author will request an exemption for this program since the methodology does not involve intervention on human subjects. Confidentiality will be ensured as follows: only one user with a strong password (the herein author) will have access to all data entered by each participant. The study title and the author will not reveal sensitive information about subjects who fill in the survey. Before data collection,

each participant will sign a letter of consent and a letter of confidentiality. Survey data will be transmitted through a secure protocol (Secure Sockets Layer-SSL and Hyper Text Transfer Protocol Secure-HTTPS), and access to the survey will be provided to each participant with a unique code.

Participants will be reminded to prevent possible violations of their privacy in their workplace by, for example, closing browsers after completing an online survey on a sensitive topic. All data will be stored in password-protected files, accessible only by the author and her academic advisor, without indicative names, using codes that uniquely identify only the participating member. The author has already completed the Collaborative Institutional Training Initiative (CITI) certification as part of her IRB application; consequently, she is aware of confidentiality and data protection requirements.

Subjects will be invited to participate in the program by a posting on Facebook.

Inclusion and exclusion criteria will also be posted on the same invitation. Inclusion criteria are: health care providers, physicians, general public, NICU staff and NICU parents, knowledge of NICU terminology, Greek citizens, fluency in English, and technology literate. Exclusion criteria are: all that is not mentioned in "Inclusion criteria."

The posting and data collection duration will be 30 days and will require 50 participants' responses. The completion of data selection will be determined either by the 30-day time frame or the number of participants, whatever comes first. Subjects will be asked to use their personal computer or laptop to visit a website specifically designed to include educational material for NDSC and neonatal OT, and surveys.

Upon reviewing the program's general information, scope, and details about becoming a program participant, each subject may proceed to join. A sign-in process will be activated, and a personal code will be assigned to each participant. Before access to the educational material and survey(s) is granted, each participant is required to sign a letter of consent and confidentiality. Following that, permission to join the program process is given.

In the following sections, the author's program evaluation research methods will be discussed. The setting, exclusion and inclusion criteria, and access to the program have already been explained and will not be repeated below. Figure 5.2. depicts the data collection methods as per each phase of the program.

### Phase 1

#### Formative/Qualitative and Quantitative Data Collection.

Appendix Q includes a "Program Evaluation Research Checklist" for formative qualitative and quantitative data collection. Questions will reflect the stakeholders' experience and view of the educational material and the usefulness of the program using a Likert-type scale with 1 to 5 rating, and a section with open-ended or short-answer questions.

#### Phase 2

Formative/Qualitative and Quantitative, and Summative/Qualitative and Quantitative Data Collection.

This phase includes the program launch. Data will be collected from the participants based on a questionnaire included in Appendix P. Questions will reflect the

participants' experience and view of the educational material and the usefulness of the program using Likert-type scale with a 1 to 5 rating and open-ended or short-answer questions.

#### Phase 3

### Summative/Qualitative and Quantitative Data Collection.

This phase reflects the long-term impact of the program. Data will be collected from stakeholders and participants using a survey to be developed in the future that will collect quantitative and qualitative data.

# Methods for Data Management and Analysis

### Qualitative Data Management and Analysis

The author will consider the descriptive method for qualitative data management and analysis (Goodrick & Rogers, 2015). Software such as LiGRE will be used as a codification tool for data analysis and generating tables, and exporting results in an SPSS or Excel compatible format to further data analysis.

### Quantitative Data Management and Analysis

For Quantitative data management and analysis, univariate statistics will be used (Newcomer & Conger, 2015). Software such as IntellectusStatistics will be used to interpret the statistical assumptions and analysis findings, and generate tables and figures that correspond to the assumptions and output (nominal variables, interval and ratio variables) as well as t-tests.

## Disseminating the Findings of Program Evaluation Research

Disseminating program evaluation research findings is an ongoing process, and the author will adopt different strategies. The message of the program in brief discussions with individuals or small groups will follow The Mom Test. The "Killer" paragraph will be used for communicating the results on Facebook, the authors' blog, to stakeholders as an invitation, and as a first paragraph of news releases (magazines or articles). The Outline method will assist in PowerPoint presentations and as a discussion guide during meetings with professionals, administrators, fundraisers, students, or stakeholders. The author will use The Two-Page Executive Summary in meetings with hospital administrators, funding agencies, government representatives, and advocacy groups. Finally, the ten-page report will be used when the results are distributed to academic circles, on the Internet, and -possibly- as a chapter in a textbook. The author will follow Grob's suggestions (Grob, 2015a; Grob, 2015b) for the evaluation's report layout. As far as the writing style is concerned, a combination of power and reflective writing best matches the author's style. Finally, report cards will be used on an ongoing basis to maintain and enhance motivation for improvement and change in NICUs and influence public policy.

In the next chapter the programs' dissemination plan will be discussed including; dissemination goals, target audiences, messengers, budget, activities, techniques, timing and responses, and evaluation of the dissemination plan's success.

#### **CHAPTER SIX – Dissemination Plan**

#### Introduction

The author's proposed multimedia, online educational program aims at establishing and increasing community awareness of Neurodevelopmental Supportive Care (NDSC) applications in Greek Neonatal Intensive Care Units (NICUs) and the role of neonatal occupational therapists (NT OT) in this process. Program participants will become familiar with the neurodevelopment of prematurity, the external factors that may hinder neurological maturity and adverse outcomes in later life, the role and components of NDSC applications, and NDSC educational resources (Pierrat et al., 2016).

Participants will learn about the qualifications and training that NICU professionals and OTs must acquire to design and implement NDSC practices. They will also contribute to the evaluation of the program, and assist in data collection for the first exploratory research on NDSC and NT OT practices in Greece. This is a new area of heath awareness and the results of the program need to be disseminated in macro levels, such as the ministry of Health and Education, and funding agencies in Greece and abroad. Moreover, the dissemination efforts include national and international organizations, societies and academic institutions that have a direct or indirect relation with prematurity, preventive medicine, early intervention and occupational therapy practice.

### **Dissemination Goals**

The main dissemination goal is establishing NDSC practices in all NICUs in Greece and the inclusion of adequately trained NT OT in NDSC applications. NDSC is the gold standard in premature and at-risk newborns' neuroprotection (Als and McAnulty,

2011). Evidence-based research indicates that NDSC improves premature infants' developmental outcomes and may prevent or lessen the possibility of neurodevelopmental disorders such as autism and cerebral palsy (Milette et al., 2017). Based on limited evidence-based information, NDSC applications and neonatal OT contributions in developmental care practices are at an incipient stage in Greece. Since the number of premature births is rising, demanding immediate specialized early intervention, the implementation of NDSC and NT OT in every Greek NICU is of utmost necessity.

The following discussion includes disseminating both the program and program evaluation goals, target audiences, key messages, sources and managers, dissemination activities, tools/techniques, timing and responsibilities, budget, and dissemination plan evaluation.

#### **Target Audiences**

### Primary Audience

The primary target audience for the dissemination efforts will be the medical, nursing, and administrative staff of NICUs nationwide. Dissemination efforts will target this audience longing to establish NDSC practices and include NT OT in their NICU teams.

### Secondary Audience

The secondary target audience for the dissemination efforts will include the Panhellenic Occupational Therapy Association, occupational therapists, occupational therapy students and educators, and directors of all public and private OT schools in

Greece. The intention is to include a) the NT OT discipline in their educational curricula and b) in the professional OT practice guide and criteria for becoming NT according to universal (EFCNI, GLANCE, NANT, NFI) standards.

#### **Dissemination Goals**

## Long Term Goal (2-3 years)

The dissemination of the program to both the primary and secondary audiences will lead to major public and private hospitals employing NDSC practices in all NICU levels and including NT OTs in their NICU interdisciplinary team.

# Short Term Goal 1: (1-2 years)

The dissemination of the program to the primary audience will lead Greece to host the first NDSC training series for NICU nursing and OT staff.

## Short Term Goal 2: (1-2 years)

The dissemination of the program to the secondary audience will result in public and private OT schools including at least one course in neonatal occupational therapy and NDSC in their undergraduate curriculum.

#### Short Term Goal 3: (1-2 years)

The dissemination of the program to the secondary audience will result in the Panhellenic Occupational Therapy Association including NT OT in their Practice Guide with criteria for becoming NT according to the European Foundation for the Care of Newborn Infants (EFCNI, 2018), the Global Alliance for Newborn Care (GLANCE, 2019), the National Association of Neonatal Therapists (NANT, 2021), and the NIDCAP Federation International (NFI, 2021) guidelines.

## **Key Messages**

## To the Primary Audience

NDSC is an essential element of newborn intensive care and preventive medicine. As the voice of preterm infants and their families, our work is raising awareness for preterm birth, and taking action in neuroprotective care. NDSC applications in the NICU provide a great opportunity to infants for positive brain growth that will ultimately affect their long-term outcome. We can move forward in this crucial time for early intervention only if there is support from all levels of professional education and practice. Present and future preterm newborns wait for us to give them an opportunity to thrive and live well.

### To the Secondary Audience

In the past four decades OT has expanded its role and contribution in neonatal developmental care. The distinct nature of the 'occupation' for the NICU infant and his/her family makes the occupational therapist an essential and core member of the neonatal team. OTs need to know this area of specialized pediatric practice. The need for early intervention in the NICU through NDSC practices require OTs to obtain advanced knowledge and skills through continuous education, supervision, research and evidence-based intervention. OT professionals, students, and educators need to acknowledge this area of practice, raise the bar in graduate and postgraduate education, seek professional guidance and training, become advocates for NT OT, initiate research and make your voice heard in the health care community. We cannot afford to miss another 40 years.

### Sources/Messengers

Several influential spokespersons can disseminate the key messages.

# Primary audience

The author will communicate with:

- a) EFCNI, GLANCE, NANT, and NFI to collaborate on materials and education.

  Greek NICU staff are more receptive to credible international organizations for acquiring information and assistance in organizing NDSC training.
- b) Ilitominon (2019), the only Greek non-for-profit organization for NICU parents.
- c) Neonatology Clinic of the National and Kapodistrian University of Athens
  (EKPA) (n.d.) at the Aiginiteio and Aretaio hospitals in Athens, Greece. They
  are the first to present online education regarding the medical complications
  of NICU infants.
- d) Vardinoyannis, M.V. Foundation (2021), a Greek non-governmental organization associated with the United Nations Economic and Social Council (ECOSOC). Mrs. M. Vardinoyannis, a United Nations Educational, Scientific and Cultural Organization (UNESCO) Goodwill Ambassador, is engaged in numerous philanthropic works, including the First Children's Oncology Hospital's founding in the Balkans.
- e) Onassis Foundation (2021), which is involved in health promotion matters.

  The author is a former scholarship recipient for graduate studies in the United States of America (USA).
- f) Hellenic Neonatological Society (2016), which is an advocate for best possible care for newborns.

# Secondary audience

The author will communicate with:

- a) Ms. Sue Lutwig, OT and president of NANT. Mrs. Lutwig is a pioneer in the establishment of NDSC practices in NICUs and NT training criteria, and the promotion of NT OT. As an NT OT, an administrator and educator, she has all qualifications to address NDSC in the OT profession.
- b) Ms. Pani Pandelides, PT, NDT/NIDCAP professional. Mrs. Pandelidis is the first NDSC trained therapist in Greece and involved in EFCNI, NIF, and Ilitominon functions. She is highly qualified to discourse NDSC training and inclusion of early intervention in OT curricula. (P. Pandelidis, personal communication, November 2, 2020).

### Budget

For both the primary and secondary audiences, budget expenses are displayed in Appendix M. The dissemination of the program will be mostly provided online.

Additional activities will require expenses for travel and printed materials. Labor, communication expenses, and supplies will be absorbed by Pediatric Institute, the author's private practice, until private funding is located.

### Dissemination Activities, Tools/Techniques, Timing, and Responsibilities

The delivery of key messages will be carried on via electronic media. The entirety of the awareness program is based online; therefore, it is logical that its dissemination will follow the same strategy. Since the Greek public prefers Facebook, LinkedIn, and email, all information (brochures, newsletters, videos, and the author's program) will be

available on these platforms. The author's office has an extensive database of contacts, including health care organizations and associations, medical and nursing societies, parent groups, occupational therapy, and other therapy groups, advocate teams, and maternal/pediatric hospital administrator addresses. The author maintains two professional Facebook accounts and will acquire an additional one for the awareness program. The website of the program will also be used, including a blog.

It is important to mention that the orchestration of the activities for the awareness program will set the stage for the dissemination plan's success. There is only one exception; the dissemination plan will include countries outside Greece by using Facebook and LinkedIn and personal notices to institutions such as the EFCNI, GLANCE, NANT, NFI, World Federation of Occupational Therapists (WFOT, 2021), the American Occupational Therapy Association (AOTA, 2021), the European Network of Occupational Therapy in Higher Education (ENOTHE, n.d.) and the Council of Occupational Therapists for European Countries (COTEC, 2021). Finally, as stated in the logical model (see Appendix G), the first NDSC training series organization will enhance the broadcasting of the program's results.

The dissemination will be continued in the future through continuous professional education, article writing for magazines and journals, participation of the author/topic in conferences, seminars, TV, podcast, and radio shows, and more expanded research on NDSC and NT OT.

