A Pilot Study of Feasibility and Acceptability of Incorporation of Nurse Administered Neurodevelopmental Assessment into Routine Clinic Practice in a Developing Country Clinic

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A Pilot Study of Feasibility and Acceptability of Incorporation of Nurse Administered Neurodevelopmental Assessment into Routine Clinic Practice in a Developing Country Clinic

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Statement of the Problem and Background: Significant progress has been made in child survival with the actual number of children dying before their 5th birthday reduced by greater than 50% since 1990 (UNICEF, 2015). The current focus is on whether those children surviving have the ability to reach their full potential given the conditions of deprivation that frequently exist (Chan, 2013). The effects of deprivation may result in deficiencies in cognition and learning, which may be life-long. To date neurodevelopmental assessment has not been included in well child care in most African settings, including the proposed clinic for this project. The Mullen Scales of Early Learning (MSEL) (Mullen, 1995), which assesses the cognitive functioning of children from birth to 6 years old has been successfully used in Benin and in Uganda by nurses as part of a research project. This project was an opportunity to determine the feasibility and acceptability of incorporation of MSEL administration to extend current nursing practice to improve child health.

Methods: MU-JHU clinic is a busy research clinic in the capital city of Kampala, Uganda focusing on women’s and children’s health and providing well child services to all study participants. Five of the MU-JHU clinic nurses were trained to administer the MSEL, which they then administered to 80 infants to determine feasibility and acceptability of incorporation of the MSEL into the MU-JHU routine nursing practice. Nineteen MU-JHU clinic nurses and Mulago Hospital nurses who had not been trained in MSEL administration participated in a post MSEL administration demonstration and questionnaire.
The assessment of feasibility included review of training records, videotape evaluation of MSEL testing sessions, MSEL score normality analysis, and in-depth interviews with the 5 MSEL administering nurses. Acceptability was assessed via the in-depth interviews with the 5 MSEL administering nurses as well as with the questionnaires for the 19 MSEL non-administering nurses and via the caregivers’ exit questionnaires.

**Results:** All 5 MSEL administering MU-JHU clinic nurses completed training and were able to administer the MSEL within reasonably expected times and with adequate accuracy and efficiency per the videotape evaluations, recorded times of administration, and MSEL score distributions for the 80 infants tested. However, they identified challenges to feasibility of incorporation into routine clinic nursing practice during the in-depth interviews. The majority of 19 non-MSEL administering nurses indicated they would like to learn the MSEL and thought it was good for infants and nurses to include in routine nursing practice. They too identified practical issues as challenges to being able to incorporate into routine practice. Caregivers all indicated they would agree to testing in the future and almost all indicated they appreciated the testing of their infants.

**Conclusions:** Incorporation of the MSEL into nursing practice for all infants in the MU-JHU clinic and in most developing country settings is likely not feasible. However, a short, easy to administer screening tool may well be practical to indicate which infants truly need MSEL testing. Having a few nurses trained to administer the MSEL, such as occurred in the MU-JHU clinic, to those infants and children who need in-depth neurodevelopmental testing would likely be much more feasible. That model of nursing practice in busy pediatric clinics would be a huge step forward to diagnose and intervene with the more than 200 million children worldwide who are at risk for neurodevelopmental delay.
This dissertation by Sheryl L. Zwerski fulfills the dissertation requirement for the doctoral degree in Nursing approved by Elizabeth Hawkins-Walsh, PhD, CPNP, PMHS, FAANP, as Director, and by Rebecca Robert, PhD, PNP-BC, FNP-BC, and Mary Glenn Fowler, MD, MPH as Readers.

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Dedication

This dissertation is dedicated to everyone who has contributed and assisted along the way and specifically to my committee (Dr. Elizabeth Hawkins-Walsh, Dr. Rebecca Robert, Dr. Mary Glenn Fowler) who spent countless hours reviewing numerous drafts and providing excellent advice and encouragement. I would also like to dedicate the dissertation to Sr. Speciosa Mbabali and Sr. Mai Nakitende for stellar on the ground project leadership and to all of the MU-JHU nurses, who performed the MSEL testing, counseled the participants, and participated in any way. I would also like to recognize Dr. Monica Nolan, Dr. Philippa Musoke, Dr. Lillian Wambuzi Ogwang, and Dr. Jim Aizire who have all assisted greatly by being generous with both resources and advice. Additionally, I would like to thank the nurses at Mulago Hospital who assisted with recruitment and participated in various aspects of the study as well as the data management staff at MU-JHU who worked so diligently on the data, and the infants and caregivers who agreed to part of the project. I would like to give a very special thank you to Dr. Michael Boivin, whose expertise on the subject of neurodevelopment in infants and children is unparalleled and who so generously gave of his time, resources, and advice. I would like to thank Dr. Carl Dieffenbach and Dr. Emily Erbelding, who provided sustained encouragement over the years to complete the project as well as flexibility to simultaneously maintain the duties of my position. Lastly, and most importantly this dissertation is dedicated to the my husband, David Zwerski, who supported all of the activities required through the years with constant encouragement, infinite patience, repeated table formatting assistance, and monetary support without which this work could not have been accomplished.
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Chapter 1:
Nature and Scope of Project

Background and Significance

Significant progress has been made in child survival with the actual number of children dying before their 5th birthday reduced by 53% since 1990 (UNICEF, 2015). However, the World Health Organization’s (WHO) Director-General, Margaret Chan, has rightly raised the question of whether those children who are now surviving have the ability to reach their full potential given the conditions of deprivation that exist for many of them (Chan, 2013).

Deprivation and the resulting toxic stresses that occur early in life can affect the brain’s actual physiology (Bick & Nelson, 2015; Huttenlocher, 2002), which may in turn affect cognition and behavior. Coping responses developed for extreme stress that are necessary and will benefit the child in the short term may well be detrimental in the long term. Deficiencies in cognition and learning as well as problems with relationships and issues with overall physical and mental health may be lifelong when children have been exposed to extreme stress either through malnutrition, illness, lack of appropriate human contact and familial or societal violence. The potential lost productivity in adulthood resulting from developmental delay in childhood could inflict a high social and economic burden on countries that can ill afford further loss of resources (Engle, Black, Behrman, de Mello et al. 2007; Engle, Fernald, Alderman, Behrman et al, 2011; Walker, Wachs, Grantham-McGregor, Black et al, 2011) The first step in ultimately being able to mitigate neurodevelopmental delays and their resulting downstream effects is to be able to accurately assess children for developmental delays in the clinics where they receive healthcare (Scherzer, Chhagan, Kaughali, and Susser, 2012).
It is estimated that approximately 200 million children worldwide are at significant risk for developmental impairment (Engle et al. 2007, Grantham-McGregor et al. 2007, Irwin, Siddiqi and Hertzman, 2007). There are myriad reasons for neurodevelopmental impairment. Stunting of a child’s potential growth and living in poverty are considered to be high on the list of potential influences (Black, Victoria, Walker, Bhutta, et al., 2013; Carba, Tan & Adair, 2009; Grantham-McGregor et al. 2007; Walker et al, 2007). Maternal educational level (Irwin et. al. 2007) infectious disease sequelae (Checkley, Buckley & Gilman, 2008; Mung’alera-Odera et al. 2006), including malaria (Bangirana, Opoka, Boivin, Idro et al., 2015; Carter et al. 2005) and HIV infection (Brahmbhatt, Boivin, Ssempijja, Kigozi et al, 2014; Busman et al, 2013; Drotar et al. 1997), iron deficiency anemia and iodine deficiency (Mireku, Davidson, Koura, Ouedraogo et al., 2015; Walker et al. 2007) as well as adverse pregnancy outcomes (Kramer, 2003) are all factors that may lead to neurodevelopmental delays. Many of these factors are common occurrences in low and middle-income countries, yet accurate measurement of neurodevelopment for infants and children in those same developing countries is often not occurring.

Nurses are often the front line providers for well child care and immunizations, and are the ones who attend to growth and development issues. Given the potential scale of neurodevelopmental delay worldwide, exploring the feasibility and acceptability of nurse administered neurodevelopmental assessments is an important potential solution to explore. If children at risk can be identified early, interventions are available now to help improve their cognitive functioning. Such interventions include center-based interventions as well as interventions that parents can be trained to implement with their children (Engle et al. 2011). One such program, the Meditational Intervention for Sensitizing Caregivers (MISC) was a
biweekly caregiver training with the aim of focusing, exciting, expanding, encouraging, and regulating the preschool children’s behaviors. The study included a sample of 120 rural Ugandan caregiver/preschooler dyads. The preschoolers were HIV-infected and without known neurodevelopmental delays. Sixty of the caregiver/child dyads were randomized to receive the biweekly MISC intervention and sixty were randomized to receive biweekly health and nutrition instruction. The children in the MISC intervention arm showed significantly better MSEL visual reception scores over time compared to controls (Boivin et al, 2013). This is just one example of an intervention that may be able to prevent or improve any neurodevelopmental delay.

**Project Plan/Rationale**

The opportunity to gather feasibility pilot information on nurse administered MSEL testing at the Makerere University/Johns Hopkins University (MU/JHU) clinic first presented itself in the context of the PROMISE study. The PROMISE study is multi-centered clinical trial that is being conducted in the MU/JHU clinic and has as its primary objectives the determination of optimal antiretroviral (ARV) regimens to reduce mother to child transmission of HIV and the elucidation of effects of those ARV regimens on maternal health. As part of this trial, which includes children who are HIV and ARV exposed, interest in neurodevelopmental testing was raised and the subsequent need for neurodevelopmental testers was identified.

Nurses are the largest sector of the healthcare workforce in the MU/JHU clinic and are skilled clinicians. There are 78 nurses and 39 physicians (including trainees, fellows, etc.). The leadership of MU/JHU thought that expansion of the nurses’ scope of practice to include neurodevelopmental testing, if possible, would benefit the nurses, clinic, and children who attend the clinic. The project included a subgroup of 5 nurses trained in MSEL administration to
evaluate in detail the process and the feasibility and acceptability of inclusion of neurodevelopmental testing in order to make evidence based decisions for the clinic.

**Setting**

This project took place at MU-JHU Research Collaboration Center and the Mulago National Referral Hospital in Kampala, Uganda. The Makerere University/Johns Hopkins University (MU/JHU) Research Center is located in Kampala, Uganda. This clinic is closely associated with Mulago Hospital, which is a government hospital that is the Uganda National Referral Center. It is also the teaching hospital for the Makerere University Schools of Medicine, Nursing, Pharmacy and other health sciences programs. MU/JHU clinic is a well-developed research clinic that has been conducting HIV related research since the late 1980s. The clinic sees an average of 50 to 80 patients per day, and almost all are enrolled in research studies. The types of studies include prevention of mother to child transmission of HIV, maternal health, women’s HIV prevention, pediatric HIV treatment, and maternal and pediatric tuberculosis. The clinic staffing also includes laboratory technicians, data management staff, and administrative and financial staff. Nurses are the largest sector of the clinic workforce, so their practice affects the logistics of the clinic overall in a very direct way.

**Evidence Based Practice Framework**

Any potential practice change requires a careful, step-wise approach, so the guiding framework for the project was the Iowa Model of Evidence-Based Practice to Promote Quality Care (Titler et al, 2001), which was originally developed in 1994 and updated in 2001. The model delineates the logical steps in instituting evidence based practice change in nursing when either recommended knowledge changes occur, such as changes in guidelines, etc., or when organizational or clinical problems (such as in this case) are identified. Figure 1 illustrates the
use of the Iowa Model, which was used as the guiding principle for the project from the initial identification of the need for nurses to administer the MSEL through the end of the project and for the steps beyond. The focus of this project was the feasibility and acceptability of nurse administered MSEL assessments with infants and young children aged 1 to 24 months. This project represented the starting point for potential expansion of nursing practice to develop a workforce skilled in neurodevelopmental testing in this clinic.

Figure 1. Evidence based practice framework
Project Objective

To determine the feasibility and acceptability of incorporating the Mullen Scales of Early Learning (MSEL) (Mullen, 1995) into nursing practice at Makerere University – Johns Hopkins University (MU-JHU) clinic in Kampala, Uganda.

Outcomes to be measured:

1.) Feasibility of training nurses to administer the MSEL in a timely and accurate manner

   Methods

   a. MSEL training completion by selected MSEL administering nurses
   b. MSEL scores distribution patterns
   c. MSEL administration times
   d. MSEL Video evaluations

2.) Nurses’ acceptability of MSEL training and actual administration of the test for children

   Methods

   a. In-depth interviews of MSEL administering nurses
   b. Post MSEL demonstration questionnaire for non-administering clinic and hospital nurses

3.) Caregivers’ acceptability of MSEL testing

   Methods

   a. Caregivers’ Exit Questionnaire
Chapter 2:  
Synthesis and Analysis of Literature  

Normal Infant and Childhood Neurodevelopment  

Brain and neurodevelopment begins early in gestation with a rapid proliferation of neurons, which continues throughout pregnancy and leads to a maximal lifetime number of neurons in the newborn (Rakic, 2006). Myelination of the neurons also begins in pregnancy, but is not fully complete until adolescence, with the brain reaching full maturity in the third decade of life (Bick and Nelson, 2015). During infancy and until about age three, many more synapses are formed between the neurons than will actually be needed. Neurons deemed unnecessary or unused due to environmental influences will be pruned back during childhood and through late adolescence, (Bick, Fox, Zeanah, & Nelson, 2015; Huttenlocher, 2002).

In recent years the understanding of neuronal plasticity has increased significantly including the influence that genetics and early experiences have on a child’s brain organization and eventual adult capabilities. The very earliest stages of brain development are largely determined by genetics (Bick et al., 2015; Skaliora, 2002), but the brain can be further molded by the early experiences of a child. In particular, these experiences can greatly influence memory and other cognitive abilities. (Bick et al., 2015; Kolb & Gibb, 2011; Johnston, Ishida, Ishida, Matshushita, et al., 2009). Early insults or deprivation such as exposure to violence, abusive or neglecting caregivers, etc. appear to significantly alter in brain pathways, including changes to the structure and function of the prefrontal cortex. These changes, which can lead to long term problems with emotion and cognition (De Brito, Viding, Sebastien, Kelly, eta l., 2013; Edmistin, Guand,
Mazure, Guiney et al., 2011; Hanson, Chung, Avants, Shirtcliff et al., 2011). This greater understanding of the potential changes to the brain though childhood makes recognition and prevention of potential insults critical. This is especially true since interventions have been developed to increase caregivers’ understanding of the need for greater interaction and stimulation (Boivin et al., 2013; Engle et al., 2011) and could be employed if potential threats to normal cognition and development are recognized early.

