Improving the Odds: Healthy Child Development



Focus on the Early Years: Neuroscience and Implications for Clinical Practice

TOOLKIT: Interdisciplinary MAINPRO CME for Family Physicians and other Primary Healthcare Providers 6th Edition 2010

Updated and Revised



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Please note that programs, services and guidelines may change, therefore the reader is encouraged to consult current sources of information.

The information herein reflects the views of the authors and no official endorsement by the government of Ontario is intended or should be inferred.

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Introduction

A Peer presenter program called "Improving the Odds: Healthy Child Development" was introduced to family physicians and other primary healthcare providers in October 2000. Many of the members of the original interdisciplinary steering committee that initially came together in the spring of 2000 to initiate the development of this program have continued to advise and support its continuance aided by new additional expertise (please see www.ocfp.on.ca for more information).

The purpose of this program is to highlight recent developments in early neurodevelopment and to explore how these developments can be incorporated into medical practice. Specific modules were developed to cover broad areas of Healthy Child Development including research evidence, risk factors, parenting, effective strategies and the role of interdisciplinary teams. This toolkit will help identify available resources to help families access support and services in a convenient, coordinated and integrated fashion. It is hoped that teams of family doctors, public health nurses, and other primary healthcare providers will be exposed to the workshop and then proceed to develop integrated, interdisciplinary programs in communities throughout Ontario. While each individual module could be a training program in itself, "Improving the Odds: Healthy Child Development" is an integrated course that considers overall child health and development and the influences on neurodevelopment.

This toolkit was developed for the interdisciplinary MAINPRO CME program in Healthy Child Development. Participants include primary healthcare providers such as physicians, nurses, nurse practitioners and midwives. The toolkit summarizes the information included in the program and can act as a reference resource following the workshop. The toolkit includes information about the Ontario Antenatal Record and the ALPHA Tool to assist in identifying and addressing concerns during pregnancy. The toolkit also describes the Rourke Record, an evidence based infant/child health maintenance guide that can be used in the primary care office setting to facilitate assessment of child development. As well, parent education tools such as the Nipissing District Developmental Screen™ are introduced to help in assessment and to provide guidance and advice to parents. Additional screening and assessment tools used by Healthy Babies Healthy Children are also discussed.

A. Long Term Consequences of Early Brain Development

Recent human development research suggests that the period from conception to age six has the most important influence of any time in the life cycle on brain development and subsequent learning, behaviour and health (Williams, 1999). Patterns that are established with the birth of the first child set the stage for long-term family cohesion and communication. Meaningful relationships require secure attachments and these are critical to the development of coping skills, competence and trust in the world. According to Dr. J. Fraser Mustard (Keating and Hertzman, 1999), "There is substantial evidence that the quality of early childhood experiences has long term effects on an individual's performance in the education system, their behaviour in adult life and their risks for chronic disease in adult life."

B. Role in Early Neurodevelopment

Family physicians and other primary healthcare providers use their understanding of human development and family and other social systems to develop a comprehensive approach for promoting health and managing disease and illness in patients and their families

throughout the life cycle. They are also adept at working to reach common ground with patients on the definition of problems, goals of treatment, and the respective roles of primary healthcare providers and the patient in management of the condition. Family doctors work together with parents and other service providers including obstetricians, pediatricians, public health nurses, family practice nurses, nurse practitioners, social workers, early interventionists, psychiatrists, psychologists, school administrators, early childhood educators, teachers and the faith community, etc. to support healthy child development. Family physicians and other primary healthcare providers are trusted professionals who can teach parents about parenting and child development while respecting parent's individual value systems, religious beliefs and cultural activities.

The philosophy of care is usually family-centred. Family Centred Services recognize the significance of family support, participation and choice. They respond to the physical, emotional and psychosocial needs of the patient and family. Care is provided within the context of the family.

Note re: Canadian Families

The authors recognize that family composition and the roles of family members vary widely in Canada. While we often think of a family as a father, a mother and their children, single parent families are growing in number. "Parents" may be of different or of the same gender and may involve biological parents and/or other adults. Parents may work outside the home, or may stay at home with their children. Often it is the mother who provides primary care for young children; however, the role of primary caregiver may be served by the father or extended family. For the sake of simplicity, this resource refers to the father and the mother of children in their early years, recognizing that families are often much more complex. We live in a multicultural society and customs and beliefs also influence parenting practices. Primary healthcare providers need to be sensitive to the variety of family structures and the range of roles served by individual family members.

It is important for primary healthcare providers to be aware of local child development services such as Healthy Babies Healthy Children, in order to provide appropriate referrals and to work collaboratively with other service providers. The primary healthcare provider also plays an important role in addressing client isolation and barriers to services such as language, disability and geographic location. Services that are culturally inclusive, available in different languages and offer home visits, childcare and transportation, can have a positive impact on client isolation and factors influencing child development.

C. Goals and Objectives

The goals and objectives of the "Improving the Odds: Healthy Child Development" Peer Presenter program for family physicians and other primary healthcare providers are to:

- -Foster preconception and prenatal health, recognizing that nutrition, drug use and other health issues have an impact on reproductive health and influence pregnancy outcomes
- -Provide education regarding the importance of healthy brain development during the first six years of life and its implication for learning, behaviour and health
- -Educate healthcare providers about the importance of parenting programs such as those offered through Early Years Centres and the need for "early referral" of all children during critical periods of development
- -Educate primary healthcare providers in the use of developmental screening tools to facilitate early identification of children with conditions such as autistic spectrum disorder and other physical, cognitive, social and emotional concerns
- -Assist primary healthcare providers in assessing for family problems that may interfere with the healthy development of children -Address the perception that early identification may be harmful where services are limited
- -Increase awareness and maximize use of local healthy child development services that meet the needs of children and families -Develop "opinion leaders" throughout Ontario who will continue to support the work of primary healthcare providers
- -Provide a forum for integration of new research evidence, government policy, coroner's jury recommendations and public health initiatives into guidelines for primary care practitioners

SECTION

THE EARLY YEARS - Research Evidence

Introduction

In the last thirty years, neuroscience has been uncovering the relationship between nature and nurture in sculpting the brain during the early years. Neurodevelopment of the fetus, infant and child is dependent on and modified by the environment. In addition, contrary to previous belief that the brain becomes more active as it grows, it is now recognized that the brain is most active during the earliest years. The quality of the early sensory experiences influences the brain's ability to think and regulate bodily functions. The effects of these experiences have implications for future physical and mental health as well as learning. In response to this newer perspective, the goal of family physicians and other primary healthcare providers must be to optimize the conditions for healthy growth and development for all children.

This section of the toolkit provides important background research evidence about early brain development, starting with a neuroscience update. Detailed information can be found in The Early Years Study (McCain and Mustard, 1999), the Early Brain and Child Development Kit (American Academy of Pediatrics, n.d.), and Early Child Development and Experience-based Brain Development: The Scientific Underpinnings of the Importance of Early Child Development in a Globalized World (Mustard, 2006) and the Ontario College of Family Physicians website (www.ocfp.on.ca).