#### **Evaluation**

To determine the dissemination plan's success on the target audiences, a set of criteria are set as seen in Appendix N.

#### Conclusion

The author's project Neurodevelopmental Supportive Care and the Role of Occupational Therapy in Greek Neonatal Intensive Care Units – A Health Awareness Program is unique both in NICUs and in OT in the country. Based on the utmost necessity for early intervention, neuroprotection of fragile newborns at risk and preterm through NDSC practices, and OT's valuable role in the NICU, the awareness program is both an innovation and long due. The dissemination of the program's success is considered the beginning of a nationwide effort to change perceptions, attitudes, and actions in developmental care toward NICU infants and their families. Moreover, it is essential to surface the NT OT profession as a significant partner to the NICU team and set the first-ever guidelines for NT specialization in Greece. The hope is that the word will disperse about the measures we can take as professionals and community members to protect the vulnerable population of newborns in danger and warrant the best quality of life possible.

### **CHAPTER SEVEN – Funding Plan**

## **Program Description**

While developing in the Neonatal Intensive Care Unit (NICU), high-risk and preterm infants are exposed to adverse stimuli that can affect their cognitive, physical, social, and emotional development, frequently resulting in neurodevelopmental disorders that will impact how they will respond to their environments and participate in occupations later in life (Bart et al., 2011).

Neurodevelopmental Supportive Care (NDSC) is an approach to individualizing infants' care for neurological development and reducing long-term cognitive and behavioral problems (Milette et al., 2017). NDSC includes various environmental modifications, equipment, handling and positioning techniques, family care, creation of assessment and follow-up protocols, and interdisciplinary communication and collaboration (Als & McAnulty, 2011). Evidence-based research indicates that NDSC improves premature infants' ability to move, learn, and think; prevents or lessens the possibility of neurodevelopmental disorders such as autism and cerebral palsy, and establishes a better quality of life for the children and their families (Milette et al., 2017). The inclusion of occupational therapists (OTs) as neonatal therapists (NTs) is an essential component of a comprehensive preventive model of family-centered NDSC services for infants at increased risk for developmental delays and their families (Craig & Smith, 2020; Rubio-Grillo, 2019).

Despite the growing number of premature births, Greece has never participated in any extensive NICU research projects and lacks empirical data regarding newborns'

intensive care (Daglas & Petousi, 2018). Specifically, there is no data regarding: (a) if, where, and how NICUs Level I, II, or III, align with NDSC standards for newborn and premature infants, (b) measured outcomes (qualitative and quantitative) of infants graduating from NDSC supported NICUs and non- NDSC supported NICUs in the first and later years of life, and (c) if, where, and how OTs as neonatal specialists are involved in NDSC applications.

To raise awareness of NDSC practices and neonatal OT's importance, the author is developing a first of its kind online educational program available to the general public; NICU personnel, and health care practitioners and administrators involved in early intervention, such as hospital managers, medical and nursing interns, parents, and pediatric therapists. It is expected that this awareness program will develop higher interest and motivation to promote NDSC and OT practices in every NICU nationwide and to promote research in this field.

# **Funding Plan**

The awareness program requires three funding phases in two time periods (Year One and Year Two). In Year One, the three funding needs are: (a) preparing and launching the program, (b) supporting and improving the program, and (c) collecting and analyzing data from the program's surveys and conducting the first experimental research on NDSC and NT OT in Greece. In Year Two, the funding needs require additional financial support as they will incorporate the establishment of an NDSC association and NDSC training series organization.

## Year One Funding Needs

In Year One, as seen in Appendix O, the only funding needed is for Facebook advertisement totalling \$200.00 for all three funding phases. If a funding source is not secured for this expense, the author's private practice – Pediatric Institute, Ltd- will donate the funds. Manpower is either voluntarily (information technology (IT) expert, volunteers for office work, and evaluators) or – until volunteers are located – Pediatric Institute's payroll will absorb the office work expenses. Pediatric Institute will also donate supplies and communication expenses. Space and office equipment are available at the author's home and business offices. Other needs, including website design, Facebook templates, brochure and newsletter templates, educational videos, and editing of Greek subtitles for the videos, are free of charge and available online. Travel expenses are not considered at this point due to COVID-19 restrictions. However, if travel were permitted, the cost for land and air transportation would be covered either by funding sources or donated by Pediatric Institute. Consequently, the total funding need for Year One is \$200.00.

#### Year Two Funding Needs

The Year Two operations and expenses for the awareness program will be the same as in Year One with two exceptions; needed funding for (a) the establishment of the Greek NDSC Association and (b) for the organization of the first NDSC training series as depicted in Appendix P. These include legal and accounting fees, expenses for purchasing a domain name, and a website's development. The NDSC Association will also require space, equipment, materials, and staff on an ongoing basis. Until funding is

tenable, the author's private practice will donate all of the above. The hosting of the first NDSC educational training series in Greece demands expenses for assembling an organization team, appointing a venue, catering, marketing, and technical aspects, covering accommodation, transportation, and fees of the speakers, reading and writing materials, and translator services. As described next, both activities (NDSC Association and NDSC training series) need the financial support from potential funding sources. It is projected that in the following years, continuous funding from public and private sectors be necessary for the sustainability and expansion of the program. In case no funding is allocated within the first two years, Pediatric Institute will absorb all costs as a tax-deductible donation. Nevertheless, the sustainability of the program beyond that time frame requires continuous financial support that may employ individual donations as well.

#### **Potential Funding Sources**

The potential funding sources for the three phases of the program and for the two first years are described next. There is a plethora of funding agencies most of which are private, non-for-profit. Federal funding by the ministry of education or the ministry of health is not available. However, the European Union (EU) offers several funding options that vary from one year to another, and require an extensive application. University funding is also non-available since the author is not associated with a Greek academic institution for her doctoral studies. International grants are another option. In most cases, the available amount for funding is determined upon application by the author. This implies that the application needs to strongly justify the social benefit of the program and

the rationale for funding. There is a higher probability to ensure funding from the "A. Onassis Foundation" since they had previously granted the author a scholarship for graduate studies in the USA. Moreover, European universities seek access to other countries research which may enable additional funding. Finally, a new option is funding from the US Embassy in Greece since the author holds both nationalities, the program is a good match for the scope of their financial support (see Appendix Q) and the project aims at health benefits.

#### Conclusion

This chapter defined the overall costs and potential funding sources needed to implement the author's health awareness program. Because of the program's online structure and the available free-of-charge resources, funding demands for the Year One are meager. In the second year, funding will be necessary to cover a significant step of the program's financial needs: establishing the Greek NDSC Association and the first NDSC training series. Funding will be sought through international and Greek sources, excluding Greek public's donations due to law restrictions. Consequently, the First Year is crucial for the marketing of the program, public relations, and funding application procedures to strengthen the possibility of funding from multiple sources. Personal investment of the author's time, effort, dedication, professional contacts, and support by her family and business environment will establish a solid foundation for the muchanticipated implementation of the first of its kind and highly needed project.

#### **CHAPTER EIGHT – Conclusion**

In the last decades, advances in medical care have increased the survival of infants born preterm. Nevertheless, preterm infants are at high risk for developing long-term neurodevelopmental impairment and may require long-term treatment in a neonatal intensive care unit (NICU) (Milette et al., 2017). In spite of NICUs' lifesaving procedures, their environment exposes neonates to repeated, randomly occurring, invasive, and stressful sensory experiences that deplete their resources and often result in problematic functioning and developmental outcomes (Hunt, 2011).

Neuroprotective measures known as Developmental Care have been increasingly employed in NICUs worldwide. Neurodevelopmental Supportive Care (NDSC) is a structured Developmental Care (DC) program that incorporates NICU environmental design, family-centered care, and non-invasive infant handling techniques (Altimier & Phillips, 2016). Jacobs (2018) emphasized that NDSC interventions have been associated with both short- and long-term positive physiological, cognitive, and emotional outcomes for infants and their families, and shorter, cost-effective hospitalization of newborns. Because of these multiple gains, NDSC has been slowly changing the delivery of care to at-risk infants and incorporated into the routine NICU management procedures.

An irreplaceable partner in NDSC applications is neonatal occupational therapy (NT OT) (Pinto et al., 2019). AOTA (2018) supported that OT's role in neonatology is a highly specialized field of practice geared towards the intervention and research on the acquisition and preservation of occupational performance of the fragile infant and his/her family. Craig and Smith (2020) mentioned that the uniqueness of NT OT is the

knowledge, clinical applications, and research founded on medical, psychosocial and ecological context to support the human occupation of infants at risk at a very early developmental stage.

In spite of the multiple benefits of NDSC, currently, there is a void of data on NDSC applications and NT OT staffing in Greek NICUs. Taking into consideration the increasing number of premature births in Greece and the consequent growing challenges for public health and preventive interventions, the need for NDSC in NICUs is paramount.

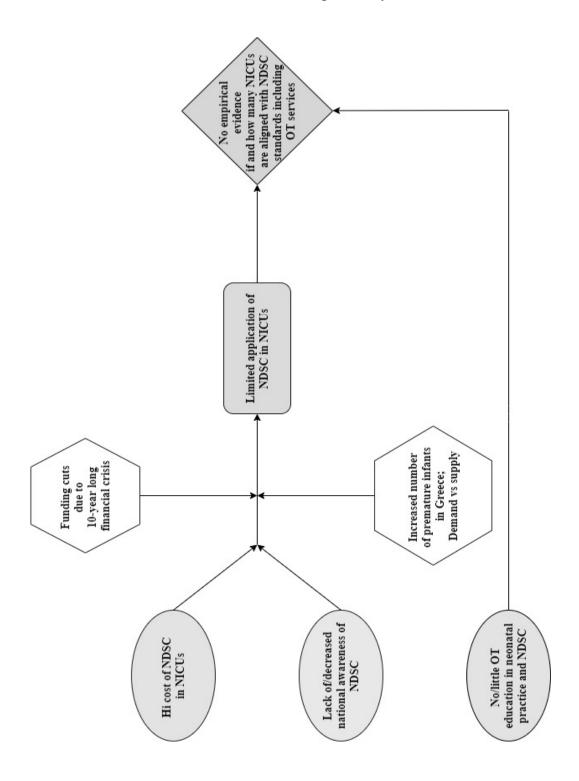
Raising awareness is the first step toward implementation of NDSC in Greek NICUs. "NEOGNO" awareness program is the first of its kind in the country. It will inaugurate interest by the NICU, medical, OT, early intervention, and other health care professional communities, parents and governmental agencies. Due to the diversity of the population the program addresses, evidence-based information will be broadly disseminated. The flexibility of the program to meet different educational needs of the participants will facilitate engagement in NDSC and NT OT matters more efficiently. The orchestration of carefully planned steps of all aspects of the program, the detailed design, strategic marketing, ongoing monitoring and interactive nature of "NEOGNO" sets the stage for a successful, wide-scale health awareness program.

The ultimate goal of this awareness program is to establish NDSC practices and NT OT in all Greek NICUs. Early intervention services will expand to ages as young as 24 weeks of gestation, providing an opportunity to the developing infant to acquire a better quality of life in the future. Eventually, it is anticipated that major changes will

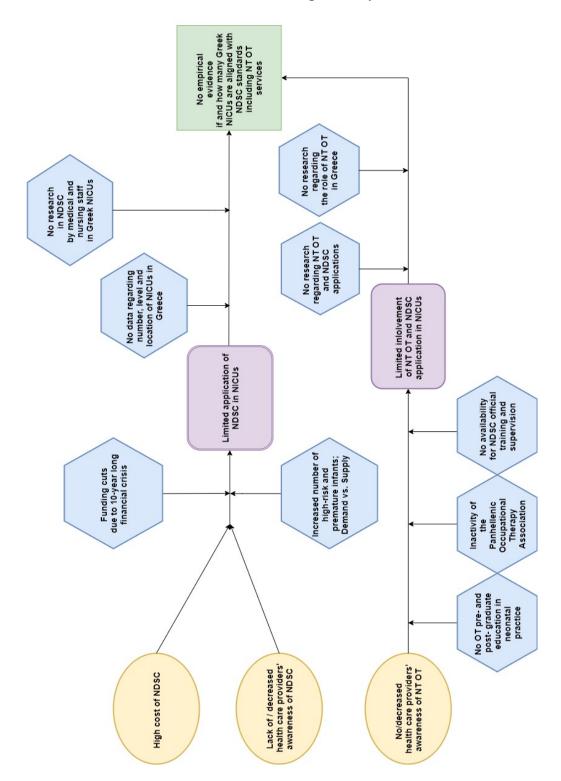
emerge, including governmental funding, NDSC training to all NICU providers, introduction to NT OT education at pre-graduate levels, NT OT certification post-graduate, and inclusion of NDSC and NT OT awareness in medical schools. It is also expected that the Panhellenic OT association will acknowledge and support neonatal OT and become an NDSC NT OT advocate. This project will ultimately increase the Department of Health's interest and investment in neonatal services and the community's efforts to advocate for early intervention at the governmental level. An ambitious but feasible outcome of this program will also be the inauguration of research in NDSC and NT OT in Greece that will contribute and support European and international efforts to validate further NDSC practices and NT OT.