**Potential Effects of HIV and Antiretrovirals on Neurodevelopment**

The potential effects of HIV and antiretroviral (ARV) exposure on developing infant brains are especially pertinent in Uganda, given that in 2014 the adult HIV prevalence in Uganda was 7.3% (UNAIDS, 2015). The rate of mother to child transmission of HIV has decreased significantly over the years, but remains at 4.6% (Government of Uganda Ministry of Health, 2014). Since the inception of the so-called Option B+ in 2013, where pregnant women initiate ARVs and are maintained on them for life, the number of HIV positive pregnant women receiving ART has increased dramatically. In the 2014 HIV and AIDS Ugandan Status Report, the Ministry of Health states that greater than 95% of all HIV positive pregnant women received ART that year. Therefore, the number of infants exposed to HIV and ARVs, but who are HIV uninfected in Uganda has risen dramatically over the past several years. Having a better understanding as to whether or not detrimental neurodevelopmental consequences result from exposure to ARVs or HIV during infants’ critical early development stages is critical for the clinic population and the country.

Most studies conducted in low and middle-income countries to assess the effect of Human Immunodeficiency Virus (HIV) infection on the neurodevelopment of infants who are HIV infected and untreated or treated late in the course of disease reveal delays. The delays range from
more subtle to very significant in the area of motor skills and/or other aspects of cognition (Abubaker, Van Baar, Van de Vijver, Holding and Newton, 2008; Drotar et al. 1997; McGrath et al. 2006; Msellati et al. 1993; Van Rie, Mupuala and Dow, 2008). Le Doare et al. (2012) reviewed 31 studies of HIV and ARV exposed infants that used standardized tools to measure neurodevelopment and found that HIV infected children had both cognitive and motor skills scores that were consistently 1 to 2 standard deviations below the mean for the particular neurodevelopmental assessment used in each study. Infants who were treated with ARVs in early life had better scores than those untreated or treated later. Most studies reviewed were from resource rich countries, but about 25% were from low and middle-income countries.

While untreated or late treated HIV infection is well accepted as negatively affecting child neurodevelopment, less is known regarding potential neurodevelopmental effects of maternal HIV infection (infant exposure to the virus in utero, but established as not infected) and antiretroviral (ARV) exposure in low and middle-income countries. The majority of information available on this topic comes from studies conducted in developed countries and reveals no evidence of global developmental delays in these children in the absence of known harms (maternal substance abuse, etc.) (Blanchette, et al., 2002; Brackis-Cott, et al., 2009; Culnane, et al., 1999; Nozyce et al., 1996). However, more subtle delays in areas of motor development and expressive language have been observed (Brahmbhatt et al., 2014; van Rie et al., 2008). More recent information regarding children in a study in Uganda indicates that children who were HIV and ARV exposed, but uninfected had receptive language delays on the MSEL compared to children who were unexposed to HIV. (Brahmbhatt et al, 2014). The neurodevelopmental data in this population, while growing, remains limited and deserves further attention.
Neurodevelopmental Assessment of Children in Developing Country Settings

Accurate measurement of neurodevelopment for infants and children in developing countries is often hampered by the lack of validated instruments. A number of different approaches to resolve this problem have been attempted with varying success. Several studies have highlighted the difficulties of these endeavors, and point to particular problems when trying to measure cognition or intelligence in a culture that is dissimilar to the one for which the test was developed. In one example researchers from the Democratic Republic of Congo attempted to use the BSID Cognition Scales, the Rosetti Infant-Toddler Language Index and the Snijders-Oomen Nonverbal Intelligence tests. Scores demonstrated high rates of impairment in the community, which were unfounded, were thought to reflect the differences in child-rearing among settings and the caregiver’s understanding of the questions in the instrument was questionable (Van Rie, et al. 2008). When researchers attempted to measure intelligence in Zambian children they encountered much the same situation and determined that “intelligence” means different things in different cultures and is not necessarily directly translatable (Kathuria and Serpell, 1998).

However, several successful attempts to adapt US based instruments for developing country settings have occurred such as the Denver Developmental Screening test (DDST II) (Gladstone, et al. 2007; Hadley et al. 2008), the Bayley Scales of Infant Development (BSID) (Richter, Griesel and Rose, 1992; Kuklina, Ramakrishnan, Stein, Barnhart and Martorell, 2005), and the Mullen Scales of Early Learning (Boivin, et al. 2011; Brahmbhatt, et al. 2010), although all with specific, limited populations.

Instruments developed specifically for use in international, non-US settings have also been validated and used in some developing country populations (Khan et al. 2008; Mung’ala-Odera et al. 2006). These include the use of The Ten Questions Questionnaire (TQQ), which is a rough
screening assessment to determine need for further evaluation for potential neurologic impairment (Christianson et al. 2002; Durkin et al. 1997; Mung’ala-Odera et al. 2004), and the Guide for Monitoring Child Development (Ertem et al. 2008), an open ended interview of caregivers used to screen for developmental delays. The latter tool can be successfully incorporated into sick child visits for minor acute illnesses per Ertem et al. (2006). Additional tools include the Malawi Developmental Assessment Tool (MDAT) (Boivin, et al. 2011; Gladstone, et al. 2010), the Developmental Assessment Tools for Anganwadis (DATA) (Nair et al. 2009), which was developed for use in Indian preschools, the Developmental Screening Inventory (Aina and Morakinyo, 2001), the Infant Neurological International Battery (Soleimani and Dadkhah, 2006), the Psychological Development Screening Test (Malik, Pradhan and Prasuna, 2007) the Disability Screening Schedule (Chopra, Verma and Seetharaman, 1999) and the Shoklo Developmental Test (Haataja et al. 2002). While studied in research settings, none of these instruments have been incorporated into care on a wide scale. Reasons for the lack of scale up in practice include time and skill to adapt assessments to the cultural context, the lack of trained providers to implement testing in many places, and the time that it takes to administer many of the instruments. There is a critical need for an instrument that a varied cadre of providers can be trained to administer in an efficient manner that gives a reasonable approximation of neurodevelopmental status in at least some specialty low and middle-income country settings.

The Mullen Scales of Early Learning

The Mullen Scales of Early Learning (MSEL, 1995) is an assessment of the cognitive functioning of young children from birth to 68 months. It is considered diagnostic for developmental delays and was normed in three phases from 1981 to 1989 on 1849 children between the ages of 2 days of life through 69 months old who had no apparent mental disability
and who resided in the United States (Research Department, 2005). The test-retest reliability of the MSEL was evaluated on a sample of 50 children for the 1 to 24 month age group. The children were each tested twice a mean of 11 days apart. The gross motor scale had a test-retest reliability of 0.96 and the other four scales had test-retest reliability in the 0.82 to the 0.85 range. The construct validity as measured by the progression of scores based on chronological age shows a steady increase over time in mean raw scores, indicating that there is reason to believe that there is good construct validity (Mullen, 1995).

The MSEL assessment requires the use of the MSEL official testing kit and manual and is based on the child’s responses to activities prepared by the examiner in a setting free from distraction. The MSEL measures five distinct skills, Gross Motor and four “cognitive” skills—Fine Motor, Visual Reception, Receptive Language, and Expressive Language. The gross motor scale is administered to children from birth to 33 months and the four “cognitive” scales are administered to children from birth to 68 months. The fine motor scale is included in the cognitive scales because it involves both visual and motor skills and reflects the output of visual organization (M. Boivin, personal communication, January 25 2013). The “cognitive” scores are summarized into an Early Learning Composite (ELC) score. The ELC, can be used as an overall estimate of cognitive development for age reflected in a standardized score for age with a standard deviation per age range. An approximate average ELC score for children of 1 to 24 months of age would be 99.73 with an average standard deviation of 14.2. This score along with the standardized scores for each of the 5 scales (see appendix A) can help to determine whether a child needs referral to a neurodevelopmental program and/or if there are activities that caregivers could undertake with the child to stimulate the brain and strengthen neurodevelopment (Mullen, 1995).
Healthcare providers from the disciplines of medicine, nursing and psychology can be trained to reliably administer the MSEL in about 4 weeks’ time. An effective method is to have the providers participate in several days of didactic instruction on the MSEL, prior to beginning observation of trained testers with children. Finally the trainees practice first with other trainees in mock testing situations and then move on to practicing testing with mother/child volunteers. After the initial training, the providers practice the assessment at least two to three times per week for approximately 2 to 4 weeks to become proficient. Initial time of administration will be slower than an experienced tester as the provider begins actual administration, but improves rapidly with repetition (M. Boivin, personal communication January 25, 2013).

The MSEL was chosen for the project based on the reliability and validity of the test in general, but more specifically because it corresponds well with Bayley Scales of Infant Development (BSID) (Bradley-Johnson, 2001), which is often considered a gold standard in assessment of child neurodevelopment. The MSEL cognitive scales have the highest correlation (.53 to .59) with the BSID Mental Development Index and much less so (.21 to .52) with the BSID Psychomotor Index, which according to Mullen (1995) indicates that the MSEL cognitive scale are truly measuring cognitive and not motor abilities (other than the gross motor scale). This is reinforced by the fact that the Early Learning Composite (ELC) score correlated well (.70) with the BSID Mental Development Index. However, the MSEL can be taught to potential administrators with greater ease than the Bayley and testers can successfully administer the MSEL in less time than the BSID battery would take (Boivin, M., personal communications, January 25, 2013 & March 18, 2016). Another reason for the choice of the MSEL is the fact that the test has been used with success in several previously mentioned studies with Uganda children with apparent success (Bangirana, et al, 2015; Bass, Nakasujja, Familiar-Lopez, Sikorskii, et al, 2016; Boivin, Bangirana, Nakasujja,
Page et al, 2013; Brahmbhatt, et al, 2014; Brahmbhatt, Boivin, Ssempija, Motuvu, et al. 2012; Busman, Page, Oka, Giordani et al, 2013; Busman, Page, Bass and Boivin, 2012; Brahmbhatt, et al. 2010; Busman, et al. 2012) and specifically with nurses as assessors in a study in Benin (Koura et al., 2013). Knowing that nurses have been trained in its use elsewhere is important because that study showed that it was feasible to utilize nurses, at least in that circumstance, to administer the MSEL.

**Nurses as Potential Neurodevelopmental Assessors**

Regardless of which neurodevelopmental assessments are chosen for the testing of children, they require precise administration. In most places in the developed world, psychologists and physicians are often the ones administering this type of testing. However, psychologists and physicians are in short supply in the developing world, which leaves a need for another cadre of providers to become well versed in neurodevelopmental testing and nurses seem to be a reasonable way forward.

In Uganda 11,673 nurses and midwives were licensed by the Uganda Nurses and Midwives Council (2015). Currently no World Bank data exist on the number of nurses per population (nurses per 100,000 population). Within the MU/JHU clinic there are 78 nurses and 39 physicians (including trainees), so nurses make up the bulk of the healthcare staff in the clinic. At this time, nurses in the MU/JHU clinic and in Uganda overall do not administer any formal developmental screening or assessment. The Uganda Health Sector Strategic Plan (2010) addresses maternal child health and focuses on antenatal care, safe birth, nutrition and infectious diseases, but it is notable that there is no specific reference to neurodevelopment in the plan.
A growing body of evidence that nurses can achieve clinical outcomes comparable to physicians in several areas of practice. A 2009 Cochrane Review on patient outcomes and patient satisfaction when nurses took over care aspects that physicians had historically been responsible for indicated that for most areas of patient care no differences between the two sets of providers were apparent. The 13 patient outcome studies included in the review ranged from 1973 to 2001 and involved both chronic care as well as urgent care. The patient outcomes were remarkably similar between physicians and nurses for almost all types of care (Laurant, Reeves, Hermens, Braspenninig, et al. 2009). A more recent meta-analysis of twelve randomized controlled clinical trials, comprising 22,617 patient outcomes where physician-nurse task shifting was studied in developed countries (mainly in Europe) was conducted by Martinez-Gonzalez, et al (2015). The studies reviewed focused on care of patients ranging from those with common and acute minor illnesses to HIV care to acute heart failure. Overall results revealed that nurses’ patient outcomes were comparable to physicians and were somewhat better in the areas of secondary prevention of cardiac disease and in lowering cardiovascular risk in diabetic patients (Martinez-Gonzalez, Tandjung, Djalali, and Rosemann, 2015).

The last several years have also seen a movement toward nurses providing a greater range of care and antiretroviral treatment to both pediatric and adult HIV-infected patients in several African countries. This phenomenon has occurred out of the need to consider alternative models of care beyond the limited supply of physician providers in order to reach more rural populations and due to an overall lack of healthcare infrastructure and financing. This phenomenon may also being influenced by the advancement of nursing education into the baccalaureate area and beyond in some low and middle income country settings. Pilot project and study outcomes in this area have all indicated that patient outcomes are as good, or in some cases better, when nurses
provided care, compared to physicians (Callaghan, Ford, and Schneider, 2010; Shambuso, van Griensven, Lowrance, Turate, et al. 2009). One pilot of note was the implementation research conducted by the Namibian Ministry of Health called the Task Shifting Demonstration Project. This project was a mixed method evaluation of physician, nurse, and patient perceptions of task shifting as well as an evaluation of quality of care provided by nurses as compared to physicians. The results indicated that both groups of providers as well as patients had a favorable view of shifting routine ARV treatment services from physicians to nurses. The results also showed a 90% or greater correlation in 8 of the 13 care indicators between nurses and physicians as assessed by expert senior clinicians. The remaining 5 indicators had an 81.3 to 87.5% correlation between the two sets of providers. The authors concluded that nurses performed very well and felt additional clinical mentoring would increase the correlations in indicators that scored below 90%. (O’Malley, Asrat, Sharma, Hamunime, et al., 2014). The outcome of this pilot is very encouraging and speaks well of nurse lead care in this setting.