Physicians and other primary healthcare providers need to fully understand the implications of these insights of the neurosciences. A child's environment and experiences have a long term impact on his or her emotional, social, cognitive and physical development. Brain development begins soon after conception. Plasticity is a feature of the brain throughout life, although to a more limited degree in the mature brain than in the developing brain. New discoveries also support the belief that the possibility of change continues throughout life. Nonetheless, the first few years are critical in laying a foundation for brain development.

Old Thinking

- •Genetics are of prime importance
- •Early experiences have a limited impact
- •Secure relationship-favourable context for development
- •Development is linear
- •Toddler's brain is less active than a young adult's brain

A. Early Neurodevelopment Processes - Neuroscience Update

Neurulation

Neurulation begins soon after conception. At 16 days, a group of ectodermal cells form a plate on the developing embryo. This neural plate folds to form a groove at 20 days and the groove fuses along the top forming a tube at 22 days. The tube is closed by 26 days, when a woman may still be unaware of the pregnancy. At the top end, the tube enlarges to form the brain.

New Thinking

- Interplay between genes & experience
- •Early experiences have an important impact
- •Early interactions affect brain wiring
- •Development is non-linear
- •Toddler's brain is twice as active as a young adult's brain (Shore, 1997)

Figure 1: Formation and Closure of the Neural Tube



Neural Tube Growth

The forebrain subdivides in the fifth week into the telencephalon. By six weeks, the areas of the pons, medulla, cerebellum, thalamus, basal ganglia, limbic system and cerebral cortex are beginning to take shape.

Figure 2: Early Human Brain Development



Cerebral Cortex Development

From the neuroepithelial cells lining the neural tube, neurons and glial cells are differentiated. As they are formed neurons migrate along glial cells outward, adding outer layers until there are six layers in the cerebral cortices. By five weeks the right and left hemispheres begin to develop. By the end of the first trimester, the mid and hind brain are well developed but the cerebral cortex is still smooth and undifferentiated. By 24 weeks, the beginnings of the major sulci or grooves in the cortex are becoming evident. Primary sulci are about the same in everyone's brain. There is more variation in secondary sulci. The tertiary sulci vary a lot and do not develop until the last month of gestation and through the first year of life. Each contains columns of neurons.

The Central Nervous System (CNS) is comprised of many different types of cells: neurons, glia, etc. Each type of cell is generated by a sequence of molecular-genetic events. The generative zone of origin (location on the neural tube) determines the kinds of cells that will be produced and where ultimately they will appear in the nervous system (see Figure 2).

Migration and Differentiation

In the cerebral cortex, neuroblasts are guided to their target destinations by radial glial cells.

Figure 3: Migration – Adapted from the Early Brain Development Kit, American Pediatric Society

Adult derivatives

-Smell

-Memory storage

-Association ("Intelligence")

Olfactory lobes

Hippocampus

Cerebrum



Neurons come in many sizes and shapes. They have a long process that conducts information away from the cell body. A series of smaller processes called dendrites receives information from other nerve cells through synaptic connections. Most cells are multipolar (several dendrites and an axon). Sensory neurons receive information directly or through nonneuronal receptor cells. Motor neurons connect with muscle or glands. Most of the CNS is composed of interneurons. There are also several kinds of glial or supporting cells that perform a variety of functions from producing myelin sheaths to regulating extracellular fluid. Intrinsic Neurons have local dendritic trees and axonal projections and do not project across multiple brain areas. Most neurons in the brain are intrinsic. Some of the most important intrinsic neurons are found in the cortex. Most of the neurotransmitter-receptoreffector systems in the cortical systems are inhibitory/refining. This means that when the neurotransmitter occupies the receptor site, changes in the membrane result in a less responsive postsynaptic neuron. The higher in the brain functionally, the more there are complex (local) regulating systems. The mature cells develop processes (axons and dendrites) and then form connections/synapses.

Figure 4: Arborization – Adapted from the Early Brain and Child Development Kit, American Academy of Pediatrics



Figure 5: Synaptogenesis – Adapted from the Early Brain and Child Development Kit, American Academy of Pediatrics



Extrinsic Neurons project axons out of their "home" area in the brain to many areas. Extrinsic excitatory neurotransmitter systems are more common lower in the brain. These neurons play a major role in coordinating and connecting the separate areas of the brain, both physically and functionally. The brain stem monoamine systems (eg. norepinephrine, dopamine, serotonin) are key examples of the important orchestrating neurons. Serotonin is an important neurotransmitter in the limbic system and is associated with emotions and memory. Some of these important systems are active in regulating the response to stress. The stress response involves extrinsic neurons, especially the neural systems comprising the reticular activating system (RAS). This system is important in consciousness and alertness. The following figure shows the projections of the norepinephric system. The centre of this system is in the locus coeruleus. This bilateral nucleus in the floor of the fourth ventricle sends projections to virtually all other brain areas. It plays a key role in orchestrating and regulating the response to threat. The norepinephrine system is illustrated as an example. Similar systems exist for serotonin and dopamine.

Figure 6: Norepinephrine System – Adapted from Andreasen and



Cellular Growth

Cellular growth continues furiously from birth to two years. New neurons are not added but dendritic growth and new synapses are formed. The cortex increases in size.









Newborn

3 Month Old

2 Year Old

Synaptic Sculpting or Pruning

From birth there is a massive increase in the number of synaptic connections. All areas of the brain go through a phase of synaptic over production, followed by a phase of pruning back or retraction of these connections. The visual area reaches a peak of over production at about the end of four months of age followed by a decline until about the fifth year. Other areas in the prefrontal area do not reach their peak until the end of the first year and gradually decline until adolescence when the adult complement of synapses is reached.

Figure 8: Synaptic Pruning – Adapted from the Early Brain and Child Development Kit, American Academy of Pediatrics



Figure 9: : Synaptic Changes – Adapted from the Early Brain and Child Development Kit, American Academy of Pediatrics



Hierarchy of the Brain

The brain is hierarchical; that is, it organizes from the inside out and from the bottom to the top, brainstem to cortex, with the simplest functions in the brainstem and the most complex in the cortex. As wave after wave of migrating neurons complete their cycles, eventually 6 layers of the cortex are formed. Importantly, these layers are formed in an inside-out fashion. This means that the deepest layers of the cortex are formed first, followed progressively by more superficial layers. Thus, the oldest part of the cortex is also the deepest part. Lastly, "columns" of related cells also form, many of which are thought to serve specific functions, such as the role of ocular dominance in vision. *Figure 10: Hierarchy of the Brain – Adapted from the Early Brain and Child Development Kit, American Academy of Pediatrics*



While somewhat simplified, it is clear that functional complexity correlates with the organizational complexity of the brain. The simplest regulatory functions are mediated by the lower, lesscomplex brainstem and the most complex functions (those that confer the most unique human properties) are mediated in the cortex. The human cortex contains approximately 40% of the total neurons in the brain. A key to understanding human behaviour is to recognize the complexity and organizational rationale of the brain. Different systems and areas of the brain mediate unique functions. The systems of the brain that allow us to "think" are different from the systems that allow us to move or to regulate our heart rate.

Myelination

In many parts of the brain the axons of neurons are myelinated. This sheath provides insulation so that the conduction is faster and smoother. Myelination is not likely completed in the prefrontal cortex until adolescence.