First and foremost, NEOGNO is paving the way for the vulnerable preterm and at-risk NICU infants to feel protected and safe as when in their mothers' womb, to survive, thrive, and enjoy life, build strong emotional and physical bridges with their parents, and become a family from day one.

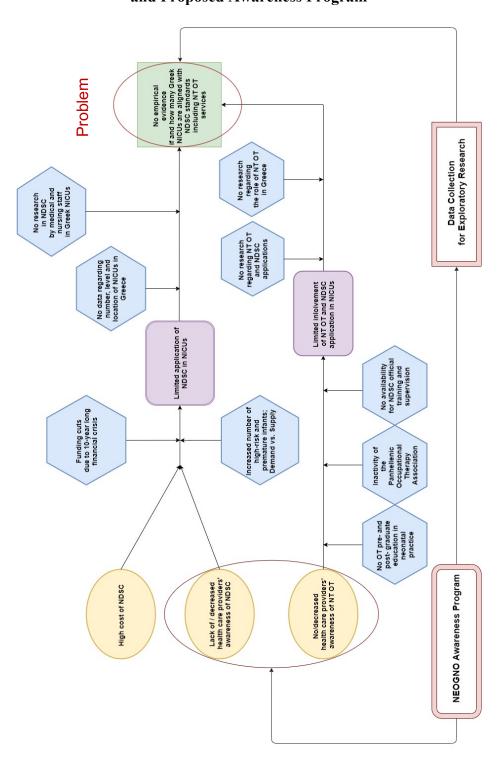
**APPENDIX A - Initial Explanatory Model** 



**APPENDIX B - Final Explanatory Model** 



APPENDIX C - Explanatory Model; Problem Areas, and Proposed Awareness Program



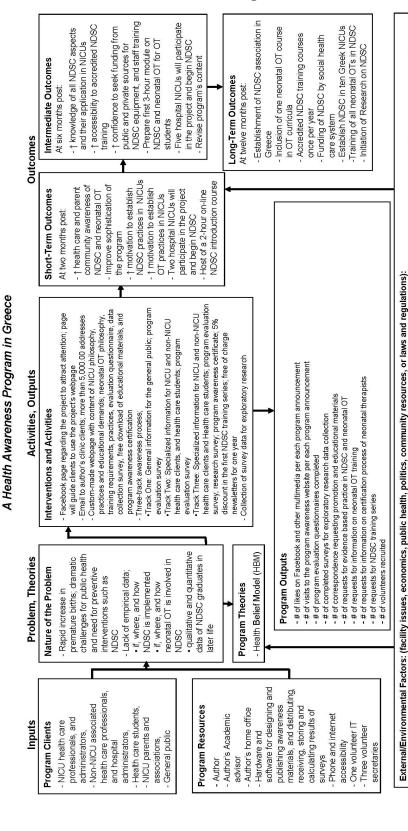
### APPENDIX D - The Health Belief Model (HBM), and

### Applications to the Awareness Program

Inter- and I	ntra- Levels
HBM Construct that supports	Program Content
<b>Perceived susceptibility</b> : one's subjective perception of a health problem	Raise NICU staff awareness of the importance of NDSC applications in the NICU
<b>Perceived severity</b> : one's subjective perception of the seriousness of a health problem	Raise NICU staff awareness of the possible consequences of non-NDSC applications (e.g., neurodevelopmental disorders)
Perceived benefits: one's subjective perception to act or not on a health problem; greatly depends on one's values and beliefs	Raise NICU staff awareness of the benefit of supporting and implementing NDSC in terms of financial and societal gains (e.g., NDSC practices reduce the need for early intervention and school-based services, as well as decrease the levels of domestic violence)
<b>Perceived barriers:</b> one's subjective perception of what obstacles may prevent or interfere with action taking for a health problem	Raise NICU staff awareness of the barriers for NDSC applications and the solutions concerning NDSC certification, NICU equipment, protocol making, etc.
Cues to action: refers to prompts (reminders, how-to charting, media, financial incentives, etc.) needed to move the person into the state where they are ready to take the prescribed action	Raise awareness about NDSC significance through media, reading material, conferences, lectures, and research to specific groups such as health-related professionals and organizations, medical associations, schools of health-related professions (i.e., OT school), and hospitals. Begin NDSC certification training. Positive reinforcement is central to this phase
Self-efficacy: This refers to the person's confidence and belief in their ability to take the given action. Self-efficacy is interdependent with self-belief and self-empowerment. Encouragement, training, and other support foster self-efficacy	NICU professionals are empowered to implement NDSC in their hospitals. Reinforce networking among NDSC trained personnel and non-trained personnel of other hospitals to enhance self- empowerment and leadership

Community Level			
HBM Construct that supports	Program Content		
Perceived susceptibility: one's subjective	Raise community awareness of the importance of		
perception of a health problem	NDSC applications in the NICU		
Perceived severity: one's subjective perception	Raise community awareness of the severity of non-		
of the seriousness of a health problem	NDSC applications in the NICU for future		
	development and severity of neurodevelopmental		
	disorders, such as autism		
Perceived benefits: one's subjective perception	Raise community awareness of the benefit of		
to act or not about a health problem; greatly	supporting and implementing NDSC in NICUs in		
depends on one's values and beliefs	terms of financial and societal gains (e.g., NDSC		
	practices reduce the need for early intervention and		
	school-based services)		
Perceived barriers: one's subjective perception	Raise community awareness of the barriers for		
of what obstacles may prevent or interfere with	NDSC applications and the solutions that exist (e.g.,		
action taking for a health problem	educational, financial, physical, social, medical, etc.)		
Cues to action: refers to prompts (reminders,	Raise community awareness about NDSC		
how-to charting, media, financial incentives, etc.)	significance through media, reading material,		
needed to move the person into the state where they	conferences, and lectures. Invite NDSC professionals		
are ready to take the prescribed action	from other countries to present NDSC on TV and the		
	Ministry of Health		
Self-efficacy: This refers to the person's	Hospital administrators and officials from the		
confidence and belief in their ability to take the	Ministry of Health are empowered to implement		
given action. Self-efficacy is interdependent with	NDSC in Greek hospitals. Reinforce networking		
self-belief and self-empowerment. Encouragement,	among these parties with NDSC experts and		
training, and other support foster self-efficacy	politicians of other countries and the WHO to		
- · · · · · · · · · · · · · · · · · · ·	enhance self-empowerment and leadership		

#### **APPENDIX E - Logic Model**



Program title: Neurodevelopmental Supportive Care in the Intensive Neonatal Care Unit and the Role of Occupational Therapy –

1) COVID-19 implications: live in-person communication, and public relations; people's motivation for new ideas due to restrictions in transportation, accessibility, and human resources; limited public and private funds in NDSC practices due to increased pandemic health needs; reluctance of overworked surveys or to engage in NDSC training; suspension of on-campus educational institutions operations may suspend OT curricula revisions; suspension of NDSC training with instructors from hospital personnel to complete overseas due to travel and personal contact restrictions, 2) Religious and cultural reasons; focus on saving lives than ensuring quality of life, 3) Shift of paradigm of

neonatal care, 4) Language barriers for NDSC educational and training, 5) Significant changes in the conception, acceptance, and implementation of new OT practice standards by the Hellenic Occupational Therapy OT Association

APPENDIX F - Program Announcement Time Frame and Thank you Note

	Announcements	Start Date	Duration	End Date	Updates
<b>A.</b>	First Announcement		One month		None
В.	Second Announcement		One month		None
C.	Third Announcement		Two months		Yes
D.	After that, every four months for two years		Four months - Three times per year		Yes
Е.	After that, twice a year		Six months – twice per year		Yes



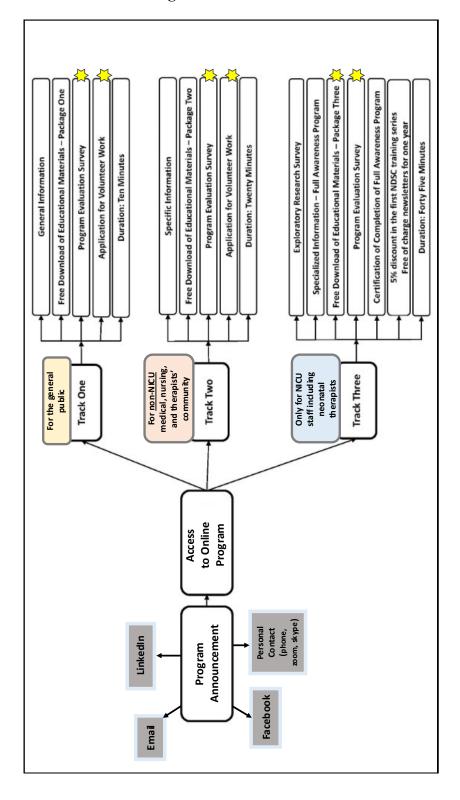
Dear

Thank you for participating in the
"Neurodevelopmental Supportive Care Awareness
Program" for premature infants.
As an expert in your field, your input in this first
Greek research project is highly valued.

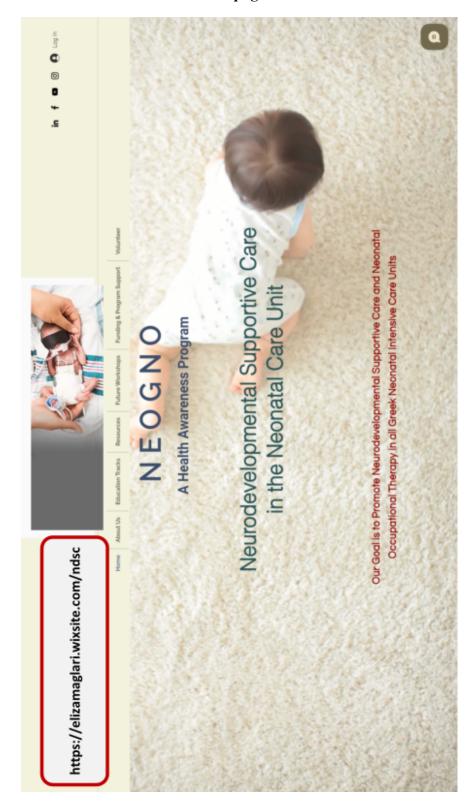
Sincerely, Eliza Maglari

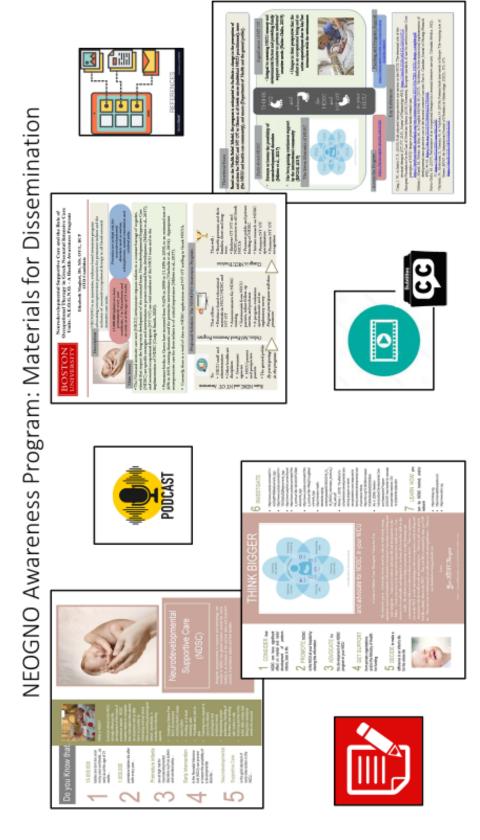
For more information please contact me at

**APPENDIX G - Program Awareness Intervention Activities** 



**APPENDIX H - NEOGNO Webpage and Dissemination Materials** 





# Do you Know that.

### 15,000,000

babies are born too soon every year worldwide...as early as at the age of 21 weeks...

### 1.000.000

premature babies die after birth every year...

# Premature infants

are at high risk for neurodevelopmental disorders such as autism and cerebral palsy...

### Early intervention

in the Neonatal Intensive Unit (NICU) can prevent or lessen the possibility of a developmental disorder...

### Neurodevelopmental

### Supportive Care

is the gold standard of early intervention in the NICU...



What is NDSC?