One of the largest efforts to document whether nurses are as capable as physicians in the provision of ARVs and care to HIV patients was conducted in South Africa and was a cluster-randomized trial between Jan 2008, and June 2010. Thirty one primary-care ART clinics in the Free State province were randomly assigned to implement the Streamlining Tasks and Roles to Expand Treatment and Care (STRETCH) program (intervention group) or to continue with standard (physician led) care (control group). Patients were stratified into two cohorts, the first included adults (aged ≥16 years) with CD4 counts of 350 cells per μL or less who were not receiving ART. The second cohort included adults who had already received ART for at least 6 months. The primary outcome in cohort 1 was time to death and the primary outcome in cohort 2...
was the proportion of patients with undetectable viral loads (<400 copies per mL) 12 months after enrollment.

The intervention group included 5390 patients in cohort 1 and 3029 in cohort 2. The control group included, and 3862 in cohort 1 and 3202 in cohort 2. The median follow-up was 16·3 months in cohort 1 and 18·0 months in cohort 2. In cohort 1, 20% of the patients in the intervention group and 19% in the control group had died by the end of follow-up. Time to death did not differ (hazard ratio [HR] 0·94, 95% CI 0·76-1·15). In cohort 2, viral load suppression 12 months after enrollment showed no difference between the intervention and control group (71% versus 70%). The authors concluded that that nurses could safely initiate and follow HIV positive patients with no difference in patient outcomes when compared to physician providers. (Uebel, K., Fairall, L., van Rensburg, D., Mollentze, W. et al. (2011).

A specific example of nurses’ ability to administer the MSEL neurodevelopmental testing comes from a study conducted in Benin. This study included neurodevelopmental assessment of 357 children born to mothers who had been enrolled in a trial comparing 2 prophylactic drugs for malaria. Nurses were trained by a Bachelor’s level psychologist to administer the MSEL. A pilot study of MSEL testing for 32 children was undertaken where nurses’ MSEL scoring was audited and reviewed by expert testers prior to the enrollment of the remainder of the children. The researchers deemed that the nurses’ administration was feasible in this setting, since their testing produced mean composite scores similar to the expected standard scores with good intra nurse reliability of scores (Koura et al, 2013). In light of the evidence regarding nurse delivered care and the successful nursing administration of the MSEL, as demonstrated in the Benin study
(Koura et al, 2013) nurse administered MSEL administration, at least in specialty clinics, should be considered given the established need for such testing.
Chapter 3:

Project Methods

Project Design

This study was an observational pilot study using mixed methods to determine the feasibility and acceptability of inclusion of a neurodevelopmental assessment, the Mullen Scales of Early Learning (MSEL), (Mullen, 1995) into standard clinical nursing practice for infants and children at the Makerere University/Johns Hopkins University (MU/JHU) Research Center. Selected clinic nurses were trained to administer the MSEL. Upon completion of training, the nurses enrolled and administered the MSEL testing to 80 children < the age of 24 months.
Chronological Sequence of Project Events

**Figure 2. Project Diagram**

**MSEL Administering Nurses Training.** The five selected MSEL administering nurses were trained on MSEL administration in an initial 5-day comprehensive training in January 2013, led by Dr. Michael Boivin, PhD (the lead expert and training on MSEL in Uganda)(Appendix B). Training consisted of didactic lectures on child neurodevelopment overall, and the Mullen Scales of Early Learning, specifically. Videos and live demonstrations of MSEL testing by expert testers was also included. To initiate MSEL administration the nurses first engaged in role play
MSEL testing with their colleagues and graduated to practice testing with child volunteers. Certificates marking successful completion of required training were issued to all five of the MSEL administering nurse participants. (Appendix C). Subsequent mock practice sessions and refresher trainings were held periodically between the end of the initial training and prior to the start of the study, which began enrollment in April of 2015.

The initial training schedule was as follows:

Day 1 – Overview of the MSEL and Overview of MSEL testing materials

Day 2 – Observe MSEL testing with question and answer period afterwards

Day 3 – Watch videos of Mullen testing in other settings, practice MSEL with other nurses, practice hand scoring of MSEL, discussion of strategies for testing with young children

Day 4 – Review of adaptations made for the African setting, overview of how the MSEL has been used in research, practice testing of MSEL and practice hand scoring of MSEL

Day 5 – Overview and debrief of week

Weeks 2 to 4 – practice MSEL with experienced testers at least 2 to 3 times per week.

**Infant MSEL Assessment Visit.** Potential infants’ caregivers were approached in either the MU/JHU clinic or the Mulago Hospital well child and family planning clinics to explain the study. If the caregiver indicated a willingness to participate in the study, she was introduced to a Nurse Counselor, who administers all informed consents for studies conducted at the MU/JHU clinic. The Nurse Counselors went through the informed consent process and the Informed Consent document. Prior to mother’s signing of the Informed Consent, the Nurse Counselor assessed their understanding of the study to ensure fully informed consent.
Next, the infant had vital signs and anthropometric assessments taken. Caregivers were asked to answer brief assessment questions regarding the possibility of acute illness and malnutrition in the infant. If, during the screening process, infants had indication of current illness (abnormal vitals, irritability, URI symptoms, etc.), a history of illness that would increase the potential for neurodevelopmental delays (birth anoxia, history of malaria or other serious illness) or were severely malnourished (below the 3rd percentile on the WHO Growth Chart) they were deemed ineligible for the study. Only one infant screened was deemed ineligible due to irritability from a recent immunization.

Once the caregivers/infants were screened and deemed eligible the MSEL administering nurse explained the MSEL testing to the caregiver and commenced with the MSEL testing. The scores were not discussed with the mothers, as they required quality assurance checks by both the administering nurse as well as the quality assurance nurse and this project only allowed for a one time visit. Therefore, the MSEL administering nurses would limit their remarks to the fact that the testing was successfully completed.

Upon completion of the MSEL testing a second nurse, not involved in the visit thus far, administered the Caregiver Exit Questionnaire and the caregiver and infant were then thanked and given travel reimbursement and offered lunch (which is available to all clinic attendees).

**Post MSEL Administering Nurse In-depth Interviews.** Following completion of MSEL testing for the 80 infants, the author interviewed the five MSEL administering nurses using the
interview guide. The interview was audio recorded and the researcher took notes during the interview.

**Post MSEL Demonstration Session.** After completion of all infant MSEL testing and the individual in-depth interviews with the MSEL administering nurses, a demonstration of the MSEL assessment for nineteen non-administering clinic and hospital nurses, who agreed to attend. The non-administering clinic nurses were consented using the Nurse Informed Consent Form, and at completion of the MSEL demonstration were asked to complete the Nurses’ Post Demonstration Questionnaire.

**Study Population and Sample Size**

**Nurse Participants.** A Nurse Coordinator and four other nurses were trained in MSEL testing by neurodevelopmental specialists. These nurses were selected from a pool of 78 total MU/JHU nurses based upon experience in other clinic studies, interest, and recommendations by MU/JHU Clinic Medical Director and the MU/JHU Director of Nursing. The Nurse Coordinator recruited the mother/infant participants and performed MSEL testing for many of the infants.

A convenience sample of 19 non-administrating MU/JHU clinic and Mulago Hospital nurses participated in the post MSEL Demonstration Session. They were self-selected in response to broad solicitation to participate in the demonstration session posted to all MU/JHU clinic and Mulago Hospital well child clinic and family planning clinic nurses. During this session, non-administering nurses gave feedback via the Nurses’ Post Demo Questionnaire.

**Caregiver/Infant Participants.** Eighty infants ≤24 months of age and their caregivers were recruited between April 2015 through June 2015 for MSEL testing. They were recruited either
during a PROMISE study visit in MU/JHU clinic, from the prevention of mother to child program or from the Mulago Hospital well child immunization and family planning clinics. All infants were well at the time of MSEL testing, with no evidence of severe malnourishment or other serious acute or long-term health problems.

Study Evaluations/Data Collection

Instruments.

Mullen Scales of Early Learning. The MSEL instrument (Appendices D - I) assessment characteristics were previously discussed in Chapter 2. The assessment of the nurses’ administration times for each assessment were evaluated by the recording of the start and stop times on each of the infants’ MSEL testing forms by the respective MSEL administering nurse.

Mullen Scoring Rubric for the PROMISE Neurodevelopment Study. The Mullen Scoring Rubric for the PROMISE Neurodevelopment Study Rubric (Appendix J) was developed and used in the PROMISE and other studies by Dr. Michael Boivin and associates, who are considered experts in the administration of the MSEL assessment. The rubric is used to evaluate a tester’s accuracy and efficiency of MSEL administration including tester performance on each of the 4 cognitive MSEL scales (visual reception, fine motor, receptive language and expressive language). The evaluation of each scale includes whether or not the nurse administrator explained the items/task correctly to the child, how the nurse tester managed the testing manual/materials and minimized unwanted stimulus during the testing, as well as the nurse tester’s seeming familiarity with each of the test items. Other rubric categories for each scale evaluated include the nurse tester’s efficiency/fluidity of administration, their use of the correct test items for each task and whether or not the tasks followed the expected order for item presentation within a given scale. The rubric also allows for general comments from the expert reviewer. Each of the six mentioned
categories are scored from 0 (poor) to 3 (excellent) and a total score is calculated (72 is highest possible) based on the sum of the 6 categories for each of the 4 scales.

**Caregivers’ Exit Questionnaire.** This questionnaire (Appendix K) was developed to assess the caregivers’ overall level of acceptability of MSEL testing, and specifically to identify any concerns with the testing as well as for collection of demographic information on caregivers. The questions were either multiple choice, polar, or open ended. In addition to basic caregiver demographics, the questions addressed whether the caregiver perceived any problems with the testing and whether or not the caregiver would allow future testing.

**Administering Nurses’ Interview.** Semi-structured Interviews with nurses who were both trained in and conducted the MSEL assessments were carried out by the principal investigator. Interviews were audiotaped and notes taken. The interview guide (Appendix L) elicited the administering nurses’ views on acceptability of incorporating the MSEL into clinic practice. Questions were open-ended and included nurses’ perceptions of their enjoyment and concerns of learning and performing the MSEL, and whether or not they would like to continue to improve their skills in MSEL administration. Questions also explored their thoughts on feasibility from their time and work perspective. Basic socio demographics were recorded such as years of nursing experience and level of education.

**Nurses’ Post Demonstration Questionnaire.** This questionnaire (Appendix M) was developed specifically to elicit the opinions of clinic and hospital nurses who attended the Post MSEL Demonstration session, but did not participate in the MSEL training and administration. Questions were either multiple choice, polar, or open ended.
Questionnaires were completed after the MSEL administering nurses gave a demonstration of performing the MSEL with a volunteer parent and child. The questionnaire was meant to capture the non-MSEL administering clinic and hospital nurses’ level of potential acceptability for learning and incorporating the MSEL into their nursing practice. The questionnaire also aimed to identify any perceived barriers to training and incorporation of the MSEL.

Two of the MSEL administering nurses organized and led this activity and clearly delineated the purpose of the meeting. Prior to the demonstration the nurse attendees reviewed and signed the Nurse Informed Consent Form.

The nurse expertly administered examples of items from each of the five scales of the MSEL. The child being tested was typical in that she was very interested in the items at the start of the testing, wanted to keep some of the test items as she went along, and then became tired as the testing wore on. The administering nurse demonstrated the test items and ways to renew a child’s flagging interest and soothe them to successfully complete the testing.

After the MSEL demonstration was completed questions were invited from the non-administering nurse attendees, who were very engaged and curious. At the conclusion of the hour-long session the non-administering nurse attendees were requested to fill out the Nurses’ Post MSEL Demonstration Questionnaire.

**Data Analysis Plan**

**MSEL Administering Nurse Training.** Each of the 5 MSEL administering nurses’ training was evaluated for completeness and included attendance at lecture sessions, viewing of testing videos, and participation in mock practice sessions.
**In-Depth Interviews.** Interview topics included the MSEL administering nurses’ desire to continue administering the MSEL in the clinic setting and their speculation about whether other nurses would be interested in learning and administering the MSEL. Finally, questions also touched on whether their experience had changed their nursing practice and what they saw as facilitators and challenges to incorporating the MSEL into routine nursing practice.

An inductive analysis approach was used, since little was currently known about nurses’ experiences and views regarding incorporation of neurodevelopmental assessment into nursing practice in this or comparable settings. Taking an inductive analysis approach meant that patterns or themes rose from the actual data rather than being informed by preconceived notions or theory.

After the interviews were completed a thematic analysis of the data was performed following the steps as outlined by Braun and Clarke (2006). During the first phase of analysis the author became familiar with the recordings by listening to and transcribing interviews (phase I). This initial phase also included reading and rereading of the individual interviews in order to become intimately familiar with the content of the interviews. The second phase of analysis included first pass codes being applied to chunks of text. After the first pass coding was completed the interviews were reread and when new codes emerged these were added to the list. The third phase of data analysis began with the search for themes once the initial rounds of coding were completed. After the initial set of themes had been developed, they were then reviewed and refined (phase IV). The themes were then given names and a thematic map was fleshed out (phase V).

**Questionnaires.** The Caregiver Exit Questionnaires and the Nurses’ Post Demonstration Questionnaires were reviewed for completeness, entered into MS Access (Kampala, Uganda,
2007) and analyzed using descriptive statistics. The open-ended comments sections of each questionnaire were reviewed, coded into response themes, and representative quotes from those sections are presented.

**MSEL Scores.** The MSEL scores were plotted using histograms and QQ Plots to test for normalcy of distribution and were used as a marker for nurses’ accuracy of testing, an important measure of feasibility. The Shapiro Wilk test was also performed to measure normality of the scores.

The MSEL scores obtained in the clinic were entered into the database MS Access (Kampala, Uganda, 2007) by trained data entry staff at MU/JHU clinic. There was a data entry quality assurance (QA) plan in place for all data entered at MU/JHU. MSEL score data cleaning activities were performed in real time and included rechecking of scores by a second nurse and by the data managers upon entry into the database. Once the score database was complete, consistency checks for extreme values in scores, missing values, and the distribution of values were performed.

**MSEL Administration Times.** The median administration times for all MSEL administering nurses were described against generally accepted administration times. The scores were stratified by age into two groups, since expected administration time varies for each age category.

**Human Subjects Considerations**

**Institutional Review Boards.** The project was reviewed and approved by the Catholic University of America (CUA) Institutional Review Board (IRB) and the Joint Clinical Research Centre (JCRC) IRB, and the Mulago Hospital IRB. Once the CUA and JCRC approvals were
received the protocol was submitted to the Ugandan National Council on Science and Technology (UNCST) who also reviewed and approved it.