Figure 11: Myelination – Adapted from the Early Brain and Child Development Kit, American Academy of Pediatrics



B. Sensitive Periods of Early Development

Neural plasticity, that is the ability of neural systems to be modified by experience, plays a central role in brain development. It allows for adaptation from internal and external inputs. This ability is most important during the postpartum period when shaping of the neural systems is underway. As development proceeds the neural systems become more stable and patterns of function emerge. However plasticity remains a feature throughout life as evidenced by the fact that adults can learn new skills such as a second language or mount recovery after brain damage. Nonetheless the degree of flexibility is reduced with maturation and shows individual variation. Some neural systems ("experience expectant"), that is, most sensory systems, depend on experience occurring during a sensitive period of time in order for optimal functioning to occur.

These "experience expectant" pathways require a set of signals or stimulation to be present to differentiate normally; synapses are formed after only minimal experience has been obtained. Stereoscopic vision depends on regions of the visual cortex receiving separate inputs from each eye. These inputs result in a separate column of cells for each eye. If input is absent from one eye, or is abnormal, then these columns fail to develop normally and stereoscopic vision is compromised.

There is clear evidence from neuroscience research that the sensitive period for the development of visual perception is well defined and is dependent upon visual stimulation. There is recent evidence that the auditory system has a similar sensitive period so that speech perception depends on hearing appropriate language sounds during this period.

There is much evidence that the regulatory systems that guide our emotional responses and how we respond to stresses and challenges, develop definite patterns during the very early years. There is also evidence that remediation in later life may be possible through a variety of avenues such as psychotherapy.

The neural connections of the brain are not all constructed at the same time. It appears that there may be different sensitive periods for different parts and interrelated functions of the brain. The evidence for this comes from both the biological sciences, including neuroscience, and observational human and animal development studies. *Figure 12:* Sensitive Periods for Early Development – Adapted from McCain and Mustard, 1999



Some neural functions retain more plasticity and are sometimes termed "experience dependent". Many aspects of motor and somatosensory functions can be modified throughout life. Particular examples include the practicing of a musical instrument bringing about change in the motor cortex or the learning of Braille recruiting the visual cortex in a blind person.

It seems that certain aspects of cognitive development may require experience at a particular time. These may relate in some way to numeracy and literacy. However, these factors as yet remain unclear. Older preschool children seem to be in an optimal period of development to lay the groundwork for skills that are embedded in their particular cultural context. In western society, literacy and numeracy are important cultural tools. But there is no doubt that changes in cognitive function are possible throughout most of the life span.

C. Early Developmental Needs

During the first years, the infant needs to learn to modulate threat, to focus attention and to interact. Through interaction the infant achieves a sense of competence in affecting his/her surroundings and in gaining trust in relationships. The infant is also learning how to give and take and about empathy through experience. If not, the infant struggles to deal with his/her reactions and frustrations. Some children are more sensitive than others and may avoid interaction. Parents may be more or less intense in their approach to the infant. Ideally, the approach becomes moderated as the child and parent adapt to each other. As the infant becomes more able to modulate his feelings and behaviour, freedom to explore and learn increases. In the process, the child develops perceptions of himself, how he fits in and can affect his environment. If the child feels heard, feels he can do things himself and feels he is valued, then he will be ready to learn, to interact with others and to be cooperative (Sutton, 1995). Early developmental needs include:

- -A responsive environment attuned to the child's needs
- -Support to modulate negative affect (physiological and physical)
- -The presence of a consistent nurturing caregiver
- -Consistent structure with the freedom to play and explore in a safe environment
- -Cognitive stimulation with particular focus on experience in gross motor, fine motor, speech and other specific developmental areas

D. Reciprocity

An ongoing nurturing relationship with an infant involves the caregiver being able to read and respond to the baby's signals. A "dance" between the caregiver and infant develops which enables the infant to learn to modulate his emotions and behaviour (Berkowitz and Grych, 1998).

Figure 13: Three Sources of Energy for Development – Adapted from Brazelton and Greenspan, 2000



A responsive and nurturing environment helps an infant to build the neurobiological base for a flexible and adaptive stress response. The sensitive caregiver protects the newborn from over or under stimulation and helps the infant attain a steady state. The development of self-regulation in the infant is believed to start at birth. The task of the infant is to develop the capacity to maintain equilibrium in the face of internal and external stimulation. The caregiver assists the infant in this process. This self-regulation is the process whereby the infant becomes more resourceful in coping with incoming stimuli and is increasingly able to explore their world. The infant begins to understand emotional cues and to respond. The responsive caregiver provides more stimulation such as singing and sounds, with careful attention to the infant's capacity to tolerate new levels of stimulation. These interactions enable the brain cells to be recruited for particular purposes.

The process of learning to regulate behaviour and modulate affect has an important impact on how the child will handle stress and change. It is through these neural pathways that early brain development comes to affect the regulation of the autonomic nervous system and the endocrine/immune system through the hypothalamic pituitary axis.

E. Hypothalamic Pituitary Adrenal Axis (HPA)

The way the brain reacts to stressful stimuli is influenced by early brain development and affects the individual's capacity to think and regulate body function. Stressful stimuli activate arousal, stimulating the sympathetic nervous system and the HPA pathway. The initial response releases chemicals that heighten sensitivity and improve memory etc. But over stimulation or sustained stress has the opposite effect and appears to actually destroy cells in the HPA axis. Further chronic stress suppresses the immune system. The quality of sensory stimulation in the earliest years helps set the template for the brain's endocrine and immune pathways. The relationship between the brain and the endocrine system seems to be the pathway that is important for competence and coping skills. Learning skills as well as disease risks are related to these pathways (AAP, no date; Perry, 1993; Teicher, 2002).



Key Points - THE EARLY YEARS

-Before age one, there is rapid and extensive neurological development.

-Brain development is very vulnerable to environmental influences.

-The influence of the early environment is long lasting.

-The early environment affects the number of cells, the number of connections and the way they are wired.

-There is scientific evidence for the negative impact of excess early stress on brain function.

SECTION 2

RISK FACTORS - Clinical Issues

Introduction

Research is providing evidence that neuromaturation is directed by genetic mechanisms whose timing is regulated by and whose unfolding is sensitive to environmental influences. Epigenetics is the term frequently used to describe this interaction between genes and environment.

"Even the process of adaptation that follows a specific insult to the brain is complex. Many times severe disabilities highlight the limitations of the central nervous system for recovery; but on the other hand, there is equal evidence of the brain's ability to adapt to a wide variety of insults with apparently few sequelae. The young brain is more adaptive than the more differentiated mature brain; that is more changes in communicative pathways can be made (rewiring). The effect of an insult to the CNS may be insurmountable or be simply a risk factor that can be neutralized by a nurturant, caregiving environment. For the child, the interactions and relationships with caregivers are the most crucial elements in the environment. If these relationships are dysfunctional, even the most biologically resilient child will be at risk for later problems. When these relationships are supportive of adaptation, the child with severe neurological vulnerabilities may have the opportunity to thrive." (Shonkoff, and Marshall, 2000)

Developmental Vulnerability

Insults to the developing nervous system of a fetus or child may have adverse consequences for later competence. The developing nervous system is vulnerable to a wide range of risks. Factors that are present in the parents prior to conception can influence reproductive health and future pregnancy outcomes. During the prenatal and perinatal period, the nervous system of the fetus is particularly vulnerable. After delivery, factors related to the child's immediate social environment are additional concerns. It is important for the primary healthcare provider to have a good understanding of strategies to identify risks to early development, and how to prevent or moderate their influence as described in Section 4 of this toolkit. In this section, information is provided on risks that may be present in the preconception, prenatal, perinatal and postnatal periods.