External stimuli in the NICU strongly influence the development of the brain of premature babies. NDSC enables babies to complete their interrupted intra-uterine development with as little harm as possible by minimizing external stress while promoting physiological stimuli. Specifically, it includes the following aspects:

- Creating a Stress-Free NICU Environment
- Assisting infant's sleepwake rhythm Avoiding, or at least
- skin
  Tailoring every aspect of
  care to the infant's
  physiological and
  emotional needs
  - Emphasizing proper positioning, handling of the infant, and feeding with mother's milk Involving parents in the entire daily routine and taking their emotional



### Neurodevelopmental Supportive Care (NDSC)

Alongside advancements in research and technology, the concept of NDSC has gained traction around the world, leading to an increase in the survival rates and long-term success of premature babies and their families

## CONSIDER that

NDSC can have significant effect on mental and motor preterm development of infants, later in life

## 2 PROMOTE NDSC

in the NICU at your hospital by sharing this information

### 3 ADVOCATE for

the development of an NDSC program in your NICU

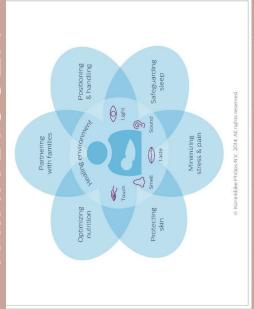
## 4 GET SUPPORT

from private organizations and/or the Ministry of Health for funding

### **5** DECIDE to make a difference in an infant's life for his whole life



# 



# and advocate for NDSC in your NICU



### 6 INVESTIGATE

- https://www.youtube.com/watch?v= sn2diojM74E&feature=emb\_logo
- https://www.youtube.com/watch?v=-Y5rDSeZq3Q&feature=emb\_logo
- https://www.babyfirst.com/en/home/ https://www.youtube.com/watch?tim e\_continue=3&v=2kCWvirMTCA&fe
- https://www.youtube.com/watch?tim e\_continue=3&v=P9elgThrxog&feat ature=emb\_logo ure=emb\_logo
  - content/uploads/2019/02/2019\_01\_ 16\_ESCNH\_Information\_brochure\_ https://newborn-healthstandards.org/wp-
- comprehensive developmental care family-centered developmental care neuroprotective core measures for https://doi.org/10.26226/morressier Altimier, L. (2016). The effect of a training program on seven of premature infants. inal\_web.pdf
- (NIDCAP): New frontier for neonatal Individualized Developmental Care 57d034d3d462b80292383b4c and perinatal medicine. DOI: 10.3233/NPM-2009-0061 and Assessment Program Als, A. (2009). Newborn

## LEARN HOW you

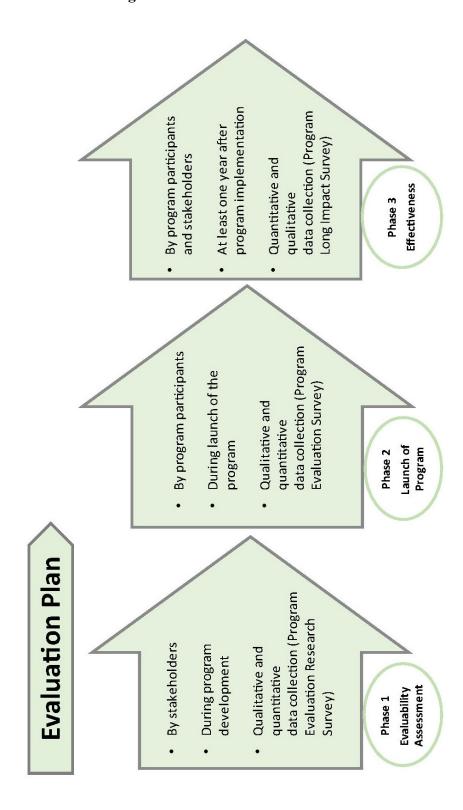
can be NDSC trained, and/or network

- https://nidcap.org
- https://neonataltherapists.com
  - https://www.efcni.org

### **APPENDIX I - Simplified Logic Model for Use with Stakeholders**

Clients Resources	<ul> <li>Neonatal Intensive Care Unit (NICU) personnel (nurses, physicians, occupational therapists, parents, NICU administrators), non-NICU healthcare providers, government agencies, and the general public</li> <li>Program Resources: Non-funded, researcher's home office, hardware and software, IT professional (volunteer), phone accessibility for program clients, author, three volunteer assessors</li> </ul>
Interventions Activities	•Use of a custom-made webpage with: program's scope and goals, information about the author, description of the philosophy, benefits, structure, education, and application of NDSC according to universal standards, description of the role of NT OT, and the educational requirements for becoming a neonatal expert, short videos on NDSC, and NT OT in NDSC practices, educational resources, links to other NDSC and NT OT websites, testimonials from professionals and NICU parents, follow-up stories from NICU graduates, and podcasts.
Program Outputs	<ul> <li>*# of visits to the program awareness website, # of program evaluation questionnaires completed</li> <li>*# of correspondence requesting promotion and educational materials, # of requests for evidence based practice in NDSC and neonatal OT, # of requests for information on neonatal OT training</li> <li>*# of requests for information on certification process of neonatal therapists, # of requests for NDSC training series</li> <li>*# of volunteers recruited</li> </ul>
Short-Term Outcomes	•↑ awareness of NDSC and neonatal OT •↑ knowledge of all NDSC aspects and their application in NICUs •↑ accessibility to NDSC training •↑ confidence to seek funding from public and private sources for NDSC equipment, and staff training
Intermediate	At 1 month post: Program coordination Recruit 2 volunteers for program expansion Host of a 2-hour introduction course to NDSC online
Long-Term Outcomes	•Establishment of NDSC association in Greece •Inclusion of neonatal OT courses in OT curriculum •Host NDSC training courses 2/ per year •Funding of NDSC by social health care system

APPENDIX J - Program Evaluation and Methods for Data Collection



### **APPENDIX K - Budget for Dissemination Plan**

	Primary Audience	Secondary Audience
<b>Funding Needs</b>	Comments	Comments
Available Local Resources		
Time that volunteers donate to the program		
Two hours per week per volunteer	Time donation to be determined if the number of volunteers and the needs of the program exceed the initial estimate	Time donation to be determined if the number of volunteers and the needs of the program exceed the initial estimate
Materials that local merchants may provide		
Pediatric Institute, Ltd	Donation of office supplies	Donation of office supplies
Local experts who can provide help/advice when needed		
IT expert and program evaluators	Will provide support on a volunteer basis	Will provide support on a volunteer basis
Colleague/friend who is willing to do some skilled work		
IT and MBA expert; spouse of the author	Web development, word processing, data mining, marketing, and technical support	Web development, word processing, data mining, marketing, and technical support
Personal acquaintances for program evaluation	One physician, one parent, one occupational therapist, and one linguistics professor	One physician, one parent, one occupational therapist, and one linguistics professor
Personnel (salary and benefits)		
Ten volunteers	Will provide support on a no- cost basis	Will provide support on a no- cost basis

Equipment	All is provided at the author's home and business offices	All is provided at the author's home and business offices	
Supplies	Funded by Pediatric Institute	Funded by Pediatric Institute	
Communication (telephone / postage)	Absorbed by Pediatric Institute's telephone business plan	Absorbed by Pediatric Institute's telephone business plan	
Website design	Free online provider (https://www.wix.com/)	Free online provider (https://www.wix.com/)	
Facebook templates	Free online provider (https://www.canva.com/face book-posts/templates/)	Free online provider (https://www.canva.com/faceb ook-posts/templates/)	
Brochure and newsletter templates	Free online provider (https://www.creativecenter.b rother/en- us/business/business- category/brochures)	Free online provider (https://www.creativecenter.br other/en-us/business/business- category/brochures)	
Videos	Free online provider (https://vimeo.com/)	Free online provider (https://vimeo.com/)	
Video/Greek subtitles	Free online provider (https://vimeo.com/)	Free online provider (https://vimeo.com/)	
Travel	Funded by Pediatric Institute, Ltd	Funded by Pediatric Institute, Ltd	
Rental of facilities	The author owns no-cost - business and home offices	The author owns no-cost - business and home offices	
Program evaluation			
Four volunteers- personal acquaintances	Will provide support on a no- cost basis	Will provide support on a no- cost basis	
<b>Budget Needs</b>			
Facebook advertisement	\$200.00		
Professional printing	\$1,000.00		
Total	\$1,200.00		

**APPENDIX L - Evaluation Criteria for Dissemination Plan Success** 

Evaluation Criteria for Dissemination Plan Success				
	Primary Audience	Secondary Audience	Both Audiences	
Criterion 1	The number of likes on Facebook followed by the number of requests for information			
Criterion 2			The number of participants in the first NDSC training series	
Criterion 3	The number of appointments among the author and NICU facilities or personnel			
Criterion 4			The number of visitors on the webpage	
Criterion 5		The inclusion of one neonatal OT course in the OT school curriculum		
Criterion 6			The number of invitations/requests (in person or otherwise) for presenting the results of the awareness program in the community	
Criterion 7			Number of acceptances for oral or poster presentations in conferences	
Criterion 8		The inclusion of NT OT in the Panhellenic Occupational Therapy Association OT Practice Guide		

### **APPENDIX M - Funding Plan: Year One**

	Phase (a)	Phase (b)	Phase (c)
Funding Needs	Comments	Comments	Comments
Available Local Resources			
Time that volunteers donate to the program			
Two hours per week per volunteer	Time donation to be determined if the number of volunteers and the needs of the program exceed the initial estimate	Time donation to be determined if the number of volunteers and the needs of the program exceed the initial estimate	Time donation to be determined if the number of volunteers and the needs of the program exceed the initial estimate
Materials that local merchants may provide			
Pediatric Institute, Ltd	Donation of office supplies	Donation of office supplies	Donation of office supplies
Local experts who can provide help/advice when needed			
IT expert and Program evaluators	Will provide support on a volunteer basis	Will provide support on a volunteer basis	Will provide support on a volunteer basis

Colleague/frie nd who is willing to do some skilled work			
IT and MBA expert; spouse of the author	Web development, word processing, data mining, marketing, and technical support	Web development, word processing, data mining, marketing, and technical support	Web development, word processing, data mining, marketing, and technical support
Personal acquaintances for program evaluation	One physician, one parent, one occupational therapist, and one linguistics professor	One physician, one parent, one occupational therapist, and one linguistics professor	One physician, one parent, one occupational therapist, and one linguistics professor
Personnel (salary and benefits)			
Three office secretaries	Until volunteers are located, the three office secretaries will accommodate their daily schedule to assist the program. There will be no increase in work hours, and therefore, no additional benefits nor pay increase.	Until volunteers are located, the three office secretaries will accommodate their daily schedule to assist the program. There will be no increase in work hours, and therefore, no additional benefits nor pay increase.	Until volunteers are located, the three office secretaries will accommodate their daily schedule to assist the program. There will be no increase in work hours, and therefore, no additional benefits nor pay increase.
One IT manager	Will provide support on a volunteer basis	Will provide support on a volunteer basis	Will provide support on a volunteer basis
Equipment	All is provided in the author's home and business offices	All is provided in the author's home and business offices	All is provided in the author's home and business offices
Supplies	Donated by Pediatric Institute	Donated by Pediatric Institute	Donated by Pediatric Institute
Communicatio n (telephone / postage)	Covered by Pediatric Institute's telephone business plan	Covered by Pediatric Institute's telephone business plan	Covered by Pediatric Institute's telephone business plan
Website design	Free online provider (https://www.wix.com/)	Free online provider (https://www.wix.com/)	Free online provider (https://www.wix.com/)

Facebook templates	Free online provider (https://www.canva.c om/facebook- posts/templates/)	Free online provider (https://www.canva.c om/facebook- posts/templates/)	Free online provider (https://www.canva.c om/facebook- posts/templates/)
Brochure and newsletter templates	Free online provider (https://www.creativ ecenter.brother/en- us/business/business -category/brochures)	Free online provider (https://www.creativ ecenter.brother/en- us/business/business -category/brochures)	Free online provider (https://www.creativ ecenter.brother/en- us/business/business -category/brochures)
Videos	Free online provider (https://vimeo.com/)	Free online provider (https://vimeo.com/)	Free online provider (https://vimeo.com/)
Video/Greek subtitles	Free online provider (https://vimeo.com/)	Free online provider (https://vimeo.com/)	Free online provider (https://vimeo.com/)
Travel	Non-available due to COVID-19 restrictions	Non-available due to COVID-19 restrictions	Non-available due to COVID-19 restrictions
Rental of facilities	The author owns no- cost business and home offices	The author owns no- cost business and home offices	The author owns no- cost business and home offices
Program Evaluation  Four volunteers- personal acquaintances	Will provide support on a volunteer basis	Will provide support on a volunteer basis	Will provide support on a volunteer basis
Needed resources – Budget			
Facebook advertisement	\$200.00		
Total:	\$200.00		

### **APPENDIX N - Funding Plan: Year Two**

	Phase (a)	Phase (b)	Phase (c)
<b>Funding Needs</b>	Comments	Comments	Comments
Available Local Resources			
Time that volunteers donate to the program			
Two hours per week per volunteer	Time donation to be determined if the number of volunteers and the needs of the program exceed the initial estimate	Time donation to be determined if the number of volunteers and the needs of the program exceed the initial estimate	Time donation to be determined if the number of volunteers and the needs of the program exceed the initial estimate
Materials that local merchants may provide			
Pediatric Institute, Ltd	Donation of office supplies	Donation of office supplies	Donation of office supplies
Local experts who can provide help/advice when needed			
IT expert and program evaluators	Will provide support on a volunteer basis	Will provide support on a volunteer basis	Will provide support on a volunteer basis
Colleague/friend who is willing to do some skilled work			
IT and MBA expert; spouse of the author	Web development, word processing, data mining, marketing, and technical support	Web development, word processing, data mining, marketing, and technical support	Web development, word processing, data mining, marketing, and technical support
Personal acquaintances for program evaluation	One physician, one parent, one occupational therapist, and one linguistics professor	One physician, one parent, one occupational therapist, and one linguistics professor	One physician, one parent, one occupational therapist, and one linguistics professor