Confidentiality. The Caregiver Exit Questionnaires, the Nurses’ Post MSEL Demonstration Questionnaires, and the in depth-interview transcripts do not contain any identifying information. No actual identifying information was kept with the notes or transcripts. Infant or parent names were used directly on the MSEL administration and scoring sheets, but no names or other identifying information will be referred to in any publication of the results of the project. All paper assessment records, informed consents, audiotapes and videotapes are kept in a locked cabinet to which only the author and data manager have access.
Chapter 4:

Results

Feasibility and Acceptability for Nurses

Qualitative Results.

*In Depth Interviews with Nurses who administered the MSEL.* The five MSEL administering nurses ranged in age from 36 years of age to greater than 50; years of nursing practice ranged from 6 to more than 25 years. Nursing education level varied from Diploma in Nursing for four of the five nurses to a Masters in Nursing for the remaining nurse.

*In Depth Interviews with Nurses who administered the MSEL.* Interviews were centered on the nurses’ experience in learning the MSEL as well as their confidence and thinking as the study progressed. Qualitative analysis led to the development of overarching themes. The first theme, a transformative experience for study nurses, included changes in their nursing knowledge, nursing practice, and nursing roles. The second theme, transforming nursing practice for the clinic and the wider nursing community, included facilitators and challenges to acceptability, and solutions for implementation. Each of the major cross cutting themes and the major codes within them are discussed below. Quotes from all of the interviews are included, but due to confidentiality concerns with such a small and familiar sample they are not identified in any way in the text.

**First Theme: Transformative Experience (Study Nurses).** The theme of a transformative experience came through the discussions about how learning and performing the MSEL had changed the nurses’ knowledge, their clinical nursing practice, and their roles. Nurses’ experience with the MSEL also opened their eyes as to what was possible for them and for the babies in the clinic and the community.
**Nursing Knowledge.** Nurses indicated that learning the MSEL had been uniformly positive for them because it provided them a new skill and because they felt the knowledge gained from learning the MSEL was more applicable broadly. Nurses mentioned integrating the knowledge gained from testing to the way they viewed all children in the clinic setting as well as at home and other settings. One nurse talked about the almost automatic observation of children that has occurred as a result of learning the MSEL.

“Like I said, the first thing that we now look at children and that because you know part of the testing, like ‘Bye’ whatever then you see that age group, the baby is “Bye” and clapping so, you that this baby is performing well.”

The interviews strongly reflected that there was an increase in the nurses’ critical thinking about pediatric neurodevelopment. Several of the nurses indicated surprise that milestones were not just physical signs that were assessed, but that they are a visible link between the physical and cognitive development. A nurse, in the quote below, illustrates this transformation in thinking very well.

“It’s transformed my thinking about babies from the physical development and the mental development....when a baby holds their head up, which is a developmental milestone I look at it physically and psychologically. So, I am really happy about it. It has changed my thinking about pediatric development.”
Nursing Clinical Practice. In addition to using the knowledge gained to assess and interact with children in the clinic the nurses indicated that knowing this information had increased their concern for the developmental welfare of the children in the larger community, as illustrated by the quotes below.

“…because at first we never knew that those things are good to babies, but now our country realize that we missed before those that have not done the Mullen…it has helped me a lot because you can recognize and see how the baby is performing.”

“I think it [MSEL] would be something helpful…I think yes, I have been working with children for a long time and I felt that something was missing.”

“…So, when you do the Mullen you bring out all of the signs of milestones within this baby, so I think that it is crucial that these babies’ Mullen should be done periodically?.”

“…so when you add the Mullen, the mothers and babies start to benefit a lot and so would the nurses to get expanded skills and of course the country would get to understand where we stand with the psychological development of our children…”

The quotes above also speak to the expanded skills nurses felt they had gained and how those skills had or would transform their practice. The quotes below are further evidence of expanded skills, which enriched their clinical practice and, were perceived to make them more marketable.
“I think it has enriched my practice. It has opened my eyes to a new procedure altogether and a very, very good one and not only that when I look at babies, even outside this clinic,...when a 3 month old smiles I would now give them a mark. It is real. I want to give that baby a score.”

“Ok, that experience as a nurse can develop my career, my nursing process, because even when you talk about it people say, ”you have some value added”. Doing it you really have some value added. I think it is important.”

“All nurse welcome expanded skills because it adds value to the nursing practice. It also widens your scope of employment, you know, those are good benefits.”

Another interesting phenomenon that emerged was that administering the MSEL with children transformed the way in which the nurses related to the babies and the mothers. The process seemed to positively influence the rapport between them as it was seen as helpful to the mothers and fun for the children, as one nurse commented below.

“The way you interact with these kids. Even the way these kids respond. Sometimes after Mullen you find a child outside there the way he welcomes you from other people you may feel at least this child is grateful, although he is young. ...Maybe you tell the mother that you have seen him doing something. Some of them even laugh or clap knowing that their child can do such things. So, it has helped us a lot as nurses through the interaction with this child and mother. Sometimes they even come back and say, “we will play today?” ...It also creates that he is your friend...you see the child coming and he grasps you.”
**Expanded Nursing Role.** The nurses indicated they gained confidence as they went along learning and then practicing the MSEL administration and they discussed becoming more expert at the skill.

“I feel good about this experience and I know that if I am giving a demonstration I will do it with confidence…”

“As we went along I gained more confidence and I felt more comfortable. Also, what made me more comfortable that as we went along I came to learn more and more about the testing items. First what they were…”

The nurses were also very proud of having participated in and led the study, as this is not traditionally the way that studies have been conducted at the clinic. Nurses are a vital part of any study done in the clinic, but have not typically been largely responsible for entire studies. The nurses led the project as Co-Principal investigator and study coordinator, worked with data management staff to set up the database, performed the MSELS, and quality controlled testing data. They also managed the Institutional Review Boards procedures. Two quotes to illustrate their pride in the experience are below.

“We did this study with the doctors’ support, but the nurses did it.”

“What is the next study that we are going to do?”
Second Theme: Transforming Nursing Practice for Wider Community.

Facilitators to Acceptability. Facilitators to acceptability of MSEL testing are broadly divided into factors related to the nurses and those related to the mothers and babies.

Nurses. Adequate training and preparation for MSEL testing were practical requisites for acceptability. Ways to increase the broader nursing community’s knowledge of the MSEL, the ideas that the knowledge? (or is it the testing results – not sure) is broadly useful and provides valuable information about the health of the children in the clinic and broader community were also identified as important.

The following quotes elucidate what could facilitate acceptability of MSEL testing for individual nurses or for the nursing community at large.

“OK, what I liked at first, I thought we couldn’t test babies because they were too young and couldn’t get anything out of it...but, as we go on I learned even the small babies you can get something. At first I thought it was impossible the babies would grab the things and do everything which they don’t do so, that was something interesting to me.”

“Yes, I would like to do it. As a regular clinic procedure? It is very good...The advantages are that you are able to detect where there are problems with the development...maybe the baby cannot perform well then you may refer the baby to neuropsyche or pediatrics so that they can advise for management...you also appreciate babies that perform well their tasks.”

“It’s a good idea they [other nurses] can also be trained about Mullen testing because it is good for each and everyone to know. Because sometimes we don’t know how well babies are performing so, it’s good for them [other nurses] to learn about Mullen testing and to do it.”
Mothers/Babies. Nurses indicated that mothers had gained significant and often transformative knowledge about what their babies were capable of and often requested repeat/serial MSEL testing to monitor the babies’ neurodevelopment progress as indicated by the quotes below.

“...it’s a skill that the mothers have loved and the babies have enjoyed and what is even more important is this aspect of looking at critical development of the baby hasn’t actually been done routinely in this country.”

“The most of the babies feel happy after they test. Those ones you do a test on a young babe of 2 months and the mother they may not even know the child can do something and you get the bull’s eye and you shake it and the baby starts looking and then the mother can be surprised like “eh, wow, even this baby can see those things.”

“...because when we are doing the Mullen testing the mother is asking us and the team will you come back to do the same thing when our babies are like 1 year, 2 years, 3 years because it has helped us to know how our babies are performing...”

“...Very good for the babies and all the mothers will ask, you know there is an exit questionnaire, and 100% of the mothers on the exit questionnaire the question is if we ask you to bring this baby back for this test, All the mothers, 100%, have said I definitely would bring my baby back.”
**Challenges to Acceptability.** Nurses identified several challenges to administering the MSEL. Perceived challenges were expressed that related to the nurses themselves or their perceptions of nurses’ potential actions were the MSEL to be incorporated more widely. Others challenges came from the mothers and the babies and the largest issues were system issues that would need to be addressed for MSEL testing to be incorporated into nursing practice on a broader basis.

*Nurses.* The quotes below illustrate the challenges that nurses themselves faced or would foresee with other nurses should MSEL testing be a required procedure.

“Yes, it *(practicing in front of the other trainees)* was making me nervous because, like I said, it was the first experience and you have to read and in the back of your mind you are thinking I am taking all of this time reading and they are watching and waiting...”

“When I first had testing anyway I was nervous and I was with my bag so, I was reading and asking the mother and being watched took 2 to 3 hours to complete. By the time I completed my baby was sleeping.”

“... I was very nervous that something would happen and the baby would not complete the test. I was so anxious for the baby’s perseverance. I was also very anxious for the mother’s patience throughout the 5 scales.”

“Oh yes, some people have different attitudes. So, you may find that some people may think that those ones doing Mullen are paid better than us. They may start complaining that you know we here are 2 and that one spends her time only with the Mullen. She doesn’t help the hospital ones.
I am all for it but, actually those things have to be there…I think if the pilot study works out I think it should be a policy that should take place. I can give you an example. People are knowledgeable about prevention of mother to child transmission of HIV (PMTCT) but, they are not practicing it…there are some people with those attitudes, don’t care attitudes.”

Mothers. Nurses voiced challenges related to the mothers’ time, managing their home responsibilities and appointment times with respect to the child’s alertness. Early morning is the optimal time to have the child fresh, awake and rested. When administered at a later time the actual testing becomes more challenging to accomplish. The following quotes illustrate the problems and potential effect.

“There are some mothers who come to the clinic to immunize babies when they have run out of their offices, when they have run out of their homes. They don’t have maids and she has left the other kids with a neighbor. So, time for both the health workers and the mother.”

“Sometimes you can’t change. Anyways there are mothers who always come late. They can report by 11:10 whereby some babies at that time are sleeping, So, we always tell them, emphasize to them be a little bit early and you can’t even count on them to come because they always say had the problem I had to go somewhere so, that is why I am late”.

System. Nurses identified significant healthcare system challenges including time, low staffing ratios, physical space needed for testing, budget for training and implementation, and an overall overburdened health care system. These challenges would need to be addressed before considering incorporation of MSEL testing into nursing practice. The quotes below exemplify some of those identified challenges.
“The barrier, I think it is time. Time for mothers, because if you are few testers mother will have to wait.”

“Our health system, as you have seen since you have been coming here, the system is clogged. You know, so many patients, so many babies, so the system is a problem. If the system wasn’t a problem it would be very, very good here at MUJHU.”

“Space may a barrier. Human resource. The health sector has few people. Skills, willing to train. You need to train all nurses on how to administer this Mullen, so you need some budget of training. You also need to train to collaborate with other stakeholders because you cannot just jump. So, time for both the health workers and the mother. Because the health worker is given another task she has to be topped up. So, that one may feel like....as much as we may want the system to adopt, but the personnel may say you have put another task on top of what I have been doing and you cannot be with specific Mullen testers every time. So, the budget thing and the sustainability of that budget. Things may start, but how to sustain it. Sometimes it may come as a policy, but sometimes the government may fail to sustain things.’

**Solutions for Implementation.**

Training. Nurses mentioned several ideas for how training for how MSEL testing might be rolled out including perceptions of critical components. Adequate training, including actual practice, videos of expert testers, and knowing the procedure manual were identified as critical components for incorporation of the MSEL into clinical practice. Nurses’ quotes below touch on some of these issues.
“I think that you really have to be practicing that because understanding the instructions are in the book. At times you don’t want to overtire this baby you are reading. As you practice a lot you get those things stuck in your head and now you know.”

“...we had liked the viewing the videos of different testers and looking at the errors that they make and looking at the good things we do. What is very interesting is how the Mullen testers keep the babies interested...”

**Time Management and Clinic Organization.** Time management and clinic organization were discussed at length with respect to implementation, as they were considered very important, given the current demands on time for nurses and for mothers. The quote below really summarizes nicely the various discussions about these issues.

“I think it needs some organization in the clinic....If there are 10 mothers and babies and they are all to be done Mullen, as they are doing Mullen, maybe 2 others are going through other procedures and because maybe if there a number of staffs, then each staff can do. But if you are like 2 people doing 10 then there is not time and it is not possible to do...so I was having an imagination of very organized clinic, like the immunization clinic where they get 50 babies a day, there I think they cannot work on all of them. There I think they would have to give appointments to come back because to so something that takes some time...so, it is doable, but on a number of babies a day...It is hard to do everyone...maybe you select specific babies, I don’t know.”
Policy. Policy regarding making the MSEL part of routine nursing care was regarded as critical to get buy in from a wider swath of the nursing community. If the procedure were seen as an “add on” instead of routine practice/requirements then commitment to MSEL testing as well as issues of salary were seen as being much more problematic.

“So, if it’s to work I think every medical person has to be trained and maybe it is incorporated into the syllabus for the nurses so, that even new nurses that are coming out, they come out and they know about what the Mullen is and how it is done....the minute you tell the mothers you know you want to test the baby to know how the neurodevelopment is, ”Ah, that is great, that’s great. Then I come to know how my child stands.””

“OK. they would not see this testing without seeing it from the perspective of it being a routine...but now I am looking at it being incorporated, the testing, the ministry has approved it and now it is part of a routine. I think that is the way we explain it to staff. Otherwise, people would be saying I am taking temperature I need money for this, but I am saying it as being incorporated into routine and people understanding that this is part of what we are supposed to do...I don’t see people saying they need special pay.”

“Anyway, if it is put in addition to what we are doing they make it a routine, I don’t think people will complain. But, if it is put as a side thing they will say they are giving us so much work, salary is still the same so, they will be complaining about that increment, but if it is put into action that we need to do this and this and this and we do vitals, I think they won’t complain.”
**Settings to Increase MSEL Testing.** The nurses were very creative in thinking about ways to test more infants and children in the current system and suggested several possible settings to increase the number of children tested with MSEL.