A. Preconception Issues

Prior to conception, a range of factors in the mother and the father can influence fertility, reproductive health and ultimately, the health of future children. These factors can be related to lifestyle factors, genetics, the social environment and medical concerns. Preconception is an opportune time to determine and reduce risks to future progeny.

Genetic Factors

Many genetic disorders are associated with neurological, cognitive and behavioural abnormalities. In multifactorial disorders, the expression of the disorder in the individual is dependent on the interactive effect of one or more genes and specific environmental factors. Genetic disorders include:

- –Chromosomal abnormalities, for example Down syndrome or Fragile X
- -Single gene defects, for example inborn errors of metabolism such as PKU
- -Mitochondrial disorders
- -Multifactorial disorders, for example neural tube defects or schizophrenia

Pre-existing Maternal Conditions

Pre-existing conditions in the mother can pose risks to fetal neuro-development if maternal health is not well managed prior to pregnancy. Diseases such as diabetes, cystic fibrosis, lupus and epilepsy can compromise the fetus. Medications such as anti-convulsants, antihypertensives, antipsychotics and lithium can potentially present threats to the fetus during pregnancy. The ideal time to assess and manage pre-existing conditions and medications is prior to conception. The risk to the fetus versus the risk to the mother may have to be balanced. Motherisk is a good source of information (<u>www.motherisk.org</u>) about pregnancy and medications (prescription or OTC), tobacco, alcohol, substance use, herbal products or occupational/environmental exposures. At Motherisk, a team of medical experts provides healthcare providers and patients with current information. See Appendix A for a more comprehensive list of preconception concerns.

B. Prenatal Developmental Vulnerability

Maternal Health Problems

Pre-existing conditions such as illness or use of medications can continue to pose risks to infant neurodevelopment if they are not well managed throughout pregnancy. Health problems that arise during pregnancy, such as eclampsia and gestational diabetes, can also pose a risk to the infant.

Maternal Nutritional Risks

Nutrition concerns that impact on neurodevelopment in the fetus include:

- -*Folic Acid:* Folic acid can substantially reduce the risk of neural tube defects, both in a first pregnancy and after an affected pregnancy. Because the development of the neural tube is already near completion when a woman may become aware of her pregnancy, folic acid supplementation must be initiated prior to conception. At least half the cases of neural tube defects can be prevented through periconceptional supplementation with folic acid (Van Allen et al., 2002). While some Canadian foods are now fortified with folic acid, the levels are insufficient to prevent neural tube defects. The 2002 Health Canada recommendation for folic acid supplementation is 0.4 mg per day for women of childbearing age. In the case of a previous neural tube affected birth, 4.0 mg per day is recommended (Van Allen et al., 2002).
- -*Nutrition Patterns:* Women need extra nutrients during pregnancy. Poor nutrition patterns can contribute to low birth weight. Some women aim to gain too little weight during pregnancy or adhere to ill-informed diets. Other women live in poverty and have little access to nutritious foods. Inadequate nutrition threatens both the mother and the unborn child. Calcium and iron are important dietary concerns. Iodine deficiency can also be a concern.

For comprehensive nutrition information, please refer to Nutrition for a Healthy Pregnancy: National Guidelines for the Childbearing Years at <u>www.hc-sc.gc.ca</u>.

Toxins

Substances that can have negative consequences on fetal neurodevelopment include:

- -Alcohol: Alcohol use in pregnancy is a leading cause of birth defects and developmental delays in Canadian children. Although Fetal Alcohol Syndrome (FAS) is usually associated with heavy or binge drinking, low levels of alcohol use are associated with conditions such as low birth weight. The full syndrome includes facial anomaly, neurological concerns and growth restriction. Effects on learning and behaviour are noted even when characteristic facial features are not evident. A newer term, Fetal Alcohol Spectrum Disorder, describes the entire range of problems associated with prenatal alcohol exposure. The prudent choice for women who are or may become pregnant is to abstain from alcohol (www.healthcanada.ca/fas).
- -*Tobacco:* The greatest concerns with tobacco use are intrauterine growth restriction and/or premature labour resulting in an increased risk for low birth weight. In addition, there is increased risk of miscarriage, tubal pregnancy and multiple other problems (see http://pregnets.org).
- -*Illicit Drugs:* Cocaine is associated with low birth weight, intrauterine growth restriction and abnormal brain growth. It has been difficult to determine the precise influence of cannabis and other illicit drugs in pregnancy due to confounding factors such as nutrition, alcohol and tobacco use as well as other lifestyle factors.
- -*Chemicals:* Many substances are harmful to the developing fetal brain. Exposure to these toxins can occur in the home and in the work place. Such substances include mercury, lead, organophosphates, solvents, etc. In northern communities, families may rely on wild game for food that may be contaminated by lead or mercury. Motherisk can provide important information about chemicals and pregnancy. Also see "Playing it Safe: Childproofing for Environmental Health" at http://www.healthyenvironmentforkids.ca.

Infection

During pregnancy, certain infections can lead to neurological impairment in the fetus including:

- -*Rubella*: While Rubella effects are rarely seen in Ontario, infections in early pregnancy are associated with more severe symptoms in the infant. 25% of affected infants have CNS symptoms at birth including increased irritability, small head size and hypotonia. By one year, one third of children have psychomotor retardation. Progressive hearing loss and progressive visual deficits related to cataracts and retinitis may occur. Often new impairments appear as development progresses.
- -HIV Infection: There is about a 30% transmission rate from infected mother to fetus without treatment. The infant may present with failure to thrive, subacute encephalopathy with delays in developmental milestones, apathy and spasticity. Subtle changes in behaviour, such as deterioration in play or mood may herald neurological regression. Ideally, HIV status should be determined and appropriate counselling regarding pregnancy initiated prior to conception. HIV screening must be offered to all pregnant women. Treatment of HIV during pregnancy significantly reduces the risk of transmission to the fetus. See http://hiv.medscape.com/ for more information.
- -*Toxoplasmosis:* 40% of infected women pass on the infection to the fetus. 10% of infants with the disease show symptoms at birth. These severe symptoms include seizures, chorioretinitis and hydrocephalus. The rest of the affected infants will develop symptoms later with chorioretinitis, motor problems, deafness and retardation. Uncooked contaminated meat is the primary source. Kitty litter also presents a risk because cats carry toxoplasmosis without symptoms and excrete the protozoa in their faeces (Shuhaiber et al., unpublished).
- -Cytomegalovirus: This is currently the most common cause of congenital infection that can lead to neurological impairment. Most infants are asymptomatic at birth but develop sensorineural hearing impairment. Some infants are more severely affected. It is usually primary infection during pregnancy that is associated with congenital infection in the fetus but it can be subsequent infection (likely a different strain). In the general population, immunocompetent individuals are not seriously affected and most are seropositive. Contact with young infants (i.e. in childcare centres) and immunocompromised individuals (i.e. in hospitals) are sources of infection through body fluids. Hand washing is stressed in these environments.