Personnel	I	I	
(salary and benefits)			
Ten volunteers	Will provide support on a no-cost basis	Will provide support on a no-cost basis	Will provide support on a no-cost basis
Equipment	All is provided at the author's home and business offices	All is provided at the author's home and business offices	All is provided at the author's home and business offices
Supplies	Funded by Pediatric Institute	Funded by Pediatric Institute	Funded by Pediatric Institute
Communication (telephone / postage)	Absorbed by Pediatric Institute's telephone business plan	Absorbed by Pediatric Institute's telephone business plan	Absorbed by Pediatric Institute's telephone business plan
Website design	Free online provider (https://www.wix.com/)	Free online provider (https://www.wix.com/)	Free online provider (https://www.wix.com/)
Facebook templates	Free online provider (https://www.canva.c om/facebook- posts/templates/)	Free online provider (https://www.canva.c om/facebook- posts/templates/)	Free online provider (https://www.canva.c om/facebook- posts/templates/)
Brochure and newsletter templates	Free online provider (https://www.creativ ecenter.brother/en- us/business/business -category/brochures)	Free online provider (https://www.creativ ecenter.brother/en- us/business/business -category/brochures)	Free online provider (https://www.creativ ecenter.brother/en- us/business/business -category/brochures)
Videos	Free online provider (https://vimeo.com/)	Free online provider (https://vimeo.com/)	Free online provider (https://vimeo.com/)
Video/Greek subtitles	Free online provider (https://vimeo.com/)	Free online provider (https://vimeo.com/)	Free online provider (https://vimeo.com/)
Travel	Funded by Pediatric Institute, Ltd	Funded by Pediatric Institute, Ltd	Funded by Pediatric Institute, Ltd
Rental of facilities	The author owns no- cost - business and home offices	The author owns no- cost - business and home offices	The author owns no- cost - business and home offices
Program evaluation			
Four volunteers from personal acquaintances	Will provide support on a no-cost basis	Will provide support on a no-cost basis	Will provide support on a no-cost basis

Needed resourc	es – Budget
Legal and accounting assistance	
Required for the establishment and operation of the Greek NDSC association	\$2,000.00
Facebook advertisement	\$200.00
Organization of the first NDSC training series	\$20,000.00
Total	\$22,200.00
Additional Budget for Dissemination (Figure 6.1 in chapter 6)	\$1,200.00
Grant Total	\$23,400.00

### **APPENDIX O - Potential Funding Sources**

Sources	Comments
Occupational Therapy Community	r Grants
The ROTOS Foundation  https://www.rotosfoundation.eu/a bout-rotos/	One of the three <u>OT-Europe</u> branches aim to improve European citizens' lives through occupation centered research and science. Funding amount is determined upon application.
The ROTOS Foundation  https://www.rotosfoundation.eu/a bout-rotos/	One of the three <u>OT-Europe</u> branches aim to improve European citizens' lives through occupation centered research and science. Funding amount is determined upon application.
The European University Association (EUA)  https://eua.eu/search.html?search word=funding&ordering=newest&s earchphrase=all	Provides unrivaled opportunities for members to shape European policies and initiatives affecting higher education and research. Funding amount is determined upon application.
WFOT Thelma Cardwell Foundation Award for Research https://www.wfot.org/resources/ wfot-thelma-cardwell-foundation- award-for-research	Provides funding to support pilot projects or small-scale feasibility projects to build and/or strengthen research capacity in occupational therapy. Funding amount is determined upon application.
Dr. Gary Kielhofner Doctoral Research Scholarship https://www.aotf.org/Grants/Kielh ofner-Doctoral-Research- Scholarship	This award is open to OT students enrolled in a doctoral research program. The purpose of the scholarship is to aid a doctoral student in his or her research. One recipient is selected each year to receive the \$5,000 award.
Scholarship Program for Therapists — AMBUCS  https://ambucs.org/therapists/sch olarship-program/	The foundation offers multiple scholarships for students in doctorate programs related to therapy ranging from \$500 to \$3,000.
The Pilot International Founders Fund	Various funds that encourage Brain Safety & Health, and/or Supporting Those who Care for Others. Amount Awarded: \$500 to \$6,000.

https://www.pilotinternational.org /grants-and-scholarships/	
The Elizabeth Casson Trust  https://elizabethcasson.org.uk/sup port-development/funding/	Offers funding support and development opportunities to qualified occupational therapists to further the profession of occupational therapy in the United Kingdom and international requests for some awards. The funding amount is determined upon application.
ScholarshipAds  https://www.scholarshipsads.com/ category/subject/occupational- therapy/	Website that locates funding for research projects internationally. The funding amount is determined upon application.
Greek Foundations	
The Alexander S. Onassis Foundation https://www.onassis.org/initiative s/scholarships	Promotes culture, education, the environment, health, and social solidarity in Greece and worldwide. The author is a former recipient of a scholarship. The funding amount is determined upon application.
The Stavros Niarchos Foundation (SNF)  https://www.snf.org/en/grants/inf ormation-for-applicants-how-to-apply/	A private, international philanthropic organization grants to nonprofit organizations in arts and culture, education, health and sports, and social welfare. The funding amount is determined upon application.
Marianna V. Vardinoyannis Foundation https://www.mvvfoundation.gr/en /ourwork/	Focuses on education, peace, health, social security, and culture aims to illuminate every aspect of children's life, sensitizing and informing the Greek and the international public opinion, pointing out weaknesses and deficiencies to contribute to the solution of problems and the coverage of needs. The funding amount is determined upon application.
John S. Latsis Public Benefit Foundation https://www.latsis- foundation.org/ell/	The Foundation is active in numerous social welfare and community development fields, seeking to respond to current social challenges by supporting initiatives that enhance social inclusion of vulnerable social groups and by

Bodossaki Foundation  https://www.bodossaki.gr/en/do nations/healthcare/	implementing projects aimed to meet the urgent needs of the Public Health sector in Greece. The funding amount is determined upon application.  Promote its vision for a society of equal opportunities for all, enabling people to realize their potential fully. The Foundation's activities are organized in four strategic priority themes:
https://www.fulbright.gr/en/grantees	<ul> <li>Promoting education</li> <li>Improving healthcare</li> <li>Protecting the environment</li> <li>Empowering civil society</li> <li>The funding amount is determined upon application.</li> </ul>
University Funding	
University Funding  FindAPhD  https://www.findaphd.com/funding/	Online platform that offers information on doctorate funding from educational institutions.
FindAPhD https://www.findaphd.com/fundin	

#### **APPENDIX P – Program Evaluation Survey by Program Participants**

### **Program Evaluation Survey for Participants**

In order to measure if the best practices are being used in this website, please complete the survey below. Please use the following code to answer questions.

Rate each item based Use the following rating system when assessing the **program** upon how important that 1- Strongly Disagree with the statement item is to you 2- Disagree with the statement 3- Undecided – you neither agree or disagree 1- Not Important 2- Somewhat Important 4- Agree with the statement 5- Strongly Agree with the statement 3- Neutral NA – Not Applicable; the statement does not pertain to 4- Important the simulation activity performed 5- Very Important N/A Items A. Ease of Use 1. This website is easy to N/A use 2. This website needs N/A upgrading Comments: What is your opinion about Ease of Use? B. Hyperlinks 3. The home page clearly directs to needed N/A information 4. I find the hyperlinks N/A Comments: What is your opinion about Hyperlinks?

website is convenient126. The structure if the website clear00	3 O	4	5	N/A	1	_	_		
	0			,	т _	2	3	4	5
website clear 1 2		О	0	0	0	0	0	0	0
	3	4	5	N/A	1	2	3	4	5
7. Navigating the website OOO	0	0	0	0	0	0	0	0	0
is easy 1 2	3	4	5	N/A	1	2	3	4	5

#### D. Relevance

8. The information is	0	0	0	0	0	0	0	0	0	0	0
relevant	1	2	3	4	5	N/A	1	2	3	4	5
9. The information is useful	0	0	0	0	0	0	0	0	0	0	0
	1	2	3	4	5	N/A	1	2	3	4	5
10. The information is	0	0	0	0	0	0	0	0	0	0	0
important	1	2	3	4	5	N/A	1	2	3	4	5

Comments: What is your opinion about Relevance?

### E. Comprehension

11. The language used is	0	0	0	0	0	0	0	0	0	0	0
clear	1	2	3	4	5	N/A	1	2	3	4	5
12. The information is easy	0	0	0	0	0	0	0	0	0	0	0
to understand	1	2	3	4	5	N/A	1	2	3	4	5

Comments: What is your opinion about Comprehension?

#### F. Completeness

13. The website provides	0	0	0	0	0	0	0	0	0	0	0
sufficient information	1	2	3	4	5	N/A	1	2	3	4	5
14. The information is	0	0	0	0	0	0	0	0	0	0	0
precise	1	2	3	4	5	N/A	1	2	3	4	5

15. The information is											
	0	0	0	0	0	0	0	0	0	0	0
clear	1	2	3	4	5	N/A	1	2	3	4	5
Comments: What is your op	inion	about	: Com	pietei	iess?						
G. Layout											
16. The website is	0	0	0	0	0	0	0	0	0	0	0
attractive	1	2	3	4	5	N/A	1	2	3	4	5
17. The website is	0	0	0	0	0	0	0	0	0	0	0
organized	1	2	3	4	5	N/A	1	2	3	4	5
H. Search Option											
18. The search option on	0	0	0	0	0	0	0	0	0	0	0
this website helps me find the right information quickly	1	2	3	4	5	N/A	1	2	3	4	5
19. The search option on	0	0	0	0	0	0	0	0	0	0	0
this website gives me useful results	1	2	3	4	5	N/A	1	2	3	4	5
Comments: What is your op	inion	about	Sear	ch?	•	•					

Thank you!

#### **APPENDIX Q – Program Evaluation Research Checklist**

### **Program Evaluation Research Checklist for Stakeholders**

Dear stakeholder,

Use the following rating system when assessing the **program.** 

- 1- Strongly Disagree with the statement
- 2- Disagree with the statement
- 3- Undecided you neither agree or disagree
- 4- Agree with the statement
- 5- Strongly Agree with the statement

NA – Not Applicable; the statement does not pertain to the simulation activity performed

Rate each item based upon how important that item is to **you**.

- 1- Not Important
- 2- Somewhat Important
- 3- Neutral
- 4- Important
- 5- Very Important

#### **Stakeholder or Stakeholder Group**

A. The Author											
Quantitative Questions	1	2	3	4	5	N/A	1	2	3	4	5
1. Will the program participants report increased perceived confidence in using the skills they have gained?	O 1	O 2	O 3	O 4	O 5	O N/A	O 1	O 2	O 3	O 4	O 5
2. Will the program participants report increased awareness in NDSC?	0 1	0 2	O 3	O 4	O 5	O N/A	0	O 2	O 3	O 4	O 5
3. Will the program participants report increased motivation in learning more about NDSC?	O 1	O 2	O 3	O 4	O 5	O N/A	O 1	O 2	O 3	O 4	O 5

4. Will the program participants report increased awareness in neonatal O.T.?	O 1	0 2	0	O 4	O 5	O N/A	0	O 2	O 3	O 4	O 5
5. Will the program participants report increased motivation in learning more about neonatal O.T.?	O 1	O 2	O 3	O 4	O 5	O N/A	O 1	0 2	O 3	O 4	O 5
Comments:					,						
Qualitative Questions	1	2	3	4	5	N/A	1	2	3	4	5
1. Was the program content and delivery sufficient for the participants to begin inquiring more about NDSC and neonatal O.T.?	0 1	O 2	0 3	O 4	O 5	O N/A	0 1	0 2	O 3	O 4	O 5
content and delivery sufficient for the participants to begin inquiring more about				_		-	_			_	

Comments:

						er Gro	oup				
B. Persons Actively I Quantitative Questions	nvoiv	ea in	Prog	ram ı	Jelive	ery					
<b></b>											
1. Was the instruction sufficient for the participants to understand?	0 1	0 2	3	O 4	O 5	O N/A	0	0 2	3	O 4	O 5
2. Was the information presented too easy or too complicated?	O 1	O 2	O 3	O 4	O 5	O N/A	O 1	O 2	O 3	O 4	O 5
3. Was education delivered at an optimal pace and intensity for learning?	0 1	0 2	O 3	O 4	O 5	O N/A	0	0 2	O 3	O 4	O 5
4. Was the information presented relevant?	O 1	O 2	O 3	O 4	O 5	O N/A	O 1	O 2	O 3	O 4	O 5
5. Was the program duration adequate, or should it be shorter or longer?	O 1	O 2	O 3	O 4	O 5	O N/A	O 1	O 2	O 3	O 4	O 5
6. Were some aspects of the program more or less useful or practical?	O 1	O 2	O 3	O 4	O 5	O N/A	O 1	0 2	O 3	O 4	O 5
7. Is there anything that should be changed to improve program content or delivery?	O 1	O 2	0 3	O 4	O 5	O N/A	0 1	0 2	O 3	O 4	O 5
8. What other key issues or problems faced by participants were not addressed in the program?	O 1	0 2	O 3	O 4	O 5	O N/A	0	O 2	O 3	O 4	O 5