“But I think in time if it were incorporated maybe we would train out in the centers, out in the hospitals, but then that would be a very wide thing and you would need supervision and follow-up of the nurses…”

“It would be nice to continue doing the Mullen, especially maybe on pediatrics wards, maybe in other studies with children. I think it would be something helpful…I think yes, I have been working with children for a long time and I felt that something was missing.”

“…I can see this testing taking place in the kindergarten and in the schools it would be expanded…and in the very first classes of primary education…but of course, you have to have a good system laid out for the data to be used, to be translated into practical use. What does it indicate we must do?”

**Framework of Transformation**

Transformation was the cross cutting theme from the analysis. Data indicated that study nurses had experienced a transformation in their nursing knowledge, practice, and roles as a result of learning and administering the MSEL testing and in taking on a significant responsibility in the study. Nurses indicated their knowledge and thinking about infant and child neurodevelopment had been transformed, which seemed to go on to help transform their nursing practice with children in the clinic and at large. Realization of their capabilities beyond the
traditional nursing roles also appeared to be transformative in the way they saw their influence and opportunities for the future.

Discussion centered on what it would take to transform nursing practice for the wider nursing community. Themes included facilitators, challenges, and the solutions for including the MSEL in routine nursing practice in the MUJHU clinic and in typical Ugandan settings.

Figure 3. Transformation Graphic

Quantitative Results.

MSEL Administration Times. Table 1 shows/displays the median administration times for all MSEL administering nurses across all eighty infants tested. They are presented by month starting with when the first infants were enrolled in mid-April of 2015 though the last infants tested at the end of June 2015. They are also grouped by age for each month, as testing times expected between the two age groups are slightly different. Accepted testing times for expert testers are generally considered to between 15 to 30 minutes for infants up to 1 year of age and from 30 to 45 minutes for children from 1 to 2 years of age (M. Boivin, personal communication, January, 25, 2013 & February 12, 2016; Mullen, 1995).
The minimum and maximum administration times for the younger group of infants do reveal outliers of very short timing (10 minutes) and a very long timeframe of (1:30). The older age group also does not vary significantly over time and is within the expected testing times. The older age group minimum and maximum testing times are slightly off expected times, but are less of an outlier than those values for the younger age cohort and not considered cause for concern.

Table 1

*MSEL Aggregate Administration Times per Age Group*

<table>
<thead>
<tr>
<th>Administration Times (minutes) 0 - 12 month infants n=59</th>
<th>All 0-12</th>
<th>April 0-12</th>
<th>May 0-12</th>
<th>June 0-12</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=59</td>
<td>N=14</td>
<td>N=19</td>
<td>N=26</td>
<td></td>
</tr>
<tr>
<td>Median</td>
<td>0:38</td>
<td>0:30</td>
<td>0:35</td>
<td>0:45</td>
</tr>
<tr>
<td>Min</td>
<td>0:10</td>
<td>0:20</td>
<td>0:10</td>
<td>0:23</td>
</tr>
<tr>
<td>Max</td>
<td>1:30</td>
<td>1:10</td>
<td>0:51</td>
<td>1:30</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>N=21</td>
<td>N=4</td>
<td>N=11</td>
<td>N=6</td>
<td></td>
</tr>
<tr>
<td>Median</td>
<td>0:40</td>
<td>0:36</td>
<td>0:40</td>
<td>0:42</td>
</tr>
<tr>
<td>Min</td>
<td>0:27</td>
<td>0:35</td>
<td>0:27</td>
<td>0:30</td>
</tr>
<tr>
<td>Max</td>
<td>1:00</td>
<td>0:45</td>
<td>1:00</td>
<td>0:55</td>
</tr>
</tbody>
</table>
The figure below shows the MSEL administration times for all five nurses over calendar time and stratified into the 2 age groups (0 – 12 months & 13 – 24 months). There is no discernible pattern to the administration times over the course of the project testing period (2 months).

Figure 4. MSEL Exam Times by Age Group
All five MSEL administering nurses had at least 1 MSEL testing videotaped and evaluated. Due to delays in getting required permissions to videotape and evaluator time constraints, the goal of having each nurse videotaped at least once every two weeks throughout the testing was not able to be met. The videos began on 05-15-15 and were completed on 06-26-15. Two of the nurses were only able to have one session videotaped, two of the nurses had two sessions videotaped, and only one nurse had four videotaped sessions for a total of 10 videos. As described in Chapter 3, an expert Mullen tester used the Mullen Scoring Rubric for the PROMISE Neurodevelopmental Study tool to evaluate each of the videos.

Each scale/category being evaluated is scored from 0 to 3 with 0 being poor, 1 being adequate, 2 being good and 3 being excellent. A minimum total score of 24 would be considered adequate performance for the videotaped test and scores above the level of 24 would indicate increasing accuracy and efficiency of testing.

All videos, with the exception of one, indicated achievement of at least a score of 24. The one video with a score less than 24 had a score of 0 under explanation of item and 0 under efficiency of administration categories on the visual reception scale resulting in a total score of 22. The scores ranged from 22 to 61, indicating at least adequate accuracy and efficiency of MSEL administration. The table below (table 2) lists actual scores for each nurse. As seen below there is improvement over time for each nurse other than the one test with a score of 22, which seems to be an outlier and it is unclear as to why this occurred.
Table 2

*MSEL video evaluations scores*

<table>
<thead>
<tr>
<th>Nurse</th>
<th>V1score</th>
<th>V2 score</th>
<th>V3 score</th>
<th>V4 Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>33</td>
<td>51</td>
<td></td>
<td></td>
</tr>
<tr>
<td>B</td>
<td>49</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>24</td>
<td>31</td>
<td>43</td>
<td>61</td>
</tr>
<tr>
<td>D</td>
<td>27</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E</td>
<td>54</td>
<td>22</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*MSEL Score Distributions.* The MSEL score histograms and QQ plots below depict the distribution of the MSEL standardized scores for the group of eighty infants tested. QQ plots are observations that are plotted against what would be expected if the data came from a normal distribution. That is, the lowest observation is plotted against the expected lowest observation from a normal distribution, the second smallest is plotted against what the second smallest observation from a normal distribution would be, etc. If the data really do come from a normal distribution, the data should fall on a line. Marked departures from the line indicate usually non-normality. However, according to Daniel and Wood (1980), even when a sample is from normal data, it will, at times, lead to unusual QQ-plots.

All MSEL scales and the ELC appear to have normal distributions as compared to expected mean standardized scores (see Appendix A) with the exception of the Gross Motor Scales. For
gross motor, the points on the left fall below the line. This means that the lowest gross motor observations were lower than what would be expected from a normal distribution and the histogram for Gross Motor indicates a similar phenomenon, namely what appears to be a longer tail on the left side of the distribution.

The Gross Motor distribution is being skewed left by the 3 lowest scores, two of which were in children who appear to be in the expected average ranges for the other MSEL scales and for the ELC. There was one child who had a very low Gross Motor Scale score and who had well below average scores on all scales as well as an ELC that is 2.98 standard deviations below the expected average standard score.

In keeping with the findings from the histograms and QQ plots, the only p value for the Shapiro Wilk statistical test that was significant was for the Gross Motor scale. The Gross Motor p = .008 further confirms that the lowest of the observations for this scale is likely truly far below what would be expected. P values for each of the MSEL scales and the ELC are listed with each of the histograms. As evidenced below, the remainder of the MSEL scales and the ELC standard scores appear to follow an expected normal distribution.
**Figure 5.** Histograms of MSEL Gross Motor Standard Scores.

**Figure 6.** Histograms of MSEL Visual Reception Standard Scores
Figure 7. Histograms of MSEL Fine Motor Standard Scores
Figure 8. Histograms of MSEL Receptive Language Standard Scores
Figure 9. Histograms of MSEL Expressive Language Standard Scores
Figure 10. Histograms of MSEL Early Learning Composite Scores
Figure 11. QQ Plot of MSEL Scores
**Nurses’ Post MSEL Demonstration.** Nineteen MUJHU clinic and Mulago Hospital Nurses attended the Post MSEL Demonstration.

Table 3 summarizes the characteristics of the non-administering nurse attendees as well as their responses to the major questions regarding the MSEL.

The Post-MSEL Demonstration Questionnaire included questions about whether or not the nurses in attendance would like to learn to administer the MSEL. Only two (10.5%) of the nineteen nurse attendees indicated they would not want to learn to administer the MSEL and their reasons listed for this response were that the testing would take too much time and that it would be too difficult to learn, respectively. The reasons provided by the remaining seventeen (89.5%) nurses who indicated they would like to learn to administer the MSEL, can be found in Table 3. Seven of the nurses (41.2%) said their reason for wanting to learn was that it was important for the children, four (23.5%) said it would make their work more interesting, four (23.5%) indicated that they would like to learn the MSEL for their own education, and two nurses (11.8%) said they felt that learning the MSEL would help them to get promoted or get another job.

When asked about whether or not the MSEL testing could be added to routine clinic visits for children five nurses (26.3%) indicated that they did not think that was possible. The nurses attending the post MSEL demonstration universally cited the idea that it would take too much time to administer in the routine clinic setting as the major barrier to adding the MSEL. When further asked about whether nurses, as a cadre of healthcare professionals, should be administering the MSEL three nurses (15.8%) indicated that nurses should not be administering the testing. The reasons given were that it would take up too much of nurses’ time, would lead to
increased workload, and that nurses are not paid enough to take on this extra work. None of the nurses indicated they felt that nurses were unqualified to learn to administer the testing nor did they indicate that the testing should remain solely the purview of physicians and others. The quotes from the comments section of the questionnaire listed below describe some of the challenges identified and the idea that the MSEL testing is important for nurses and children.

‘If it is added as a routine examination of babies, then you really need more time for the children and nurses for this exercise’.

“Testing needs a lot of time and seems to be very hectic to the staff and the child”.

“This is a good test for children because in case of any problem in a child, it can be detected early”.

“This testing should be added to course units for nursing”.

“This kind of test is important and useful and there is a need to put it in the day to day nurse pediatric care”.

Table 3

*Nurse Post MSEL Demo Questionnaire Results*

<table>
<thead>
<tr>
<th>Age</th>
<th>Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average (need sd)</td>
<td>43.6</td>
</tr>
<tr>
<td>Min</td>
<td>25</td>
</tr>
<tr>
<td>Max</td>
<td>70</td>
</tr>
<tr>
<td>Level of Education</td>
<td>Percentage (n)</td>
</tr>
<tr>
<td>Diploma</td>
<td>26(5)</td>
</tr>
<tr>
<td>BSN</td>
<td>68(13)</td>
</tr>
<tr>
<td>Mid-wife</td>
<td>5(1)</td>
</tr>
<tr>
<td>Years of Nursing Practice</td>
<td>Percentage</td>
</tr>
<tr>
<td>1-5</td>
<td>7.7(1)</td>
</tr>
<tr>
<td>6-10</td>
<td>36.8(7)</td>
</tr>
<tr>
<td>11-15</td>
<td>31.6(6)</td>
</tr>
<tr>
<td>16-20</td>
<td>5.3(1)</td>
</tr>
<tr>
<td>21-25</td>
<td>5.3(1)</td>
</tr>
<tr>
<td>26-30</td>
<td>5.3(1)</td>
</tr>
<tr>
<td>&gt;30</td>
<td>10.5(2)</td>
</tr>
<tr>
<td>Question</td>
<td>Percentage - Yes</td>
</tr>
<tr>
<td>Want to Learn MSEL Testing</td>
<td>89.5(17)</td>
</tr>
<tr>
<td>Add MSEL to Routine Clinic Visits</td>
<td>73.7(14)</td>
</tr>
</tbody>
</table>
**Caregiver Acceptability.**

*Caregiver Exit Questionnaire.* Table 4 shows selected demographic information for the caregivers and their answers to the major questions. The study had been structured to allow caregivers of various relationships to participate with the infant, but all eighty caregivers were the mothers of the infants tested.

The eighty infants were all recruited from either the MU/JHU study clinic or the well child and family planning clinics at Mulago Hospital. The reason for the infant’s visit at one of the clinics is indicated in the Table 4, with the majority of them having come for immunization and/or mothers family planning needs. As indicated in the table the mothers ranged in age from 19 to 40 years of age, with the average being 25.6 years old. There was also a significant range of educational levels from no formal schooling (4%) to university (8%). The majority of the mothers had completed primary schooling or higher level of schooling (62%). More than 1/3 (35%) had completed some secondary schooling. All caregivers indicated they understood the Mullen testing was done during this visit only, and that this it was considered outside the usual clinic routine for their infants.

The caregivers were almost uniformly happy about the MSEL testing, with only one caregiver (1%) indicating that she was unhappy with the testing. This caregiver, however, did go on to indicate that there was nothing she specifically disliked about the testing and that she would allow the child to be tested again in the future if she were asked. The remaining seventy nine caregivers (99%) all indicated they were happy with the testing, that there was nothing about the testing that they disliked, and that they would allow their child to be test again in future should they be asked to. The quotes below from the comments section of the questionnaire further solidifies the idea that the MSEL testing was acceptable to this group of mothers.
“I have got to know that my baby has good working brains”.

“I liked getting to know my child’s mental development”.

“I have understood what my child can do and cannot do”.

“My baby was doing things that surprised me”.

“My baby has done what I never expected him to do”

“I saw that my baby was not dull”.