-Other Infections: There are other infections of concern in the prenatal period including Malaria, Listeria and Brucella (often contracted from unpasteurized cheese), Parvovirus 19 and Varicella (commonly contracted in childcare settings).

Social Factors

Social factors such as a mother's experience of abuse and low levels of social support are predictive of higher risk pregnancies and of problems after the infant is born. In these multifactorial situations, the incidence of low birth weight and preterm births is higher. See Appendix B for the ALHA tool.

- -Lack of Social Support: Even in the absence of abuse, pregnant women without support (such as women with an absent or unsupportive partner, single women, women with limited community or family supports or women living in an isolated area) are at risk for depression and unhealthy behaviours such as poor nutrition and substance use. Pregnant teens may be especially vulnerable due to isolation from peers etc.
- -Abuse: Studies on violence against women show that 40% of abuse starts during pregnancy (Johnson, 1996). Abuse frequently escalates during pregnancy. Women abused in pregnancy are more likely to experience severe violence. They are also very likely to experience violence in the first three months after the baby is born. Abuse during pregnancy threatens the well being of the mother and the fetus and increases the likelihood of other risks such as substance abuse, depression, and poor nutrition (Beck et al., 2000). Physical abuse increases the risk of miscarriage, prematurity and low birth weight. Verbal abuse, isolation and neglect of pregnant women must be considered, as well as physical abuse.

C. Perinatal Developmental Vulnerability

Neonatal Risk Factors

During the perinatal period, a range of risk factors can present difficulties for the developing infant brain. These include:

- –Birth Trauma
- -Prematurity (low birth weight, periventricular leukomalacia (PVL), intracranial haemorrhage)
- -Metabolic/endocrine e.g. hypothyroidism, hypoglycemia -Infection
- -Rh ABO incompatibility kernicterus

Premature infants who have a low birth weight are more susceptible to neurological insults that can be related to future neurosensorial and neurodevelopmental impairment. In the extremely premature infant, it should be remembered that the brain may not be ready for the sensory stimulation present in a normal nursery environment and the infant may require a specialized, quieter setting.

When hypothyroidism in the newborn is untreated, it can lead to irreversible neurodevelopmental impairments. In some conditions, such as PKU, neurodevelopmental harm can be ameliorated by preventive treatment (PKU through diet).

Multiple screening of newborns for numerous congenital metabolic abnormalities has replaced present routine screening for hypothyroidism and PKU in Ontario. Early recognition and treatment for some of these problems may prevent or ameliorate subsequent developmental problems (see Appendix F).

Through the Infant Hearing Program, hearing screening is performed on all Ontario newborns, acknowledging the longterm consequences of delays in the development of language due to undiagnosed infant hearing loss. The initial screening test uses Automated Distortion Product Otoacoustic Emissions (ADPOAE) technology. Positive screening will be followed up with a subsequent test using Automated Auditory Brainstem Response (AABR) technology. Together these tests are more reliable. Babies with abnormal screening results are then referred for audiology assessment and followup. Support and counselling are provided for parents regarding the future communication needs of their infant when identified as deaf or hard of hearing.

Impact of Neonatal Issues

There are many factors that are considered risks to the infantparent relationship because they increase the amount of care and stress involved in parenting the infant. Some infants are relatively easy to care for; others require more time and energy. While some parents may be able to manage with an easier infant, infants with complex medical and behavioural needs may overwhelm the parents. The risk of parental depression and child abuse increase when the infant requires a high level of parental care.

- -*Prematurity:* The parent may be overwhelmed by the needs and care of the small infant. These fears may interfere with the parent-infant bonding and attachment.
- -Health Problems in the Neonate: Parents may have difficulty coming to terms with a child who has congenital anomalies or is seriously ill. When a child is born with congenital

anomalies, the family may be in shock and may need time to grieve. Coping can be difficult. The extra care requirements for the infant significantly alter family dynamics and may increase isolation for the family. In addition, the infant's cues may be more difficult to read.

-Difficult Infant Behaviour: The extra sensitive infant who is hard to soothe may undermine the parent's confidence. The parent's expectations about infant development may interfere with optimal responsiveness and understanding, thus hindering secure attachment.

Maternal Risk Factors

A mother who is able to practice good self-care is more likely to do a better job of caring for her infant. Social support continues to play an important role in the mother's ability to adopt a healthy and positive approach to parenting. For example, a mother who is breastfeeding may require information and support around her caloric needs, calcium and iron supplementation and hydration. A mother with health problems or physical disabilities may need extra supports to cope with the physical demands of caring for an infant.

In the first weeks and months after the baby is born, the mother's capacity to be involved with her infant is critical to early neurodevelopment. Information and support can help mothers to be emotionally available to the infant, to be able to read the infant's emotional cues and meet the emotional needs of the infant. Postpartum depression is a maternal risk factor of primary concern in the perinatal period.

Postpartum Depression

Postpartum depression can interfere with the mother's ability to be attentive to the baby. There are a number of predisposing factors that increase the risk for postpartum depression. Many of these also indicate possible risks for abuse. In the presence of a depressed mother, a positive infant interaction with the father and/or other family members may partially counteract the mother's decreased ability to be sensitive to the needs of her infant (Shonkoff and Meisels, 2000). Even when improved, mothers with postpartum depression tend to demonstrate less attentive behaviour towards their infants. There are reminders about postpartum depression on the Postnatal Visit Form which can be found on the reverse side of the pink copy of the Antenatal Record II. See appendix C and R for more information on post partum depression (Chokka, 2002a):

- -Adolescence: Teen parents may be in a developmental period when their focus is more on themselves rather than others. They may have difficulty being aware of the needs of an infant. In studies of adolescent mothers, it has been found that conduct disorder is a major risk factor for early pregnancy. Poor nutrition, drug and alcohol use, and other risk taking behaviours may be of concern. Other problems relate to depression. Although about 6% of teen parents had major depression and 20% had minor depression at 6 weeks, by the time the infant was over one year of age, 54% met the criteria for depression. Other problems relate to substance abuse. Conduct disorders have been associated with insensitive mothering (mothers who are less responsive to their babies). In contrast, depressed mothers were more controlling than unresponsive. Both of these patterns have deleterious effects on the mother-infant relationship (Cassidy et al., 1996; Osofsky and Thompson, 2000). Teen parents also have a higher risk of having children with language delays. It may be useful to provide teen parents with suggestions on how they can stimulate their children's speech and language development.
- -Previous Psychiatric Illness: Postpartum depression can occur in the absence of risk factors. However previous psychiatric illness carries significant risk. More than 50% of all women experience mild transient postpartum "blues" that should abate by 2 weeks, however up to 20% suffer significant depression. Postpartum depression tends to start in the first weeks after delivery and may persist for several months. If mild to moderate, it may be insidious. Healthcare providers must search carefully for symptoms. Postpartum depression is particularly important because of the effect on the quality of the mother-infant interaction. Regular use of the Edinburgh Postpartum Depression Screen at well baby visits and the six week post partum visit is advised.