9. Did participants find the educational resources useful?	O 1	O 2	O 3	O 4	O 5	O N/A	O 1	O 2	O 3	O 4	O 5
10. Did participants value the need for NDSC application in Greek NICUs?	0 1	0 2	O 3	O 4	O 5	O N/A	0	O 2	O 3	O 4	O 5
11. Did participants value the need for neonatal O.T.s in Greek NICUs?	O 1	O 2	O 3	O 4	O 5	O N/A	O 1	O 2	O 3	O 4	O 5
Comments:	•		1	1	1						
Qualitative Questions											
1. Did participants gain more awareness of neonatal O.T. consistent with program goals?	O 1	O 2	O 3	O 4	O 5	O N/A	O 1	0 2	O 3	O 4	O 5
2. Did participants gain confidence to require more information about NDSC consistent with program goals?	O 1	O 2	O 3	O 4	O 5	O N/A	0	O 2	O 3	O 4	O 5
3. Did participants gain confidence to require more information about neonatal consistent with program goals?	O 1	O 2	O 3	O 4	O 5	O N/A	0 1	O 2	O 3	O 4	O 5
4. Did participants gain perceived confidence in their ability to seek training in NDSC?	O 1	O 2	O 3	O 4	O 5	O N/A	O 1	O 2	O 3	O 4	O 5

5. Did participants gain perceived confidence to become volunteers in the application of the research program?	0 1	0 2	O 3	O 4	O 5	O N/A	0	0 2	O 3	O 4	O 5
6. Did recipients of the intervention improve in terms of desired performance consistent with program goals?	0 1	0 2	O 3	O 4	O 5	O N/A	0 1	O 2	0 3	O 4	O 5
7. Did undesirable behaviors or other characteristics (hesitation, resistance, indifference) in recipients of the intervention decrease consistent with program goals?	0 1	O 2	O 3	O 4	O 5	O N/A	0 1	O 2	O 3	O 4	O 5
8. Did participants gain more awareness of NDSC consistent with program goals?	0 1	O 2	O 3	O 4	O 5	O N/A	O 1	0 2	O 3	O 4	O 5

Comments:

#### **APPENDIX R – Exploratory Research Survey**

### Neurodevelopmental Supportive Care and The Role of Occupational Therapy in Greek Neonatal Intensive Care Units NEOGNO: A Health Awareness Program

#### **EXPLORATORY RESEARCH SURVEY**

	Date: / /
Dear NICU staff member,	
Thank you for participating in this research project to Boston University and is the first to be investigated in Greed questionnaire requires approximately 10 minutes to complerefer to the application of Neurodevelopmental Supportive Neonatal Care Unit (NICU) of any level (I, II, III and IV), and Occupational Therapy (NT) in the NICU.	ce. The following ete. The questions Care (NDSC) in your
Your assistance is highly valued. Your name and the you work at will Not be disclosed in the research process; ir number will be provided.	<u>-</u>
The results of this study will be forwarded to you as complete. Again, thank you for your significant contribution	
Sincerely,	
Eliza Maglari, MS, OTR, BCP OTD Student – Sargent College - Boston University	
ilovekid@edu.bu elizamaglari@yahoo.com +30 697 898 4354	

Participant's Code:	Date:							
NICU Specialty: ☐ Nurse ☐ Therapist (PT, OT, SLP) ☐ Physician ☐ Administrator ☐ Other (specify)								
1. HOSPITAL INFORMATION								
1.1 Level of NICU:								
1.2 Public or Private Hospital	☐ Public ☐ Private ☐ Urban ☐ Rural ☐ Suburban							
1.3 Number of NICUs in the hospital:	□1 □2 □3 □4 □6 □6							
1.4 Year NICU was established:								
1.5 Please check the age range of infants the NICU attends to	☐ less than 28 weeks ☐ 28 to 32 weeks ☐ 32 to 37 weeks ☐ 38 to 40 weeks							
2. NICU NEURODEVELOPMENTAL SUPPORTIVE CARE (NDSC)								
2.1 Does your hospital implement Neurodevelopmental Supportive Care (NDSC)?	☐ Yes ☐ No ☐ Not Sure							
2.2 To what age ranges does the hospital apply NDSC?								
Extremely preterm (less than 28 weeks)	☐ Yes ☐ No ☐ Not Sure							
Very preterm (28 to 32 weeks)	☐ Yes ☐ No ☐ Not Sure							
Moderate to late preterm (32 to 37 weeks)	☐ Yes ☐ No ☐ Not Sure							
Full term (38 to 40 weeks)	☐ Yes ☐ No ☐ Not Sure							

2.3 The reasons for Not having a NDSC environment and education are:						
Financial	☐ Yes ☐ No ☐ Not Sure					
Administrative	☐ Yes ☐ No ☐ Not Sure					
Governmental	☐ Yes ☐ No ☐ Not Sure					
Do Not know what is NDSC	☐ Yes ☐ No ☐ Not Sure					
Aware of NDSC but no one is trained	☐ Yes ☐ No ☐ Not Sure					
Aware but Not convinced it works	☐ Yes ☐ No ☐ Not Sure					
Other: (explain)						
2.4 Future Implementation						
Is your hospital thinking of creating a NDSC?	☐ Yes ☐ No ☐ Not Sure					
When?						
What type (i.e., NIDCAP, etc.)						
IF YOU CHECKED "NO" OR "NOT SURE" IN SECTION 2.1, STOP HERE.						
3. NICU (ALL LEVELS) DESIGN						
Is the NICU environment designed to promote growth and developmental care according to developmental maturity?	☐ Yes ☐ No ☐ Not Sure					
Is a uterine-like environment created for each preterm infant to support an environment of growth and development?	☐ Yes ☐ No ☐ Not Sure					

4. INDIVIDUALIZED CARE	
4.1 OBSERVATION	
Are the preterm infant's cues and behaviors read by the caregiver?	☐ Yes ☐ No ☐ Not Sure
Do staff respond to cues and behaviors?	☐ Yes ☐ No ☐ Not Sure
Does the caregiver continuously and systematically assess and evaluate the preterm infant's developmental needs?	☐ Yes ☐ No ☐ Not Sure
Is care adapted accordingly?	☐ Yes ☐ No ☐ Not Sure
4.2 CARE	
Is care provided according to individual developmental maturity?	☐ Yes ☐ No ☐ Not Sure
Are autonomic, motoric, and behavioral cues identified and used to support individualized caregiving?	☐ Yes ☐ No ☐ Not Sure
5. FAMILY-CENTERED CARE PHILOSOPHY	
5.1 PARENTS AS ACTIVE PARTICIPANTS	
Do parents see their preterm infant immediately after birth (before transfer to the NICU)?	☐ Yes ☐ No ☐ Not Sure
Are parents allowed to touch their preterm infant immediately after birth (before transfer to the NICU)?	☐ Yes ☐ No ☐ Not Sure
Do parents hold their preterm infant in the NICU?	☐ Yes ☐ No ☐ Not Sure
How many times per day do parents hold their preterm infant in the NICU?	☐ Yes ☐ No ☐ Not Sure
Are parents involved with childcare activities, e.g., feeding, bath, Kangaroo care?	☐ Yes ☐ No ☐ Not Sure

Are parents allowed to personalize their preterm infant's bed space?	☐ Yes ☐ No ☐ Not Sure
Are mothers encouraged to breastfeed / pump milk for their preterm infants?	☐ Yes ☐ No ☐ Not Sure
Do you have discharge training to parents?	☐ Yes ☐ No ☐ Not Sure
5.2 PRIVACY AND COMFORT	
Is the nursery atmosphere warm, comfortable and soothing, with a homelike appearance?	☐ Yes ☐ No ☐ Not Sure
Is privacy provided for parents?	☐ Yes ☐ No ☐ Not Sure
Is information shared between parents and professionals regarding preterm infant developmental needs?	☐ Yes ☐ No ☐ Not Sure
5.3 VISITATION	
Are parents allowed to visit 24-hours?	☐ Yes ☐ No ☐ Not Sure
May siblings visit?	☐ Yes ☐ No ☐ Not Sure
5.4 PARENT SUPPORT GROUPS	
Does the hospital have parent support groups?	☐ Yes ☐ No ☐ Not Sure
6. POSITIONING	
6.1 ANATOMICAL PRETERM INFANT POSITIONING (containment, flexion)	symmetry/midline,
Is the preterm infant positioned anatomically?	☐ Yes ☐ No ☐ Not Sure
Containment -	
Is the preterm infant contained?	☐ Yes ☐ No ☐ Not Sure
Does the preterm infant have firm boundaries that fit snugly?	☐ Yes ☐ No ☐ Not Sure
Midline	
Is the body position symmetrically?	☐ Yes ☐ No ☐ Not Sure

Is the neck in a neutral position? Head in midline and in line with the body?	☐ Yes ☐ No ☐ Not Sure
Are the shoulders protracted?	☐ Yes ☐ No ☐ Not Sure
Are the arms in midline?	☐ Yes ☐ No ☐ Not Sure
Flexion	
Are the knees flexed?	☐ Yes ☐ No ☐ Not Sure
Are the hips flexed in a neutral position with some adduction?	☐ Yes ☐ No ☐ Not Sure
Is preterm infant kept in flexion (limbs and shoulders) during positioning with postural support?	☐ Yes ☐ No ☐ Not Sure
Transitions	
Do you maintain a total flexed position when you move or transfer the preterm infant?	☐ Yes ☐ No ☐ Not Sure
6.2 ORIENTATION	
In what position is the preterm infant positioned mostly	у
Prone?	/ % of the time
Side-lying?	/ % of the time
Supine?	/ % of the time
6.3 INDIVIDUALIZED BEDDING	
Is individualized bedding used?	☐ Yes ☐ No ☐ Not Sure
6.4 POSITIONING AIDS	
Which of the following are used for positioning?	
Gel pads	☐ Yes ☐ No ☐ Not Sure
Bendy bumpers	☐ Yes ☐ No ☐ Not Sure
Rolls	
Nons	☐ Yes ☐ No ☐ Not Sure

Gel wedges	☐ Yes ☐ No ☐ Not Sure
Squishon	☐ Yes ☐ No ☐ Not Sure
Air mattresses	☐ Yes ☐ No ☐ Not Sure
7. FEEDING	
Are preterm infants prepared for feeding?	☐ Yes ☐ No ☐ Not Sure
Are preterm infants positioned in a way that prevents repositioning after feeding?	☐ Yes ☐ No ☐ Not Sure
<b>Are non-nutritive</b> sucking periods offered during gavage feeding?	☐ Yes ☐ No ☐ Not Sure
<b>Are non-nutritive</b> sucking periods offered?	☐ Yes ☐ No ☐ Not Sure
Do you offer <b>feeding</b> to:	
extremely preterm (less than 28 weeks)	☐ Yes ☐ No ☐ Not Sure
very preterm (28 to 32 weeks)	☐ Yes ☐ No ☐ Not Sure
moderate to late preterm (32 to 37 weeks)	☐ Yes ☐ No ☐ Not Sure
Do you offer <b>non-nutritive sucking</b> to:	
extremely preterm (less than 28 weeks)	☐ Yes ☐ No ☐ Not Sure
very preterm (28 to 32 weeks)	☐ Yes ☐ No ☐ Not Sure
moderate to late preterm (32 to 37 weeks)	☐ Yes ☐ No ☐ Not Sure
full-term (38 to 40 weeks)	☐ Yes ☐ No ☐ Not Sure
8. HANDLING TECHNIQUES (TRANSITION SUPPORT)	
8.1 CARE ACCORDING TO MATURATION	
Does care changes as the infant matures?	☐ Yes ☐ No ☐ Not Sure

8.2 STATE CHANGES		
Does the caregiver support gradual state changes	☐ Yes ☐ No	□ Not Sure
(using transitional touch)?		
8.3 PROMOTION OF REST PERIODS		
Does the infant receive at least 2-3 hours	☐ Yes ☐ No	□ Not Sure
uninterrupted sleep?		
Does the unit have quiet times when all routine care	☐ Yes ☐ No	□ Not Sure
is delayed?		
8.4 MODIFIED HANDS-ON CARE-GIVING		
Are care interventions clustered around sleep?	☐ Yes ☐ No	□ Not Sure
Are calm, gentle, containment and facilitation	☐ Yes ☐ No	□ Not Sure
provided during handling procedures to support		
flexion?		
Is the infant provided with 'time-out' or rest periods	☐ Yes ☐ No	□ Not Sure
according to his/her cues?		
Is direct hands-on-caregiving modified by providing	☐ Yes ☐ No	☐ Not Sure
positive tactile stimulation?		
8.5 POSITIVE TACTILE STIMULATION		
Is positive tactile stimulation provided, e.g., stroking	☐ Yes ☐ No	□ Not Sure
of massage if applicable?		
Is containment or still hold provided?	☐ Yes ☐ No	□ Not Sure
Are parents allowed to do skin-to-skin care	☐ Yes ☐ No	□ Not Sure
(Kangaroo Care) with their preterm infants?		
8.6 MOVEMENT (KINESTETIC STIMULATION)	•	
Are infants swaddled? Tightly wrapped in blanket,	☐ Yes ☐ No	□ Not Sure
limbs flexed, hips neutral without rotation, shoulders		
forward, head neutral and hands accessible for		
exploration		
Are infants moved slowly, as a whole, keeping the	☐ Yes ☐ No	□ Not Sure
body and head aligned and the limbs tucked in?		