“I see that I need to buy playing materials for my child”.
Table 4

*Caregivers’ Exit Questionnaire Results*

<table>
<thead>
<tr>
<th>Caregivers Exit Questionnaire n= 80</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td><strong>Years (range)</strong></td>
</tr>
<tr>
<td>Average</td>
<td>25.6 (19-40)</td>
</tr>
<tr>
<td>Level of Education</td>
<td>Percentage (n)</td>
</tr>
<tr>
<td>No Schooling</td>
<td>4 (3)</td>
</tr>
<tr>
<td>Some Primary</td>
<td>25(20)</td>
</tr>
<tr>
<td>Completed Primary</td>
<td>8(6)</td>
</tr>
<tr>
<td>Some Secondary</td>
<td>35(28)</td>
</tr>
<tr>
<td>Completed Secondary</td>
<td>16(12)</td>
</tr>
<tr>
<td>Diploma/College</td>
<td>5(5)</td>
</tr>
<tr>
<td>University</td>
<td>8(6)</td>
</tr>
<tr>
<td><strong>Reason for Clinic Visit</strong></td>
<td><strong>Percentage</strong></td>
</tr>
<tr>
<td>Immunization</td>
<td>53.8(43)</td>
</tr>
<tr>
<td>Promise Study Visit</td>
<td>35.0(28)</td>
</tr>
<tr>
<td>Other</td>
<td>11.3(9)</td>
</tr>
<tr>
<td>Question</td>
<td>Percentage</td>
</tr>
<tr>
<td>Happy with MSEL Testing</td>
<td>99(79)</td>
</tr>
<tr>
<td>Allow Future Testing</td>
<td>100.0(80)</td>
</tr>
</tbody>
</table>
Chapter 5:
Discussion and Conclusion

Importance of Clinical Practice Problem

Neurodevelopmental delays effect not only the individual child, but can inflict a high social and economic burden on countries that can ill afford further loss of resources in the form of lost productivity. The false dichotomy of needing to choose between investment in children’s development and economic development must cease. There is increasing evidence that they are one and the same, especially in regards to the long-term future of nations. Lack of investment in young children by countries will almost certainly guarantee that they will not be able to realize their economic and human development potential nor meet the United Nations Sustainable Development Goal #8, which addresses equitable economic development for countries (United Nations, 2015). An integrated approach to sustainable development needs to be realized and all aspects of child health and development must be considered to be a vital part of the long-term economic development of any country (Shonkoff et al, 2012). In keeping with those ideas, the author, in collaboration with the MU/JHU team, took the first steps along the road to changing nursing practice for the MU/JHU clinic in order to address the neurodevelopment in their HIV exposed and infected population of patients.

Feasibility of Nurse Administered MSEL Testing at MU/JHU Clinic. The evidence from this project indicates that nurse led MSEL testing of select children is feasible in the MU/JHU clinic. The MSEL administering nurses successfully completed the MSEL training and were able to administer the MSEL testing with a cohort of eighty infants in a reasonably timely and accurate manner, as compared to expected times and as indicated by actual MSEL testing times, video evaluations, and MSEL score distributions.
The lack of discernible patterns and significantly improved testing times faster testing times over the course of the project testing period may be a function of the fact that there was a relatively short elapsed (slightly over 2 months) time from the beginning of the MSEL testing to completion of the eighty infant cohort. Although the median administration times for the younger infants were at the higher end of expected testing times and actually rose over time, they would not be considered so far outside the spectrum of usual to be alarming and require retraining (M. Boivin, personal communication, March 14, 2015).

Timing of administration, while an important indicator of experience and efficiency with MSEL administration is also very dependent on the mood and cooperation of each individual child tested, which is rarely consistent from child to child. One of the challenges of MSEL testing (and most other such testing) is to maintain the fidelity of the testing while managing each child’s own personality, level of attentiveness, and interest (M. Boivin, personal communication, January 25, 2013).

The score histograms and QQ plots of the MSEL scores indicated that the nurses are not likely having significant challenges with accurate MSEL administration, since the scores appear to follow a normal distribution, with the exception of the gross motor scores. In the video evaluations done there are no problems evident with the administration of the gross motor scale. The scores for that scale do appear to reflect actual lower than expected performance for 3 infants as discussed in Chapter 4.

Acceptability of Nurse Administered MSEL Testing at MU/JHU Clinic. The MSEL administering MU/JHU clinic nurses indicated that the idea of incorporating MSEL testing into routine nursing practice at the MU/JHU clinic was acceptable. The incorporation of the MSEL
testing into practice was felt to be a worthwhile goal, although significant challenges were identified, both in their own (MU/JHU) clinic, and certainly on a wider scale. Through the in-depth interviews nurses voiced their unanimous support of continuing to administer the MSEL.

While MSEL administering nurses thought that incorporating MSEL testing the MSEL testing in the MU/JHU clinic and for the wider community was eventually possible, they were realistic in their concerns. They identified administration time as a major barrier. The nurses also discussed the idea that there would have to be support from the government through policy with a realistic plan and budget for training to achieve eventual incorporation of the MSEL into practice. Several nurses mentioned inclusion of MSEL testing training into nursing course work as a way to expose more nurses to the need and basis for testing as well as to begin their training in application to eventually do so.

The large majority of the non MSEL administering clinic and hospital nurses who attended the Post MSEL Demonstration also indicated their acceptance of the MSEL testing as part of routine nursing care. They indicated interest in the MSEL testing for their own education, because it was good for children, because it would expand their skills as nurses, make their work more interesting and possibly increase their marketability. The two nurses who responded that they would not be interested in learning to administer the MSEL stated that it was it would be too time consuming to learn and perform. The idea that the system is already overloaded and time is at a premium came through from almost all of the nurses from both cohorts (MSEL administering and non MSEL administering) in one way or another.

The caregivers almost unanimously indicated acceptability of the MSEL testing and many of them expressed joy and wonder at seeing their infant’s capabilities. Many of them indicated they
would like to have periodic testing of their infants and inquired into when that would occur. Having the opportunity for serial testing would not only pick up delays earlier and allow opportunity for referral. It could also reinforce the need for parents to provide stimulating activities for their children. The repeat encounters that serial testing would afford in this setting could lead to more frequent discussion of the importance of parents’ role in cognitive stimulation.

**Transformation of Nursing Role.** The MSEL administering nurses’ role in this study was globally different than in previous studies conducted in the MU/JHU clinic. Traditionally, a physician or psychologist leads and often coordinates the study while nurses are responsible for recruitment, informed consent, and routine study procedures such as taking vital signs, performing phlebotomy, case report form (CRF) completion, and quality assurance of the CRFs. For this study the nurses were study leaders and coordinators and not only the administrators of the actual MSEL testing. They were responsible for recruitment planning, informed consent, vitals and anthropometric measurements. They were also responsible for scoring the MSEL tests and recording and quality checking the scores. In short, the nurses were supported by the physician leadership in the clinic, but were essentially responsible for the study overall, including the MSEL testing.

The experience of training for and administering the MSEL appears to have also changed the level of the MSEL administering nurses’ interaction with the children in the clinic and spurred them to think more globally about neurodevelopment for the children of the wider community and the country overall. They discussed envisioning being able to eventually have neurodevelopmental testing be a more routine part of care for children in Uganda and had ideas about how that might eventually be achieved. They also indicated appreciation of their expanded
skills and viewed their nursing role in the clinic as expanded overall due to their participation in the project. Three benefits that were expressed included: (1) the confidence gained through the MSEL administration, the increased global knowledge of normal child neurodevelopment, and the experience of leading the study overall.

The project experience adds to a growing body of evidence that nurses can perform functions outside their historically expected duties in an exemplary manner, much like the instances where nurses are now providing HIV care and treatment in many settings, especially in Sub-Saharan Africa (Callaghan, Ford, and Schneider, 2010; Shambuso, van Griensven, Lowrance, Turate, et al. 2009; O’Malley, Asrat, Sharma, Hamunime, et al., 2014; Uebel, K., Fairall, L., van Rensburg, D., Mollentze, W. et al., 2011) In keeping with the idea of transforming nursing practice, the Institute of Medicine (IOM) report on the future of nursing (2011) major recommendations include “(1) ensure that nurses can practice to the full extent of their education and training, (2) improve nursing education, (3) provide opportunities for nurses to assume leadership positions and to serve as full partners in health care redesign and improvement efforts, and (4) improve data collection for workforce planning and policy making” (page 1). This pilot project was an example of implementation of recommendations numbers 1, 3, and 4 from that report. The project allowed the clinic nurses to function on a different level than traditionally expected, take leadership roles, and has set up a model for moving the nursing role in the MU/JHU clinic forward. This was truly a paradigm shift in the thinking of the MSEL administering nurses and a gratifying result that will hopefully continue to evolve.

**The Way Forward.** Any change in practice requires careful consideration and beginning at a sub-institutional level with this pilot project allowed for a detailed examination of possible
practice and role changes. This was a necessary step for determining longer-term feasibility and acceptability and it was important to start in a controlled way to ensure quality. A deficiency in quality would have rendered the continuation of the MSEL testing infeasible, given the importance of careful adherence to the specified test administration and scoring.

The evidence from this pilot study assisted in the decision to continue the pilot with the current MSEL administering nurses, at least through the ongoing PROMISE Neurodevelopmental Study. The MU/JHU clinic leadership recognizes the importance of continuing dialogue at every stage of the process to insure best practices. In order to facilitate that dialogue the leadership have instituted a Neurodevelopment Interest Group that meets regularly to discuss any problems with testing and ideas for improvement. As a result of that group’s deliberations they have instituted mandatory periodic refresher training. Consideration for training of additional MU/JHU nurses is also being contemplated. Wider dissemination of the project results include a plan to present the project findings to the College of Nursing at Makerere University as well as the medical students early Fall of 2016 in order to raise awareness of the outcome of the project and to broaden collaboration to include the College of Nursing and the Mulago Hospital leadership in possible next steps.

Limitations

The conclusion that continuing the MSEL testing is feasible in the MU/JHU clinic is not generalizable to other clinics. The issues of time, staffing, and budgets for training and testing likely make the MSEL testing infeasible for routine care in settings outside of research, or other relatively well resourced, settings. That being said, MSEL administration for all children is also probably unnecessary in settings where the majority of the population is expected to be well children with normal neurodevelopment. Nursing administration of a broader and easier to
administer screening tool, such as the TQQ (discussed in Chapter 2), is likely more feasible and should detect the majority of potential disabilities. Having a select few nurses in these settings learn the MSEL would be important, so that testing for those children with suspected delays could be accomplished easily and efficiently.

Generalizability of the findings is also limited by the small sample size of MSEL administering nurses and the fact that the non-MSEL administering nurses were from a self-selected convenience sample. Further limitations include the fact that children were recruited from essentially one site, comprised of the research clinic and the hospital ward that is on the same campus.

Lessons learned included the realization that videotaping of each testing session is required for greatest understanding of both the scores and the nurse administrators’ efficiency and accuracy. It is very difficult to go back after the fact and completely understand either aberrant scores or differences in administration times without an actual visual record of the testing. Therefore, the understanding of the difference in the gross motor scale and the lack of patterns in administration time was limited by the decision to only require intermittent video recordings.

Conclusions

The importance of the task of incorporating neurodevelopmental surveillance and screening into routine clinical care for children, even in low and middle-income countries (LMIC) has been recognized by Scherzer et al (2012). The authors lay out a plan to improve child development in low and middle income countries that includes the following: broader sensitization to child development, healthcare conceived as not only a reduction of morbidity and mortality for
children, but more broadly as important for optimal child development; installation of simple, culturally relevant surveillance systems to monitor child development; further research to improve training, education, and acceptance by healthcare providers; and increased local community understanding and capacity building surrounding child development. They conclude by saying that some of these principles can and should be implemented immediately.

The importance of the information to be gathered through wider neurodevelopmental testing should spur creative thinking about how to achieve their incorporation of screening and testing into nursing practice more broadly. This project was an important first step in exploring what is needed to achieve that goal and practical ways to begin the process and move it forward, albeit likely on an incremental basis. As a result of this project the 5 MSEL administering nurses trained for this and the other continuing neurodevelopment projects at the MU/JHU clinic are the only nurses known to be performing the MSEL or any other neurodevelopment testing in Uganda (S. Mbabali, personal communication, March 20, 2016), which is an important step forward. The commitment of the project nurse participants and the Nursing and Medical leadership at MU/JHU clinic have made the progress to date possible and they are committed to continuing to move towards greater emphasis on child neurodevelopment despite the challenges associated with that undertaking. This project not only established the ability to undertake the needed neurodevelopmental testing for the children in the MU/JHU clinic, it also moved nursing practice forward in that setting by allowing the nurses to gain expanded skills and to experience leadership in research, which is a step forward indeed.
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### Appendices

#### Appendix A

Mean and standard deviations of scale T Scores and composite Standard scores for the standardization sample by age

| Age in Months | N  | Scale       | Mean | SD  | Mean | SD  | Mean | SD  | Mean | SD  | Mean | SD  | Mean | SD  | Mean | SD  | Mean | SD  | Mean | SD  | Mean | SD  |
|---------------|----|-------------|------|-----|------|-----|------|-----|------|-----|------|-----|------|-----|------|-----|------|-----|------|-----|------|-----|------|-----|
|               |    | Gross Motor| 50.6 | 9.0 | 49.1 | 8.7 | 51.1 | 8.5 | 47.2 | 6.7 | 48.9 | 6.5 | 98.5 | 11.2 |
| 1–2           | 111| Visual Reception| 50.2 | 7.5 | 50.9 | 6.1 | 49.7 | 7.2 | 50.4 | 6.5 | 46.1 | 6.5 | 100.3 | 12.5 |
| 3–4           | 110| Fine Motor   | 51.4 | 9.0 | 50.9 | 6.8 | 50.4 | 8.1 | 49.9 | 8.9 | 19.3 | 8.4 | 100.5 | 14.1 |
| 5–6           | 102| Receptive Language| 50.3 | 9.2 | 50.2 | 6.9 | 51.2 | 10.0 | 50.0 | 9.6 | 52.1 | 11.1 | 102.0 | 15.9 |
| 7–8           | 97 | Expressive Language| 49.4 | 10.2 | 48.8 | 9.7 | 49.1 | 10.0 | 49.3 | 9.4 | 46.4 | 9.8 | 98.5 | 16.2 |
| 9–10          | 99 | Early Learning Composite| 50.1 | 10.4 | 50.2 | 10.7 | 47.7 | 9.5 | 49.9 | 10.3 | 50.2 | 8.7 | 99.3 | 15.4 |
| 11–12         | 84 |            | 48.0 | 10.3 | 47.7 | 10.1 | 48.4 | 8.7 | 48.0 | 9.4 | 46.0 | 8.6 | 98.4 | 14.5 |
| 13–14         | 90 |            | 49.4 | 8.6 | 49.7 | 8.7 | 48.7 | 7.5 | 49.6 | 8.7 | 46.9 | 8.3 | 98.7 | 13.1 |
| 15–17         | 81 |            | 51.5 | 7.9 | 52.5 | 8.4 | 50.6 | 9.5 | 51.0 | 8.9 | 50.7 | 9.4 | 102.5 | 14.0 |
| 18–20         | 51 |            | 51.3 | 9.8 | 50.9 | 10.1 | 49.8 | 9.5 | 50.0 | 8.9 | 49.9 | 9.2 | 100.6 | 15.0 |
| 21–25         | 136|            | 51.0 | 8.9 | 49.3 | 10.4 | 49.9 | 9.9 | 50.3 | 9.3 | 48.4 | 9.7 | 99.7 | 16.3 |
| 27–32         | 156|            | 50.2 | 10.2 | 50.2 | 10.2 | 50.2 | 9.9 | 49.5 | 10.1 | 100.3 | 16.1 |
| 33–38         | 120|            | 50.1 | 10.7 | 50.4 | 10.4 | 50.1 | 10.5 | 51.0 | 10.5 | 101.6 | 16.9 |
| 39–44         | 127|            | 50.1 | 10.4 | 48.8 | 9.4 | 50.3 | 10.5 | 50.7 | 10.1 | 100.7 | 15.6 |
| 45–50         | 137|            | 50.4 | 10.0 | 51.8 | 10.7 | 50.9 | 11.5 | 51.1 | 10.7 | 102.3 | 16.8 |
| 51–56         | 135|            | 50.2 | 9.7 | 50.5 | 10.5 | 51.4 | 10.7 | 50.4 | 10.5 | 101.8 | 15.8 |
| 57–62         | 105|            | 48.0 | 9.9 | 48.1 | 7.3 | 47.6 | 7.6 | 49.3 | 8.5 | 96.8 | 11.6 |
| 63–68         | 108|            | 50.2 | 9.3 | 50.0 | 9.7 | 49.9 | 9.4 | 48.8 | 9.5 | 49.9 | 9.5 | 100.1 | 15.0 |