Postpartum psychosis also develops in the first few weeks after delivery, but is rare. Postpartum psychosis is an emergency requiring immediate treatment. Woman with postpartum psychosis may present with labile mood, disorganized behaviour with confusion, delusions or hallucinations that may involve the infant. The safety of the infant needs to be considered and at times drastic measures such as hospitalization or foster care may need to be instituted urgently. In cases of uncertainty, information and support is available from child protection services.

-Partner Unsupportive, Abusive, Absent: Changes occur in men in their anticipated or actual role as fathers. With the shift in attention from the couple to the infant, the dynamics in the relationship change. An unsupportive partner may feel threatened by the coming of the infant. Discord between partners may increase the risk for maternal depression as well as deprive the infant of the benefit of father-infant attachment. There is fair evidence (class B) of an association between child abuse and poor marital adjustment, especially if abuse is involved. Physical or other types of abuse increase the risk of maternal depression and substance use. See Appendix B for the ALPHA tool.

-Limited Social Networks/Support: Supportive social networks help a woman to feel positive about her role as a parent and less overwhelmed by the new parenting tasks. The mother with poor social supports during pregnancy is also at risk for postpartum depression. Social supports are buffers against stress, offer emotional support and physical resources. Mothers with social networks are more likely to make use of other community resources and less likely to be isolated and to feel overwhelmed.

Social isolation can occur in different ways. New immigrant families or ethnic minorities who are separated from their families and communities may be at risk. Similarly, the woman who is leaving her job to begin motherhood may also feel a loss of a support network. If a woman was abused or neglected as a child, she may have increased risk for depression and/or poor attunement to her baby especially if her social supports continue to be limited.

-Substance Abuse: The parent who abuses drugs or alcohol may be physically present but psychologically unavailable to the infant. Depression is often a factor. When a parent abuses substances, unpredictability and chaos may characterize the home. Emotional unavailability and abandonment as well as the risk of abuse are present. Children in homes where parents abuse drugs or alcohol are also at risk for issues such as inadequate parenting, poverty, excess stress and exposure to violence (Shonkoff et al., 2000). Substance use should also be considered as a possible symptom of psychiatric illness as women may self medicate for undiagnosed depression. Healthcare providers have an obligation to notify child protection services when parental substance use puts the child at risk.

Paternal Issues

The neonatal period is a period of transition for infant and family. It is a time when the patterns of bonding and attachment between the infant and parent begin. Changes also occur in the relationship between the partners. A positive mutual adjustment between parents determines the future health of the family and the child.

- -*The Changing Role of the Father:* Often the role of the father is overlooked. Although fathers do not undergo the physical and emotional adjustments that women experience, men often experience changes in their sense of responsibility and in their relationship to their partner. Cultural differences in the perceived role of the father can create conflicts particularly for some groups who are translocated.
- -Isolation: Some studies have found that the transition to fatherhood can pose a psychological risk for some men. They may feel isolated as their perspective shifts. Although their major priorities stay the same (they tend to see themselves as providers and protectors), they feel less certain regarding their role with the infant. Fathers generally recognize that a new baby implies an increased family workload; however, they still expect to receive attention and affection from their spouse, have a reasonable social life and pursue some of their own interests. They are at risk of feeling sidelined during this period. A new father who feels incompetent handling an infant may back away particularly if his spouse is perceived as critical of his attempts. Present day expectations of fathers to be nurturing may create conflict and uncertainty when many young men face parenthood without nurturing role models (Watson et al., 1995).
- -Depression, Chronic Mental Illness: The mental health of the father is often overlooked yet is a critical factor in the overall health and well being of the family. The Edinbugh Post Partum Depression screen has been validated for use in men and can be a useful tool for identification for those new fathers at risk for mood disorders.

These paternal factors may compound the mother-infant issues that have been identified as risks to the care and nurturing of the infant and the development of a healthy relationship. Some of these factors are related to the mother and her social situation, and others to the infant. All the risks may be additive.

D. Infant Developmental Risks

Infant Developmental Risk Factors

As the infant begins to grow in the context of the family there are a number of factors that now present risks to the infant's further neurodevelopment.



Development Delays

The four-way arrow in this diagram indicates the strong interplay between these issues. Although problems in each area can originate independently, there is a need to be aware of the possibility of the presence or development of problems in the other areas. Problems in one area may be a factor for each of the others. The interplay can increase the risks to ongoing neurodevelopment. It is important for the primary healthcare provider to consider the following infant concerns:

- -Failure to thrive relates to physical growth and health of the child
- -Developmental delays relates to observed behaviour of the child
- -Abuse, neglect, deprivation relates to the quality of the child's environment and care
- -Attachment problems relates to the nature of the parentinfant relationship

More information on each of these developmental risk factors is provided below:

Failure to Thrive

Failure to thrive is described as a failure of the infant to grow in weight and height along an expected growth pattern. Infants that fall below the 3rd percentile are of concern as well as children who show a drop off of two major percentile lines on the growth curve or a major difference in weight and height percentiles. Although some children are simply of small stature and are otherwise healthy, failure to thrive needs careful investigation and its potential effect on neurodevelopment should be recognized. It is helpful to consider the child's failure to grow in terms of his/her nutritional intake. (Hilliard, 2000):

- Inadequate intake of nutrients or calories (inadequate supply, difficulty eating, lack of interest in food, refusal to eat)
 Increased loss of nutrients
 - -From gastrointestinal tract (vomiting or lack of digestion or absorption such as occurs in coeliac disease or cystic fibrosis)
 - -Other loss of nutrients (sugar in diabetes mellitus or protein in nephrotic syndrome)
- -Underutilization of nutrients (such as occurs in some syndromes, chronic disease or infection)
- -Overutilization (hypermetabolic states such as in hyperthyroidism or a malignancy)

This toolkit will not discuss such investigation specifically, but will focus on some of the direct and indirect effects of failure to thrive on neurodevelopment.

-*Malnutrition:* The effects of malnutrition are particularly important from midpregnancy to the second year during the phase of rapid brain development. In the third and fourth year malnutrition has a negative impact on the rapid period of myelination and elaboration of dendritic branching and synaptic connections. The timing of any nutritional insult as it relates to the maturational state of the brain will indicate the long-term effects. Intellectual impairment as well as behavioural characteristics can occur as a result of malnutrition.

Medical disease can result in undernutrition. In some cases, even in the presence of a supportive home and appropriate stimulation, cognitive function can seem intact but there may be subtle deficiencies in short-term memory and attention present.

Deficiencies in specific nutrients can produce developmental sequelae. In particular, iron deficiency anemia in infancy has been associated with decreased motivation, shortened attention span and cognitive impairments. There is a risk of the impairment persisting after the deficiency is corrected. (Shonkoff and Marshall, 2000). Premature infants are at greater risk of developing iron deficiency than full term infants. Restriction of dietary fat is not recommended before 2 years of age because it may compromise healthy growth and development (CPS, 1998).