Are waterbeds and sheepskin used?	☐ Yes ☐ No ☐ Not Sure
Are multiples co-bedded?	☐ Yes ☐ No ☐ Not Sure
8.7 SELF-REGULATION	
Is self-regulation promoted?	☐ Yes ☐ No ☐ Not Sure
Is the infant provided with opportunities for grasping?	☐ Yes ☐ No ☐ Not Sure
Is state regulation promoted?	☐ Yes ☐ No ☐ Not Sure
Is non-nutritive sucking provided to support self-regulation?	☐ Yes ☐ No ☐ Not Sure
Do you provide day and night cycle by modifying the environment and the routines in the NICU?	☐ Yes ☐ No ☐ Not Sure
9. ENVIRONMENTAL MANIPULATION	
<b>9.1 REDUCTION OF NOISE</b> (Which of the following are reduction in noise?)	e employed to ensure
	e employed to ensure
reduction in noise?)	e employed to ensure
reduction in noise?)  Ambient environment	
reduction in noise?)  Ambient environment  Avoid radio and stereo equipment, telephones  Sound-rated frames and doors - Doors & drawers	☐ Yes ☐ No ☐ Not Sure
reduction in noise?)  Ambient environment  Avoid radio and stereo equipment, telephones  Sound-rated frames and doors - Doors & drawers padded with felt strips or whether stripping	☐ Yes ☐ No ☐ Not Sure ☐ Yes ☐ No ☐ Not Sure
reduction in noise?)  Ambient environment  Avoid radio and stereo equipment, telephones  Sound-rated frames and doors - Doors & drawers padded with felt strips or whether stripping  Bottoms of trashcans padded	☐ Yes ☐ No ☐ Not Sure ☐ Yes ☐ No ☐ Not Sure ☐ Yes ☐ No ☐ Not Sure
reduction in noise?)  Ambient environment  Avoid radio and stereo equipment, telephones  Sound-rated frames and doors - Doors & drawers padded with felt strips or whether stripping  Bottoms of trashcans padded  Measure sound levels in NICU	☐ Yes ☐ No ☐ Not Sure

Monitor alarms kept at a safe minimum volume (or vibrating/flashing)	☐ Yes ☐ No ☐ Not Sure	
Respond of staff to sound alarms quickly	☐ Yes ☐ No ☐ Not Sure	
Immediate preterm infant environment		
Use of incubator covers	☐ Yes ☐ No ☐ Not Sure	
Soft ear plugs / covers	☐ Yes ☐ No ☐ Not Sure	
Close portholes quietly using the button latch	☐ Yes ☐ No ☐ Not Sure	
Measure sound levels inside the incubator	☐ Yes ☐ No ☐ Not Sure	
No water in ventilator tubes	☐ Yes ☐ No ☐ Not Sure	
Minimal background noise	☐ Yes ☐ No ☐ Not Sure	
Staff generated		
No tapping or charts on top of incubator	☐ Yes ☐ No ☐ Not Sure	
Keep voices down & away from bedside	☐ Yes ☐ No ☐ Not Sure	
<b>9.2 REDUCTION OF LIGHT</b> (Which of the following are employed to ensure reduction in light?)		
Ambient light		
Reduced ambient light (dimmer)?	☐ Yes ☐ No ☐ Not Sure	
Are blinds closed during daylight hours?	☐ Yes ☐ No ☐ Not Sure	
Are staff activity levels kept as low as possible?	☐ Yes ☐ No ☐ Not Sure	
Immediate preterm infant bed space		
Are incubator covers used?	☐ Yes ☐ No ☐ Not Sure	
Is direct bright light avoided?	☐ Yes ☐ No ☐ Not Sure	
Is individual bedside controlled / titrated light used?	☐ Yes ☐ No ☐ Not Sure	
Are light levels measured inside the incubator?	☐ Yes ☐ No ☐ Not Sure	

Are eyes protected with phototherapy?	☐ Yes ☐ No	□ Not Sure
Is one source of daylight used together with shading devices?	□ Yes □ No	□ Not Sure
Are overhead lights dimmed?	☐ Yes ☐ No	□ Not Sure
Are procedures kept to the minimum to ensure minimal handling?	□ Yes □ No	□ Not Sure
Are toys, picture and music in the incubator used carefully to reduce sensory monotony?	□ Yes □ No	□ Not Sure
Cycled light		
Is cycled light provided?	☐ Yes ☐ No	□ Not Sure
Does the unit support a day and night cycle with at least 12 hours of lower light and sound at night?	□ Yes □ No	□ Not Sure
Olfactory Stimulation		
Is olfactory stimulation provided, such as mom's smell inside the incubator?	□ Yes □ No	□ Not Sure
10.PAIN MANAGEMENT		
Is oral sucrose administered as pain management option?	□ Yes □ No	□ Not Sure
Is non-nutritive sucking provided during pain and minor procedures?	□ Yes □ No	□ Not Sure
Do you offer <b>pain management techniques</b> to:		
extremely preterm (less than 28 weeks)	□ Yes □ No	
very preterm (28 to 32 weeks)	☐ Yes ☐ No	□ Not Sure
moderate to late preterm (32 to 37 weeks)	☐ Yes ☐ No	□ Not Sure
full-term (38 to 40 weeks)	☐ Yes ☐ No	□ Not Sure

11. APPLYING DEVELOPMENTAL CARE ON TRAN	SPORT	
11.1 PARENT		
One parent is usually invited to travel in the ambulance with their infant.	☐ Yes ☐ No ☐ Not Sure	
Nurse on a 'Squishon' mattress to absorb some of the vibrations during the journey	☐ Yes ☐ No ☐ Not Sure	
Ear protectors can reduce the sound levels to at least 7 decibels	☐ Yes ☐ No ☐ Not Sure	
Incubator covers can reduce noise and lighting levels inside the incubator and provide privacy whilst being transferred between hospital departments and the ambulance	☐ Yes ☐ No ☐ Not Sure	
Offer a pacifier (with parental permission) to reduce pain and stress if the baby needs/wants it	☐ Yes ☐ No ☐ Not Sure	
Use a Trans warmer mattress to reduce thermal stress if the incubator temperature is Not sufficient	☐ Yes ☐ No ☐ Not Sure	
Non-ventilated infants can remain clothed and be swaddled in the position most comfortable for their individual needs	☐ Yes ☐ No ☐ Not Sure	
On arrival at the receiving unit ensure that the staff are aware of the infants' developmental care needs	☐ Yes ☐ No ☐ Not Sure	
12.KNOWLEDGE OF PRETERM INFANT DEVELOPMENT		
12.1 STAFF		
Are staff members able to read preterm infant cues and behaviors during interaction with the preterm infant?	☐ Yes ☐ No ☐ Not Sure	
Is knowledge shared between professionals?	☐ Yes ☐ No ☐ Not Sure	

Does the unit apply a multidisciplinary team approach in the NICU?	☐ Yes ☐ No ☐ Not Sure
12.2 PARENTS	
Are parents taught preterm infant behavioral cues and stress signs?	☐ Yes ☐ No ☐ Not Sure
Are parents taught how to interact with their preterm infant?	☐ Yes ☐ No ☐ Not Sure
Are parents taught to understand when their baby has had enough stimulation?	☐ Yes ☐ No ☐ Not Sure
Are parents taught how to observe their baby's individual milestones reached - each step forward is part of the process of getting home.	☐ Yes ☐ No ☐ Not Sure
Do you provide and encourage parents to keep memory boxes?	☐ Yes ☐ No ☐ Not Sure
13.FAMILY-CENTERED CARE PHILOSOPHY	
13.FAMILI-CLIVIERED CARL I IIIE0301 III	
13.1 FAMILY SUPPORT	
	☐ Yes ☐ No ☐ Not Sure
13.1 FAMILY SUPPORT  Do the staff provide family-centered care to support	☐ Yes ☐ No ☐ Not Sure ☐ Yes ☐ No ☐ Not Sure
13.1 FAMILY SUPPORT  Do the staff provide family-centered care to support parental empowerment and family involvement?  Do the staff encourage parents to contact parent	
13.1 FAMILY SUPPORT  Do the staff provide family-centered care to support parental empowerment and family involvement?  Do the staff encourage parents to contact parent support groups?  Do the staff make visiting hours for siblings and other	☐ Yes ☐ No ☐ Not Sure

13.2 FAMILY EDUCATION	
Do the staff educate parents about the NICU	☐ Yes ☐ No ☐ Not Sure
environment, their infant's condition and relevant	
procedures helps facilitate their active participation	
in family-medical discussions.	
Do the staff provide family education to support	☐ Yes ☐ No ☐ Not Sure
parental interaction with their preterm infants	
Do the staff provide parent information leaflets?	☐ Yes ☐ No ☐ Not Sure
Do the staff provide parents with online information?	☐ Yes ☐ No ☐ Not Sure
Do the staff help parents understand their infant's	☐ Yes ☐ No ☐ Not Sure
condition and any proposed treatment in order to	
make informed choices?	
Do the staff show the parents how their baby is	☐ Yes ☐ No ☐ Not Sure
responding to them, how the baby calms if the	
parents are handling him/her?	
13.3 FAMILY PROFILE	
Do the staff identify parent profile to address high-	☐ Yes ☐ No ☐ Not Sure
risk profiles	la res la No la Not sure
risk profiles	
14.STAFF	
14.1 STAFF EDUCATION	
Does NICU staff receive education regarding preterm	☐ Yes ☐ No ☐ Not Sure
and full-term infant development?	
14.2 MULTIDISCIPLINARY TEAM	T —
Does NICU staff ensure a multi-disciplinary approach	☐ Yes ☐ No ☐ Not Sure
to contribute to successful operationalization of the	
NDSC	
4.4.0 CMA DE ATMITIUDE	
14.3 STAFF ATTITUDE	
Does NICU staff create a positive staff attitude	☐ Yes ☐ No ☐ Not Sure

15.SYSTEMS	
15.1 COMMUNICATION	
Does NICU staff ensure effective communication between health care professionals, and health care professionals and parents?	☐ Yes ☐ No ☐ Not Sure
15.2 PROTOCOLS	
Does NICU staff develop protocols to support implementation of interventions?	☐ Yes ☐ No ☐ Not Sure
15.3 MANAGEMENT SUPPORT	
Does NICU staff ensure management support on different levels to contribute to successful NDSC operationalization?	☐ Yes ☐ No ☐ Not Sure
15.4 RESOURCES	
Does NICU staff ensure availability of resources?	☐ Yes ☐ No ☐ Not Sure
15.5 IMPLEMENTATION TIME	
Does NICU staff ensure implementation over extended period of time?	☐ Yes ☐ No ☐ Not Sure
16.EQUIPMENT	
Is the NICU equipped according to NDSC standards?	☐ Yes ☐ No ☐ Not Sure
Do you have <b>NDSC equipment</b> for:	
extremely preterm (less than 28 weeks)	☐ Yes ☐ No ☐ Not Sure
very preterm (28 to 32 weeks)	☐ Yes ☐ No ☐ Not Sure
moderate to late preterm (32 to 37 weeks)	☐ Yes ☐ No ☐ Not Sure
full-term (38 to 40 weeks)	☐ Yes ☐ No ☐ Not Sure

17.PHYSICAL SPACE	
Is the NICU in a physical location that promotes NDSC?	☐ Yes ☐ No ☐ Not Sure
Do you have <b>NDSC physical space</b> for:	
extremely preterm (less than 28 weeks)	☐ Yes ☐ No ☐ Not Sure
very preterm (28 to 32 weeks)	☐ Yes ☐ No ☐ Not Sure
moderate to late preterm (32 to 37 weeks)	☐ Yes ☐ No ☐ Not Sure
full-term (38 to 40 weeks)	☐ Yes ☐ No ☐ Not Sure
18.NICU STAFF	
Neonatologist	☐ Yes ☐ No ☐ Not Sure
Neonatal Fellow	☐ Yes ☐ No ☐ Not Sure
Pediatric Resident	☐ Yes ☐ No ☐ Not Sure
Head neonatal nurse	☐ Yes ☐ No ☐ Not Sure
Neonatal nurses	☐ Yes ☐ No ☐ Not Sure
Pharmacist	☐ Yes ☐ No ☐ Not Sure
Orthopedist	☐ Yes ☐ No ☐ Not Sure
Surgeon	☐ Yes ☐ No ☐ Not Sure
Respiratory therapist	☐ Yes ☐ No ☐ Not Sure
Lactation consultant	☐ Yes ☐ No ☐ Not Sure
Ultra-sonographers	☐ Yes ☐ No ☐ Not Sure