Note: Gross Motor N counts vary for some age groups. N = 69 (15-17 months), N = 33 (16-20 months), N = 66 (21-26 months), and N = 27 (27-32 months). The total sample N counts for the other subtests are as follows: Visual Reception N = 1,936, Fine Motor N = 1,937, Receptive Language N = 1,945, and Expressive Language N = 1,944.
Appendix B

NEURODEVELOPMENT Study Training Schedule

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
<th>Target audience</th>
<th>Facilitator</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:30 am – 9:15 am</td>
<td>Registration</td>
<td>Open</td>
<td>Ms. Mai Nakitende</td>
</tr>
<tr>
<td>9:15 am – 9:30 am</td>
<td>Welcome and Introduction</td>
<td>Open</td>
<td>Dr. Mac Mallewa/ Dr. Jim Aizire</td>
</tr>
<tr>
<td>9:30 am – 10:15 am</td>
<td>ND study overview – part 1</td>
<td>Open</td>
<td>Prof. Mary Glenn Fowler</td>
</tr>
<tr>
<td>10:15 am – 10:45 am</td>
<td>ND study overview – part 2</td>
<td>Open</td>
<td>Prof. Michael Boivin</td>
</tr>
<tr>
<td>10:45 am – 11:15 am</td>
<td>Break time</td>
<td>Open</td>
<td>Prof. Michael Boivin</td>
</tr>
<tr>
<td>11:15 am – 12:00 pm</td>
<td>DVD program overview</td>
<td>Open</td>
<td>Dr. Jim Aizire</td>
</tr>
<tr>
<td>12:00 am – 12:45 pm</td>
<td>Participant recruitment</td>
<td>Open</td>
<td>Dr. Jim Aizire</td>
</tr>
<tr>
<td>12:45 pm – 2:00 pm</td>
<td>Lunch</td>
<td>Open</td>
<td>Dr. Lillian Wambuzi</td>
</tr>
<tr>
<td>2:00 pm – 2:45 pm</td>
<td>Participant follow-up considerations</td>
<td>Open</td>
<td>Mullen testers, coordinators, clinicians, data</td>
</tr>
<tr>
<td>2:45 pm – 3:30 pm</td>
<td>Power point presentation overview of the Mullen early Learning Scales</td>
<td>Mullen testers, coordinators, clinicians, data</td>
<td>Prof. Michael Boivin</td>
</tr>
<tr>
<td>3:30 pm – 4:30 pm</td>
<td>Overview of Mullen testing materials -1</td>
<td>Mullen testers, coordinators, clinicians, data</td>
<td>Prof. Michael Boivin</td>
</tr>
<tr>
<td>4:30 pm</td>
<td>End of Training for the day -- Tea</td>
<td></td>
<td></td>
</tr>
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</table>
Appendix C

Certificate of attendance
Appendix E

Scale 1: Gross Motor

<table>
<thead>
<tr>
<th>Stage</th>
<th>Item</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3</td>
<td>enjoys being held/realigns (Up)</td>
<td>0</td>
</tr>
<tr>
<td>4</td>
<td>Holds upright, holds head steady (Up)</td>
<td>0</td>
</tr>
<tr>
<td>5</td>
<td>6.   Sits supported, head steady (SS1)</td>
<td>1</td>
</tr>
<tr>
<td>7</td>
<td>Rolls over (P to S)</td>
<td>0</td>
</tr>
<tr>
<td>8</td>
<td>Holds on to fingers/pulls self to sit (SS1 to 5/2S)</td>
<td>1</td>
</tr>
<tr>
<td>9</td>
<td>Shifts weight, reaches (P)</td>
<td>1</td>
</tr>
<tr>
<td>10</td>
<td>Stands with hands held, bounces</td>
<td>1</td>
</tr>
<tr>
<td>11</td>
<td>Sits with arms free (SS0)</td>
<td>1</td>
</tr>
<tr>
<td>12</td>
<td>Pulls self to stand (Sit to stand)</td>
<td>1</td>
</tr>
<tr>
<td>13</td>
<td>Gets from sitting to hands and knees (SS1)</td>
<td>1</td>
</tr>
<tr>
<td>14</td>
<td>Walks with one hand held</td>
<td>1</td>
</tr>
<tr>
<td>15</td>
<td>Stands alone (1-2 seconds)</td>
<td>1</td>
</tr>
<tr>
<td>16</td>
<td>Walks alone (4-5 steps)</td>
<td>1</td>
</tr>
<tr>
<td>17</td>
<td>Throws a ball underhand</td>
<td>1</td>
</tr>
<tr>
<td>18</td>
<td>Gets to stand by rolling to side (SS2 to stand)</td>
<td>1</td>
</tr>
<tr>
<td>19</td>
<td>Stands, squats, stands</td>
<td>1</td>
</tr>
<tr>
<td>20</td>
<td>Walks up stairs with help, nonalternating</td>
<td>1</td>
</tr>
<tr>
<td>21</td>
<td>Runs stiffly</td>
<td>1</td>
</tr>
<tr>
<td>22</td>
<td>Kicks a 10- to 15-inch ball (2 of 5 trials)</td>
<td>1</td>
</tr>
<tr>
<td>23</td>
<td>Stands on one foot, with help</td>
<td>1</td>
</tr>
<tr>
<td>24</td>
<td>Walks 4 to 5 steps, one foot on line</td>
<td>1</td>
</tr>
<tr>
<td>25</td>
<td>Walks up stairs by self, nonalternating</td>
<td>1</td>
</tr>
<tr>
<td>26</td>
<td>Jumps down from bench, &amp; 1 foot</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>&amp; 2 feet</td>
<td>1</td>
</tr>
<tr>
<td>27</td>
<td>Jumps in place, feet together (one jump)</td>
<td>1</td>
</tr>
<tr>
<td>28</td>
<td>Walks on tiptoes (4-5 steps)</td>
<td>1</td>
</tr>
<tr>
<td>29</td>
<td>Walks on line, using arms to balance (6-7 steps)</td>
<td>1</td>
</tr>
<tr>
<td>30</td>
<td>Walks down stairs by self, alternating</td>
<td>1</td>
</tr>
<tr>
<td>31</td>
<td>Gets to stand/forward to sit (SS2 to stand)</td>
<td>1</td>
</tr>
<tr>
<td>32</td>
<td>Balances on one foot (2-3 seconds)</td>
<td>1</td>
</tr>
<tr>
<td>33</td>
<td>Runs, turns corner, stops</td>
<td>1</td>
</tr>
<tr>
<td>34</td>
<td>Hops two times</td>
<td>1</td>
</tr>
<tr>
<td>35</td>
<td>Walk on line; arms at side (6 steps)</td>
<td>1</td>
</tr>
</tbody>
</table>

BASAL LEVEL: 3 consecutive items with at least 1-point scores
CEILING LEVEL: 3 consecutive items with scores of 0
### Appendix F

**Scale 2: Visual Reception, Scale 3: Fine Motor**

<table>
<thead>
<tr>
<th>Scale 2: Visual Reception</th>
<th>Score</th>
<th>Scale 3: Fine Motor</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Floats on and tracks triangle (S)</td>
<td>2 1 0</td>
<td>1. Arms flexed/hands fisted (S)</td>
<td>1 0</td>
</tr>
<tr>
<td>2. Tracks schematic face 90 degrees (S)</td>
<td>1 0</td>
<td>2. Holds ring reflexively (S)</td>
<td>1 0</td>
</tr>
<tr>
<td>3. Tracks moving ball’s-eye 180 degrees (PP)</td>
<td>1 0</td>
<td>3. Brings fist to mouth (P)</td>
<td>1 0</td>
</tr>
<tr>
<td>4. Localizes alternating red ball and schematic face (PP)</td>
<td>1 0</td>
<td>4. Bilateral orientation in midline (S)</td>
<td>1 0</td>
</tr>
<tr>
<td>5. Stares at own hand (S)</td>
<td>1 0</td>
<td>5. Grasp reflex integrated (S)</td>
<td>1 0</td>
</tr>
<tr>
<td>6. Localizes ball’s-eye near and far (SSS)</td>
<td>1 0</td>
<td>6. Grasps peg (ulnar palmar) (PP or SSS)</td>
<td>1 0</td>
</tr>
<tr>
<td>7. Looks for dropped spoon (A/V) (SSS)</td>
<td>1 0</td>
<td>7. Reaches for and grasps block (oral/motor grasp) (SSS)</td>
<td>1 0</td>
</tr>
<tr>
<td>8. Pulls cord to obtain disc (SSS)</td>
<td>1 0</td>
<td>8. Transfers, bangs, drops (SSS)</td>
<td>1 0</td>
</tr>
<tr>
<td>9. Looks for ring hidden under washcloth (S)</td>
<td>2 1 0</td>
<td>9. Refined grasp/thumb opposition (S)</td>
<td>1 0</td>
</tr>
<tr>
<td>(i) partially hidden</td>
<td>1 0</td>
<td>10. Uses pincer grasp (S)</td>
<td>2 1 0</td>
</tr>
<tr>
<td>(ii) fully hidden</td>
<td>1 0</td>
<td>(i) partial pincer</td>
<td>1 0</td>
</tr>
<tr>
<td>10. Turns cup right-side up</td>
<td>1 0</td>
<td>11. Uses two hands together</td>
<td>1 0</td>
</tr>
<tr>
<td>11. Makes object association</td>
<td>1 0</td>
<td>12. Takes blocks out, puts blocks in</td>
<td>3 2 1 0</td>
</tr>
<tr>
<td>(i) brush</td>
<td>1 0</td>
<td>Task 1: 1 block</td>
<td>1 0</td>
</tr>
<tr>
<td>(ii) spoon</td>
<td>1 0</td>
<td>Task 2: 4 blocks</td>
<td>1 0</td>
</tr>
<tr>
<td>(iii) cup</td>
<td>1 0</td>
<td>Task 3: 7 to 8 blocks</td>
<td>1 0</td>
</tr>
<tr>
<td>12. Looks for car under two washcloths</td>
<td>1 0</td>
<td>Task 4: in or out</td>
<td>1 0</td>
</tr>
<tr>
<td>13. Shows interest in book as hinge</td>
<td>1 0</td>
<td>Task 5: in or out</td>
<td>1 0</td>
</tr>
<tr>
<td>14. Attends to picture (A/V)</td>
<td>1 0</td>
<td>13. Uses two hands together</td>
<td>1 0</td>
</tr>
<tr>
<td>15. Looks for toy covered, then displaced</td>
<td>1 0</td>
<td>14. Turns pages in a book</td>
<td>2 1 0</td>
</tr>
<tr>
<td>16. Discriminates forms on card (board)</td>
<td>4 3 2 1 0</td>
<td>(i) several at a time</td>
<td>1 0</td>
</tr>
<tr>
<td>(ii) one at a time</td>
<td>1 0</td>
<td>15. Imitates crayon lines</td>
<td>3 2 1 0</td>
</tr>
<tr>
<td>17A. Matches objects with naming (A/V) (19 months or younger)</td>
<td>3 2 1 0</td>
<td>Task 1: (i) any direction</td>
<td>1 0</td>
</tr>
<tr>
<td>OR</td>
<td>1 0</td>
<td>(ii) vertical line</td>
<td>1 0</td>
</tr>
<tr>
<td>17B. Matches objects without naming (20 months or older)</td>
<td>3 2 1 0</td>
<td>Task 2: (i) horizontal line</td>
<td>1 0</td>
</tr>
<tr>
<td>(i) one object with naming</td>
<td>1 0</td>
<td>16. Puts pennies in slot, horizontal and vertical</td>
<td>2 1 0</td>
</tr>
<tr>
<td>(ii) two objects without naming</td>
<td>1 0</td>
<td>Task 1: (ii) 3 pennies/horizontal</td>
<td>1 0</td>
</tr>
<tr>
<td>(iii) three objects without naming</td>
<td>1 0</td>
<td>Task 2: (ii) 3 pennies/vertical</td>
<td>1 0</td>
</tr>
<tr>
<td>18. Nests nesting cups</td>
<td>2 1 0</td>
<td>17. Stacks blocks vertically</td>
<td>3 2 1 0</td>
</tr>
<tr>
<td>(i) nests three cups</td>
<td>1 0</td>
<td>(i) 3-5 blocks</td>
<td>3 2 1 0</td>
</tr>
<tr>
<td>(ii) nests four cups</td>
<td>1 0</td>
<td>(ii) 6-8 blocks</td>
<td>3 2 1 0</td>
</tr>
<tr>
<td>19. Sorts spoons and blocks by category</td>
<td>1 0</td>
<td>(iii) 9 or more blocks</td>
<td>3 2 1 0</td>
</tr>
<tr>
<td>20. Matches by shape</td>
<td>1 0</td>
<td>18. Imitates four-block train</td>
<td>2 1 0</td>
</tr>
<tr>
<td>(i) circles</td>
<td>1 0</td>
<td>(i) train</td>
<td>1 0</td>
</tr>
<tr>
<td>(ii) squares</td>
<td>1 0</td>
<td>(ii) train with driver</td>
<td>1 0</td>
</tr>
<tr>
<td>(iii) triangles</td>
<td>1 0</td>
<td>(iii) unscrews, screws nut and bolt</td>
<td>1 0</td>
</tr>
<tr>
<td>21. Matches pictures</td>
<td>1 0</td>
<td>19. Strings beads</td>
<td>1 0</td>
</tr>
<tr>
<td>(i) shoe</td>
<td>1 0</td>
<td>20. Strings beads</td>
<td>1 0</td>
</tr>
<tr>
<td>(ii) cup</td>
<td>1 0</td>
<td>21. Imitates four-block tower</td>
<td>2 1 0</td>
</tr>
<tr>
<td>22. Matches by size, color</td>
<td>1 0</td>
<td>22. Copies circle, circle and line</td>
<td>2 1 0</td>
</tr>
<tr>
<td>(i) large red circles</td>
<td>1 0</td>
<td>Task 1: (i) circle</td>
<td>2 1 0</td>
</tr>
<tr>
<td>(ii) small red circles</td>
<td>1 0</td>
<td>Task 2: (i) circle and line</td>
<td>2 1 0</td>
</tr>
<tr>
<td>(iii) large yellow circles</td>
<td>1 0</td>
<td>23. Draws in path</td>
<td>2 1 0</td>
</tr>
<tr>
<td>(iv) small yellow circles</td>
<td>1 0</td>
<td>Example: Figure 1</td>
<td>2 1 0</td>
</tr>
<tr>
<td>23. Memory for one picture</td>
<td>1 0</td>
<td>Figure 2</td>
<td>2 1 0</td>
</tr>
<tr>
<td>(i)</td>
<td>1 0</td>
<td>Figure 3</td>
<td>2 1 0</td>
</tr>
<tr>
<td>24. Spatial details II</td>
<td>2 1 0</td>
<td>24. Cuts with scissors</td>
<td>2 1 0</td>
</tr>
<tr>
<td>(i) flower</td>
<td>1 2 3 4</td>
<td>(i) 1 inch cut</td>
<td>2 1 0</td>
</tr>
<tr>
<td>(ii)</td>
<td>1 0</td>
<td>(ii) 2 inch cut</td>
<td>2 1 0</td>
</tr>
<tr>
<td>25. Memory for objects</td>
<td>1 0</td>
<td>25. Folds paper three times</td>
<td>1 0</td>
</tr>
<tr>
<td>(i) big ball</td>
<td>1 0</td>
<td>26. Imitates drawings</td>
<td>3 2 1 0</td>
</tr>
<tr>
<td>(ii) small car</td>
<td>1 0</td>
<td>Task 1: (i) circle in circle</td>
<td>2 1 0</td>
</tr>
<tr>
<td>26. Memory for objects</td>
<td>1 0</td>
<td>Task 2: (ii) square</td>
<td>2 1 0</td>
</tr>
<tr>
<td>(i) big ball</td>
<td>1 0</td>
<td>Task 3: (i) left diagonal</td>
<td>2 1 0</td>
</tr>
<tr>
<td>(ii) small car</td>
<td>1 0</td>
<td>27. Touches fingers I</td>
<td>2 1 0</td>
</tr>
<tr>
<td>27. Discriminates spatial position</td>
<td>1 0</td>
<td>28. Touches fingers II</td>
<td>2 1 0</td>
</tr>
<tr>
<td>(i) form</td>
<td>1 2 3 4</td>
<td>29. Folds paper twice to form square</td>
<td>2 1 0</td>
</tr>
<tr>
<td>(ii)</td>
<td>1 0</td>
<td>30. Copies shapes and letters</td>
<td>5 4 3 2 1 0</td>
</tr>
<tr>
<td>28. Spatial details III</td>
<td>2 1 0</td>
<td>Task 1: (i) cross</td>
<td>2 1 0</td>
</tr>
<tr>
<td>(i) dog</td>
<td>1 2 3 4 5</td>
<td>Task 2: (i) square</td>
<td>2 1 0</td>
</tr>
<tr>
<td>(ii)</td>
<td>1 0</td>
<td>Task 3: (i) LED</td>
<td>2 1 0</td>
</tr>
<tr>
<td>29. Memory for forms</td>
<td>2 1 0</td>
<td>Task 4: (i) triangle</td>
<td>2 1 0</td>
</tr>
<tr>
<td>(i) form</td>
<td>1 2 3 4</td>
<td>Task 5: (i) X</td>
<td>2 1 0</td>
</tr>
<tr>
<td>(ii)</td>
<td>1 0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Visual Reception Raw Score**