In developing countries, calorie and protein deprivation during the prenatal and early childhood period has resulted in cognitive delays and behaviour problems. Marasmus and Kwashiorkor, two severe forms of malnutrition that can occur in the first two to three years of life, can alter brain growth. Malnutrition is often associated with poverty especially in developing countries. Severe diarrhoea in the young infant in these countries also contributes to malnutrition. When these children survive, not only is their physical size compromised but their impaired learning ability may persist for a lifetime. Canada is a multicultural society with many immigrants and refugees who may come to this country having experienced harsh living conditions in their country of origin. It is important to obtain a thorough history of a child's early years if malnutrition is considered a factor in the clinical presentation. There is a need to be aware of family dietary preferences such as strict vegetarianism that could cause deficiencies for the infant and toddler.

Breastfeeding provides both optimal nutrition and stimulation for newborns and infants. Breastfeeding provides opportunities for the infant to be in close contact with the mother. All attempts to encourage breastfeeding are important for the long-term positive effects that this can have on optimal child development. If breastfeeding is not possible, then feeding needs to mimic the nutritional components and the closeness of breastfeeding. For more information on breastfeeding and infant nutrition please refer to Appendix P and Health Canada's: Nutrition for Healthy Term Infants and Nutrition for a Healthy Pregnancy at <u>www.hc-sc.gc.ca</u>.

-*Chronic Illness:* Inherent genetic or primordial disease such as chromosomal abnormalities, intrauterine infections and a variety of pediatric syndromes are associated with poor growth regardless of intake. Medical illness and treatments for cancer, cystic fibrosis etc. are associated with failure to thrive.

Chronic illness may interfere with the infant's interaction with the caregiver and their environment in addition to any direct effect that the disease process or its treatment may have on developing brain cells. A supportive, caring environment may ameliorate the effects of disease. Unfortunately, it is not uncommon for chronic illness to cause severe family stress. The family copes with grief over the affected child as well as the special needs of the child. The risk of dissatisfaction between parents and of marital separation is significant. Parental confidence regarding care of their children may be decreased and the incidence of depression in parents is high. These factors can impact further on children with special needs and siblings. Parental overprotection in response to the child's illness may actually impede development rather than foster it. These children are also at increased risk for abuse and neglect, as are the siblings. Siblings' needs may be forgotten or underestimated because their needs are deemed less critical. It may be difficult for these families to find enough emotional or physical resources for all family members.

- -Interactional: Situations that lack supportive interaction may result in poor infant growth, sleeping and/or eating problems, in the absence of specific disease.
- -Environmental Toxins: We should be aware of the effects and sources of environmental toxins such as lead and pesticides on neurodevelopment. Environmental toxins can be present in many situations. Pesticides and herbicides are commonly used in farms and parks. Playgrounds may be situated on old dumps or factory sites (see Motherisk for more information or "Playing it Safe: Childproofing for Environmental Health" at www.healthyenvironmentforkids.ca).

Developmental Delays

With infant growth, development is expected in motor, language and communication, cognitive and psychosocial areas. Although there is variation from one infant to another, lack of progress beyond certain limits indicates that delays may be present. Any regression in skills is also important. Examples of developmental delays include:

- -Motor delays, for example not sitting by seven months
- -Language and communication delays, for example not babbling at seven months
- -Cognitive delays, for example not looking for dropped objects by seven months
- -Psychosocial delays, for example not laughing in playful situations by eight months

These delays may become apparent as part of a known problem or may represent a new issue. Such delays are important as markers of problems but are also important because they may in themselves contribute to further neurodevelopmental compromise either because of the environmental response (extrinsic) to the child or the limitations that the delay imposes on the child (intrinsic). For example, the infant who does not make eye contact and whose caregiver does not use opportunities to try to engage the infant may miss the learning of social cues.

Attachment Problems

The early parent-child relationship mediates and influences the course of a child's development. Attachment was the term first used by Bowlby in 1969 to describe the importance of the protective role of the caregiver, referred to as the "attachment figure". The infant's confidence in this person was referred to as "attachment". While attachment refers to the attitude of the infant towards the caregiver, bonding refers to the feelings of the caregiver to the infant.

Attachment behaviour was researched by Ainsworth in 1979 (Chodirker, 2001). She outlined different patterns of infant interaction with their caregiver in a structured strange environment. In her studies, a one year old infant and his/her mother were placed in a room with age appropriate toys. A friendly female stranger was present part of the time. The mother and the stranger both entered and left the room twice. The infant and parent interaction was monitored. The infant's responses when the mother returned were found to be the most informative. Three main patterns emerged:

- -Secure: Infants showed a balance of attention between the mother and the toys while the mother was present. When mother left, there was a wide range of reactions in the infants. When their mother returned, the infants responded positively to the mother. If they were upset they quickly settled and returned to exploring. Observed in their homes, these mothers were quick to respond to their infant's distress.
- -*Insecure, Avoidant:* Infants showing this pattern appeared independent and were busy with the toys when mother was present. They showed little response when mother left and tended to ignore her on her return. Observed in the home, when their infant was distressed, these mothers did not provide comfort and the infant did not appear to bring their feelings of distress to their parent. Mothers of infants with an insecure avoidant attachment may demonstrate a pattern of rejecting, ignoring care, and/or speaking to their baby in negative terms.
- -Insecure, Resistant: Infants showing this pattern reacted intensely on the mother's return and were hard to comfort. They were less interested in exploring. In the home, the mothers seemed to react to distress in the infant but were less responsive to positive situations.

Attachment is affected by both maternal and infant factors. Secure attachment is not like glue but rather more like elastic. It stretches

and the infant is able to move away to explore the world. It is a condition for learning and being curious about other things and relationships.

The two categories of insecure attachment (avoidant and resistant) are considered normal patterns for infants. However more secure patterns of attachment are associated positively with sociability, cognitive development and lower incidence of future behaviour problems. Another insecure pattern has been described:

-Disorganized/Disoriented: The infant shows an inconstant pattern of behavior and has no strategy for eliciting comfort when stressed. Sometimes the infant looks secure and sometimes not. In the home the parent's reactions are described as unpredictable and sometimes hostile. Mothers are often victims of former trauma such as abuse or domestic violence and suffer from unresolved loss. The infant is frightened and so is the parent. This pattern is predictive of future behaviour, learning and mental health problems in the child.

In the presence of maternal depression, increasingly insecure patterns are seen. Depressed mothers are more intrusive and more disengaged but also less responsive. The infants are less positive and show more negative affect. Unfortunately, research is showing that even after the depression has passed there may not be an improvement in the pattern unless efforts are made to change the parent-child interaction. Early detection of depression in the parent is vital. Prolonged separation and loss of the caregiver are also threats to infant attachment.

Factors that affect attachment are both maternal and infant:

-Parental Factors:

- -Attending ability and responsiveness
- -Personal experience of care
- -Perception of infant's demands
- -Capacity to set limits and console
- -Developmental expectations
- -Sense of competence

-Infant Factors:

-Temperament - Infants are different in their reactions from birth. Very sensitive infants may be hard to soothe and may fuss excessively. Some infants are intense and active. Others are more placid and easygoing; such infants may have cues that are hard to read. Sometimes there is a mismatch between infant and parent temperament and this situation can cause problems with attachment. -Ability to use mother as a base - Some infants have trouble with attaching and using a parent as a secure base. In this situation even a responsive parent may tend to back off or become frustrated or intrusive. A variety of problems including autism spectrum disorders may be present. Vision and hearing may need review. Physicians and other primary healthcare providers need to enquire and listen regarding infant characteristics because parents may need help and support to respond constructively to their infant.