Dietician	☐ Yes ☐ No ☐ Not Sure
Social worker	☐ Yes ☐ No ☐ Not Sure
Psychologist	☐ Yes ☐ No ☐ Not Sure
Physical therapist	☐ Yes ☐ No ☐ Not Sure
Speech language pathologist	☐ Yes ☐ No ☐ Not Sure
Auditory technician	☐ Yes ☐ No ☐ Not Sure
Radiographers	☐ Yes ☐ No ☐ Not Sure
Hospital Chaplain	☐ Yes ☐ No ☐ Not Sure
Head of the Dept	☐ Yes ☐ No ☐ Not Sure
Clerical staff	☐ Yes ☐ No ☐ Not Sure
Cleaners	☐ Yes ☐ No ☐ Not Sure
Other (please indicate specialty)	
19.RESEARCH	
Has your hospital conducted any NDSC research?	☐ Yes ☐ No ☐ Not Sure
Have you conducted <b>NDSC research</b> for:	
extremely preterm (less than 28 weeks)	☐ Yes ☐ No ☐ Not Sure
very preterm (28 to 32 weeks)	☐ Yes ☐ No ☐ Not Sure
moderate to late preterm (32 to 37 weeks)	☐ Yes ☐ No ☐ Not Sure
full-term (38 to 40 weeks)	☐ Yes ☐ No ☐ Not Sure

20.NEONATAL OCCUPATIONAL THERAPY				
Do you have neonatal Occupational Therapists in the NICU?	□ Yes	□ No	□ Not Sure	
IF YOU ANSWER "NO" OR "NOT SURE", STOP HERE.				
21. NEONATAL OCCUPATIONAL THERAPY (NT OT)				
21.1 ROLE OF OT				
How many OTs are in the NICU?	□ 0 □ 3			
Do you have a head OT?	□ Yes	□ No	□ Not Sure	
How long have OTs been in the NICU? $\square$ <1 yr. $\square$ 1-3 yrs. $\square$ 4-7 yrs. $\square$ 8-10 yrs.	□ >10	yrs.		
Are OTs involved in decision making in the NICU?	□ Yes	□ No	□ Not Sure	
Is NICU staff familiar with the role of neonatal OT?	□ Yes	□ No	□ Not Sure	
Are OTs equal members of the NICU team?	□ Yes	□ No	□ Not Sure	
21.2 OT NICU EDUCATION				
What level of education do the OT(s) have?  □ 2-year (OT assistant) □ 4-year (OTR)  □ Graduate (MS or MA) □ Doctorate				
Has any OT received Neonatal Specialty?	□ Yes	□ No	□ Not Sure	
If yes, from what program?				
21.3 OT NDSC EDUCATION				
Is/are the OT(s) trained in NDSC?	☐ Yes	□No	□ Not Sure	
What is the name of their NDSC training (i.e., NIDCAP)?				

Where did they get NDSC trained?		
When did they get NDSC trained?		
Does the hospital provide ongoing NICU education to OTs?	☐ Yes ☐ No	□ Not Sure
Does the hospital provide ongoing NDSC education to OTs?	☐ Yes ☐ No	□ Not Sure
21.4 APPLICATION OF NDSC		
Do OTs apply NDSC on a daily basis?	☐ Yes ☐ No	□ Not Sure
Are they being supervised in the application of NDSC?	☐ Yes ☐ No	□ Not Sure
Who supervises them (discipline)?		
COMMENTS		
Thank you for being part of this important project!		

### **APPENDIX S - Executive Summary**

# Background Information on Neurodevelopmental Supportive Care and Neonatal Occupational Therapy in Greece

Neurodevelopmental Supportive Care (NDSC) is a developmental theory and intervention that supports neuroprotection of premature infants in the neonatal intensive care unit (NICU). NDSC guides clinical neonatal and family care practice, and fosters preterm infants' long-term development (Milette et al., 2017). Since the 1980s, occupational therapy has evolved as a neonatal specialty, a critical discipline in the NICU team and most importantly, as a valuable provider of NDSC practices (Rubio-Grillo, 2019). Neonatal occupational therapists (NT OTs) are integral to assessing sensory and environmental factors impacting critical elements of development and creating an environment and family support conducive to preterm newborns' sensitive needs.

There has been an increase in premature births in Greece from 9.62% in 2008, to 11.18% in 2010, to an estimated rate of 20% in 2019 (Vlachadis et al., 2014). The same authors reported that this increase has created dramatic challenges for public health and preventive interventions. Providing appropriate neuroprotective care for these infants is of critical importance (Milette et al., 2017). According to L. Vavouraki, MD (personal communication, March 19), there is no data on NDSC application and NT OT staffing in Greek NICUs. In order to facilitate implementation of these practices in Greece, it is important to first raise awareness of NDSC and OT NT to the NICU personnel, other healthcare disciplines, government agencies, and the general public. The author's proposed online awareness program will: promote hospital and NICU administration to

consider NDSC and recognize OT NT as a NICU discipline, endorse NDSC research, ratify public and private funding so that all NICUs in Greece are NDSC supported, and inform perspective and NICU parents to become advocates of these practices.

## **Awareness Program Description**

The "Neurodevelopmental Supportive Care and the Role of Occupational Therapy in Greek Neonatal Intensive Care Units - A Health Awareness Program" is a dynamic, first of its kind evidence-based awareness program concerning NICUs and NT OT in Greece. It consists of two distinct paths Path 1 is an initial awareness program, and Path 2 is an exploratory research based on data collected from the awareness program. It is theoretically grounded in the Health Belief Model (Amraei et al., 2020) and anticipated to facilitate a change in the perception of NDSC and NT OT in Greece at all levels: micro (individual NICU practitioners), meso (the NICU and health care community), and macro (Department of Health and the general public).

### Path 1

The program's launch will be initiated by announcements on social media such as Facebook and email which are the two most preferred media venues in Greece. It will be hosted on a custom-made website that will include three tracks of information depending on the viewer's level of expertise in NICU matters, available time, and desired depth of education. All tracks will offer evidence-based educational materials in NICU NDSC and OT NT, free download of brochures and newsletters, NDSC and NT OT videos with Greek subtitles, resources and links worldwide, announcements for NDSC training and other events, testimonials from NICU parents and staff, infant follow-up stories,

podcasts, and a program evaluation questionnaire. Track one lasts ten minutes, is suitable for the general public and governmental agencies, and contains the materials described previously. Track two is a 20-minute program, includes all information mentioned earlier but in greater detail and sophistication addressing an audience familiar with the NICU environment. Track three is 40 minutes long and suitable for the NICU staff. It provides highly specialized information on NDSC and NT OT, training and certification, protocols, and funding sources. In addition to the program evaluation questionnaire in Track three, an exploratory research survey will be included with specific questions regarding NDSC and NT OT in the participants' NICUs.

### Path 2

The data from the exploratory survey will be further used for the first exploratory research of its kind in Greece initiated within six months from the awareness program's initiation. The research will address NICU staff attitudes, perceptions, demographics, philosophy, obstacles, ethics, applications, training, and education regarding NDSC and OT NT. The results of the research will be disseminated to facilitate more awareness about the status of NDSC and NT OT and propose changes.

### **Program Evaluation and Desired Outcomes**

### Formative Program Evaluation Research Plan

All program participants will be asked to complete short surveys at the end of the program to assess the program's implementation and the participants' outcomes in terms of knowledge, skills, and attitudes of NDSC and NT OT. The program's implementation (i.e., formative program evaluation) will be assessed by collecting feedback about the

awareness package content, the usefulness of the author's method of delivering the information, and participants' ratings of their experiences and satisfaction following the awareness program.

### Summative Program Evaluation Research Plan

The program's outcomes (i.e., summative program evaluation) will confirm if desired changes in knowledge, skills, and attitudes in NDSC and neonatal OT were a result of participating in the awareness program. Program evaluation research will be ongoing to ensure and demonstrate the extent to which objectives for the program and its participants were achieved.

### **Desired Clinical Outcomes**

This program's outcomes will primarily benefit premature infants and their families by providing evidence-based NDSC and NT OT practices at a crucial developmental stage in the infant's life. As Milette et al (2017) state NDSC may lessen or eliminate the possibility of future neurodevelopmental disorders and the need for supportive services. Raising awareness will significantly benefit NICU medical, nursing, and OT staff. It is anticipated that hospital administrators will recognize the importance of NDSC and NT OT, and establish these practices in their NICUs.

One large group that is expected to be particularly affected are OTs. The program may influence OT schools to add neonatal OT and NDSC courses in the educational curriculum and encourage the Panhellenic Occupational Therapy Association to support NT OT. The program may ultimately raise interest and investment in neonatal services by the Department of Health and encourage the community's efforts to advocate for early

intervention at the medical and governmental level. In time, every NICU in the country will endorse OT NT and NDSC practices according to international standards and the most current evidence-based practice. Clinical changes will establish a foundation for further research on NDSC efficacy in neonatal care and developmental outcomes in premature infants and infants at risk. The awareness program will be the catalyst for research by Greek institutions and facilitate collaborations with significant associations such as the European Foundation for the Care of Newborn Infants (2018). As a clinical and a research outcome, this program may pave the way for Greece to strengthen its position in the universal world of early intervention neuroprotective medicine.

### **Conclusions and Future Directions**

Neurodevelopmental Supportive Care (NDSC) identifies both the antecedents and consequences of consistent neuroprotective care as crucial to delivering quality care in the neonatal intensive care unit (NICU). Neonatal occupational therapists (NT OTs), working as part of the interdisciplinary NICU team, have comprehensive abilities in NDSC, and a unique perspective and experience needed to support newborns and premature infants and their families. Greece needs to rise to the occasion and provide the highest quality of neonatal services by establishing NDSC practices, establish official NDSC training series, encourage the OT community for NT specialization, and promoting OT NTs as a significant partner to NICU intervention. Furthermore, Greece should focus on NDSC and NT OT research to scientifically contribute to the European and international efforts for NDSC and NT OT validation and evidence-based practices in the NICU. The proposed awareness program is a critical piece of the path from current

practices in Greek NICUs to more optimal, comprehensive, and evidence-based practices using Neurodevelopmental Supportive Care and the inclusion of Neonatal Occupational Therapy as an invaluable discipline.

### **APPENDIX T - Fact Sheet**



Main Issues

Neurodevelopmental Supportive Care and the Role of Occupational Therapy in Greek Neonatal Intensive Care Units: N.E.O.G.N.O. - A Health Awareness Program

### Elizabeth Maglari, BS, MS, OT/L, BCP OTD Candidate



NEOGNO is an innovative, evidence-based awareness program advocating neuroprotection practices for premature infants and the inclusion of neonatal occupational therapy in all Greek neonatal intensive care units.

15.000.000 infants are born prematurely every year worldwide; 1 in 10 newborns and as early as at the age of 21 weeks.

Preemies are at high risk for neurodevelopmental disorders such as autism, schizophrenia, mental retardation and cerebral palsy.

- The Neonatal intensive care unit (NICU) environment exposes infants to a constant barrage of negative, stimuli that impact the long-term development of the neonatal brain. Neurodevelopmental Supportive Care (NDSC) are specific strategies and interventions to protect neonatal brain development (Milette et al., 2017), and neonatal occupational therapists (NT OT) are vital members of the NICU team and to the implementation of NDSC (Craig & Smith, 2020).
- Premature births in Greece have increased from 9.62% in 2008 to II.18% in 2010, to an estimated rate of 20% in 2019, creating dramatic need for preventive interventions (Vlachadis et al., 2014). Appropriate neuroprotective care for these infants is of critical importance (Milette et al., 2017).
- Currently, there is a void of data on NDSC applications and NT OT staffing in Greek NICUs.

### Proposed Solution: The NEOGNO Awareness Program

# Raise NDSC and NT OT Awareness:

### To:

- NICU staff and administration
- Other healthcare disciplines
- Government agencies
- NICU parents and perspective parents
- The general public

By participating in the program:



### That offers:

Online, Self-Paced Awareness Program

- Evidence-based educational materials in NICU NDSC and NT OT
- Announcements for NDSC training
- Testimonials from NICU parents, infant follow-up stories, and podcasts
- A program evaluation questionnaire and an exploratory survey

Program participants will then promote:



### That will:

Change in NICU Practices

- Benefit preemies and their families, short and longterm
- Endorse OT NT and NDSC practices in all Greek NICUs
- Promote public and private funding of NDSC
- Initiate research on NDSC
- Promote NT OT specialization
- Promote NT OT recognition

### Theoretical Basis

Based on the Health Belief. Model, the program is anticipated to facilitate a change in the perception of and action for NDSC and NT OT in Greece at all levels: micro (individual NICU practitioners), meso (the NICU and health care community), and macro (Department of Health and the general public).

### Facts about NDSC

- Prevents or lessens the possibility of neurodevelopmental disorders (Milette et al., 2017)
- Has been gaining continuous support by the international community (EFCNI, 2019)

The Seven Elements of NDSC



THINK LIG

and advoce

for NDSC and NT OT

in your NICU

### Significance of NT OT

- Integral to assessing NICU sensory and environmental factors and providing family support conducive to preterm newborns' sensitive needs (Rubio-Grillo, 2019)
  - Unique in their perspective that the infant is an occupational being and an active coparticipant due to his/her interaction with the environment



Access the Program

https://elizamaglari.wixsite.com/ndsc

Funding and Program Support

https://elizamaglari.wix.ste.com/ndsc/fundingprogram-support

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## **CURRICULUM VITAE**