**Fine Motor Raw Score**
Appendix G

Receptive Language, Scale 5: Expressive language
Appendix H

Receptive Language and Expressive Language

<table>
<thead>
<tr>
<th>Receptive Language</th>
<th>Expressive Language</th>
</tr>
</thead>
<tbody>
<tr>
<td>30. General knowledge</td>
<td>18. Picture vocabulary</td>
</tr>
<tr>
<td>1) name</td>
<td>1) phone</td>
</tr>
<tr>
<td>2) boy or girl</td>
<td>2) spoon</td>
</tr>
<tr>
<td>3) age</td>
<td>3) bed</td>
</tr>
<tr>
<td>4) eyes</td>
<td>4) television</td>
</tr>
<tr>
<td>5) wash hands</td>
<td>5) comb</td>
</tr>
<tr>
<td>6) half</td>
<td>6) ball</td>
</tr>
<tr>
<td>7) time</td>
<td>7) bird</td>
</tr>
<tr>
<td>8) legs</td>
<td>8) house</td>
</tr>
<tr>
<td>9) money</td>
<td>9) hand</td>
</tr>
<tr>
<td>10) refrigerator</td>
<td>10) door</td>
</tr>
<tr>
<td>11) fingers</td>
<td>11) umbrella</td>
</tr>
<tr>
<td>12) roof</td>
<td>12) purse</td>
</tr>
</tbody>
</table>

23. Answers questions

1) thirsty + -
2) hungry + -
3) sleepy + -

24. Verbal analogies

1) big/ + -
2) light/ + -
3) hot/ + -
4) table/ + -
5) breakfast/ + -

6) sidewalk/ + -
7) awake/ + -
8) hard/ + -
9) light/ + -
10) wood/ + -

26. Oral vocabulary

1) hat + -
2) car + -
3) boots + -
4) umbrella + -
5) letter + -
6) hammer + -
7) dime + -
8) basket + -
9) candle + -
10) tire + -
11) goat + -
12) glue + -
13) faucet + -
14) canoe + -

27. Practical reasoning

1) dirty + -
2) rain + -
3) street + -
4) cut + -
5) store + -
6) fire + -
7) dark + -
8) swim + -
## Appendix I

### Score Summary

**Table: Score Summary**

<table>
<thead>
<tr>
<th>Scale</th>
<th>Raw Score</th>
<th>T Score</th>
<th>Standard Score</th>
<th>Standard Error</th>
<th>T Score Range</th>
<th>Percentile Rank</th>
<th>Description Category</th>
<th>Age Equivalents</th>
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**Diagram: Scale T Score Profile**

**Notes:**

- Observations:

### Age Equivalents

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<th>T Score 20</th>
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<th>T Score 40</th>
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**Notes:**

- Age Equivalents are approximate and may vary based on individual performance.

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Appendix J

Mullen scoring rubric

MULLEN SCORING RUBRIC FOR THE PROMISE NEURODEVELOPMENT STUDY.

INSTRUCTIONS: Please indicate whether the test is poor, adequate, good or excellent at each evaluation category. After each category, give a comment explaining reasons for score obtained.

A general comment at the end of the evaluation process should be given on the entire administration process in which a tester's shortcomings or mistakes will be commented and also the way forward given.

TESTER'S CODE: ___________________________
CHILD'S ID: ___________________________
SITE CODE: ___________________________

SCORING KEY: EXCELLENT (superior; good knowledge), GOOD (acceptable performance or basic knowledge), POOR (substantial or desired performance, has required quality), and INEXCELLENT (superior, excellent, satisfactory and children of test)

<table>
<thead>
<tr>
<th>MULLEN SUBTEST</th>
<th>EVALUATION OF TEST</th>
<th>MANUFACTURER'S ATTENDANCE/EXPERIENCE</th>
<th>COMMENTS</th>
<th>TESTER'S EVALUATION WITH ADVISORY</th>
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<tbody>
<tr>
<td>SENSORY</td>
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<tr>
<td>AGGRESSIVE LANGUAGE</td>
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</tbody>
</table>

COMMENT: ___________________________________________
Appendix K

Caregiver’s Exit Questionnaire

Good Morning! We are interested in learning about your experience here in the clinic today. We would like to ask you some questions about the visit.

1.) What was the reason you brought your child to the clinic today?
   a.) MSEL testing
   b.) To see how my child is growing and developing
   c.) Study visit
   d.) Other

2.) Was there anything that was different that was done with your child today then what is done with your child for usual sorts of visits? If so, what was it?

3.) How did you feel about the testing that was done with your child today?
   a.) Happy it was done
   c.) Unhappy that it was done
   d.) Worried about the actual testing
   e.) Other

4.) What, if anything, did you like about the testing that was done?
5.) What, if anything did you dislike about the testing that was done?

6.) Do you think that your child liked the testing that was done?
   a.) Yes
   b.) No
   c.) Liked some of it/disliked some of it

7.) Would you be interested in having this type of testing at your child’s regular clinic visits?
   a.) Yes  b.) No

8.) If the answer to question #7 was no, please briefly describe why you would not like to see this testing done during regular clinic visits.
   a.) Takes too much time
   b.) Made the child cry
   c.) Think it was too hard for the child
   d.) Other Reason

9.) If you were asked to allow your child to be tested again what would your answer be?
   a.) Yes  b.) No
10.) What is your age?

11.) Please tick how far you went in school:

   Some Primary School
   Completed Primary School
   Some Secondary School
   Completed Secondary School
   Diploma College
   University

12.) Please tick your relationship to the child.

   Mother
   Father
   Aunt/Uncle
   Grandmother
   Grandfather
   Other blood relative
   Guardian (non-blood relative)

Signature of Nurse Completing Form:

Date of Form Completion:
Appendix L

Administering Nurses’ Interview Guide

Hello I am Sheryl Zwerski and I would like to ask you some questions to better understand your experience of learning and administering the MSEL. There are no right or wrong answers and you are free to also bring up things that are not specifically asked about if you think they are important. You can also refuse to answer any of the questions you are asked. Your responses are being audio (tape) recorded and I will be taking notes during the interview as well. The tapes will be transcribed verbatim after the interview is over. All of the information will remain confidential as to what you have individually said. I will present the analysis of the interviews all together, but not specifically who said what.

1.) Tell me about which studies you typically work on here in the clinic and how you came to be selected for the MSEL training and administration.

2.) Walk me through a typical visit for the MSEL administration from beginning to end.

3.) Tell me about the training for the MSEL.
   a. Tell me about what you liked about the training.
      i. New skill
      ii. Something other than usual work day
   b. Tell me about what you would change about the training.
      i. Time it took
      ii. Classroom style
      iii. Having to practice in front of others

4.) Thinking back to when you first started administering the MSEL, tell me about how the experience has changed over time.
   a. Tell me about your level of confidence in the beginning
   b. And now.
      i. (Scale of 1 to 10)

5.) Tell me about how you feel about doing the MSEL testing now.
6.) Tell me about whether you would like to continue performing the Mullen testing in the clinic setting?
   a. What are the advantages?
   b. What are the disadvantages?

7.) Tell me about whether you think that other nurses in the clinic can perform this testing?
   a. Why or why not?

8.) Tell me about what problems, you foresee with incorporation of this type of testing into routine clinic visits, when appropriate?
   a. Time
   b. Routine
   c. Added stress
   d. Criticism from other nurses
   e. Lack of Pay
   f. Mother’s refusing/not understanding

9.) How has learning and doing the testing changed your nursing practice?

10.) What is your age range?

11.) What is your nursing education?
     a. Diploma in Nursing/Midwifery, Bachelor’s degree in Nursing, Master’s degree in Nursing, Doctorate?

12.) How many years have you practiced nursing?
     a. 0 – 5, 6 – 10, 11 – 15, 16 – 20, 21 – 25, >25?
Appendix M

Nurses’ Post Demonstration Questionnaire

1.) Would you want to learn to perform the testing that was just demonstrated?
   a.) Yes  b.) No

2.) If you indicated you would like to learn to perform the testing, but have some concerns about it please explain in the space below.

3.) If you answered no to question #4, please tick all the answers that best describes why you would not want to learn to perform the testing.
   a.) Takes too much time
   b.) Too difficult to learn
   c.) Not interested
   d.) Not appropriate for nurses to perform
   e.) Not getting paid enough to add to workload
   f.) Other reason ________________________________

4.) If you answered yes to question #4, please tick the answer that best describes why you want to learn to perform the Mullen.
   a.) I am interested in learning this new skill for my own education.
   b.) I think that this type of testing is important for the children
   c.) I would like to learn to do this testing so that my work is more interesting.
   d.) I think that learning to do the testing will help me to be promoted or to get another job.
   e.) Other reason ________________________________
5.) Regardless of whether you personally want to perform the testing, do you think that this testing could be added to routine clinic visits or children when needed?

a.) Yes  b.) No

6.) If you answered no to question #7 please tick why you think it could not be added to routine clinic visits.

a) Not important to do
b.) Caregivers will not like/agree
c.) Takes too much time
d.) Other reason.

7.) Do you think that nurses should be performing this type of testing with children?

a.) Yes  b.) No

8.) If you answered no to question #9, please tick the answer that best describes why you think that nurses should not be performing this type of testing.

a.) This testing is the Doctor's area of expertise/responsibility
b.) Nurses are not qualified to perform this testing
c.) Nurses do not have enough time to perform this testing
d.) Nurses are not paid enough to add this testing to their responsibilities

9.) Is there anything else about the testing that you want to comment on? If so, please do so here.

10.) What is your age range? Tick the appropriate age range
11.) How many years have you practiced Nursing? Tick the appropriate answer

- 0 – 5
- 6 – 10
- 11 – 15
- 16 – 20
- 21 – 25
- >25

12.) Please tick the one below which best describes the level of nursing education you have completed.

a.) Diploma in Nursing/Midwifery
b.) BSN
c.) Midwife
d.) MSN
e.) Doctorate