Additional information about attachment can be found in IMPrint, the Attachment Collection, 2002.

Abuse, Neglect, Deprivation

Early brain development is adversely affected by absence of stimulation or chaotic traumatic stimulation. Deprived Romanian orphans, who were in the orphanages in their very early years and then adopted into Canadian homes, have shown persistent intellectual impairment, serious behaviour and relationship problems. If adoption occurred before four months of age, less difference from children who were born in Canada was noted as they grew. If they were adopted after eight months, the number and severity of their problems increased with the length in time they spent in an orphanage. These children who were adopted later in life showed significantly higher evening sterol levels.

Both animal and human studies are yielding new information as to the effects of abuse on neurodevelopment. The brain structure and function of adults who have suffered severe abuse as children, show a variety of differences from non-abused control adults. EEG abnormalities have been documented in the left temporal and frontal brain areas. Several studies involving MRI scans have shown reduction in the left hippocampus and amygdala, two critical areas of the limbic system related to memory formation and retrieval. The change in size in the hippocampus has not shown up in studies in abused children or adolescents. This observation is due to the fact that effects of chronic stress on the hippocampus are protracted and are not apparent until later in life.

Differences in the integration of function between the two cortical hemispheres can be detected by sophisticated EEG techniques. In recalling painful or neutral memories, subjects with a history of abuse tended to involve their right or left hemispheres exclusively, whereas normal subjects showed a balance of activity in both hemispheres. In spite of right-handed dominance in an abused individual, there was less development in the left hemisphere when compared to their right hemisphere. In addition, the left hemisphere was less developed than in a normal subject. The corpus callosum also showed reduction in size. Here neglect exerted the most powerful effect in boys and sexual abuse, the greatest in girls (Teicher, 2002).

The infant raised in an unpredictable, abusive or neglectful environment will develop a poorly organized dysregulated CNS catecholamine system. If the environment is unpredictable, chaotic and violent, a hyper vigilant, hyper-reactive arousal system is adaptive, where survival is the goal. The ramifications for learning, social interactions, mental and physical health, are enormous (Perry, 1993). An example of an unpredictable environment is one where there is conflict or abuse between parents. A child who has been exposed to abuse may be at risk even if not abused directly.

Neurological effects of physical abuse and neglect should be mentioned. Shaken baby syndrome can be responsible for brain damage. Accidents in small infants and toddlers are often a result of carelessness or ignorance on the part of the caregiver. Less blatant neglect and deprivation can occur when overburdened parents can't respond to the child, use the television extensively as babysitter, or leave the child in non responsive childcare situations. Harsh, hurried care may not constitute abuse but is less than optimal for development. It is not unusual for suboptimal patterns to develop in all socioeconomic groups (Perry, 1993; Teicher, 2002). Healthcare providers have an obligation to report abuse and exposure to abuse to child protection services.

E. Resilience

In spite of adverse conditions, some children mature into welladjusted competent adults. Some factors seem to make a difference. In addition to having an easy sociable temperament, these children manage to connect with some other adult in their environment, such as a grandparent or an older sibling. They appear able to handle themselves in the midst of the situation and still make significant connections in their environment. They seem able to find a social environment that reinforces and supports their coping ability (Werner, 2000).

Factors that Contribute to Resilience

- -Easy going temperament
- -Available caring adult
- -Good self-management skills and a supportive environment

Studies around resilience are helping in the search to determine the types of interventions that might help to optimize the development of all children.

F. Social and Economic Factors

Economic factors can be risks to child development. Poverty leads to a pattern of deprivation at the personal, family and community level. Risk factors such as poverty, minority group status, and social impoverishment are known to be associated with increased infant mortality and with child maltreatment. However these factors are not causative. Not all poor communities are socially impoverished. Socially impoverished communities are not necessarily poor. There is good evidence that social environments, which are mutually supportive where "neighbours" have a sort of cultural network of mutual respect and positive interaction, provide protective factors for their children's development.

Social policies also have an impact. In societies where there are no policies to ease the impact of poverty, the correlation of poverty and poorer child outcomes is higher. Thus, socioeconomic status is a more important predictor of child maltreatment in the USA than some European countries as well as Canada where more universal social support programs exist (Garbarino and Ganzel, 2000).

In the National Longitudinal Study of Children and Youth, children were identified with difficulties on the basis of learning or behaviour problems. Family income is not the most powerful influence on how well children are doing. Socioeconomic status of the family has an effect on children. However, the gradient makes it clear that other factors must be involved. If not, all the well-off children would do well and all the poorest children would have difficulties. This is not the case. *Figure 16: Prevalence of Children with Difficulties by Family Income – Adapted from Wilms, 1999*



The chart summarizes the relationship between children with difficulties (verbal skills, mathematics and/or behaviour) and family income. Note that 35% of the children in the bottom quartile are in difficulty while more than 20% of the top quartile are in difficulty. The majority of children who are not doing as well as they could are in lower-middle and upper-middle income families. Such findings support the need for universal programs that encompass all populations.

The research findings from the National Longitudinal Survey of Children and Youth point to parenting practices as a powerful influence on how well children are doing. Reading to children, responding to questions and concerns, and setting limits seem to make a big difference. Both positive and negative parenting practices are found across all socioeconomic sectors (Wilms, 1999).

Key Points - RISK FACTORS

- -Risks to neurodevelopment can occur in the preconception, prenatal, perinatal and postnatal periods.
- -Neurodevelopmental risk factors are additive, compounding their effects.
- -Neurodevelopmental delays become risk factors themselves both because of the direct effect on the infant and the indirect effect on the family.
- -Nature and nurture are continuously interacting and changing in response to the ongoing interaction between the infant and his environment for positive or negative outcomes.
- -Children and families can become "at risk" at any time as circumstances change.
- -Early detection and intervention to reduce risks is of paramount importance.

G. Transactional Model

Another way of understanding the interplay between environmental factors is to view the outcome as a product of the ongoing dynamic interactions between the child and his/her family and social context. This understanding is important because it emphasizes the fact that the child's individual differences play a part in what the child triggers in his/her environment and what the child is able to take from this environment. Understanding this transactional process makes it easier to recognize the complex nature of interactions and may assist in developing strategies that may improve outcomes. Happily, the evidence that early intervention makes a difference in outcomes for children has a solid research base and is growing rapidly (Sameroff and Fiese, 2000).



Transactional Model



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PARENTING - Key Concepts

Introduction

Most people would agree that children are a country's most important resource. In spite of this belief, preparation for parenthood is given less attention than most other tasks performed including driving a car. Most people rely on their own past experiences of being parented and on intuition. This perspective is still prevalent in a society that has changed a great deal over the past 50 years. Over recent decades there has been growing interest regarding the effect of societal changes on young children and their families. There has been a steady increase in the number of families with preschool children in which both parents work outside the home, as well as the number of children in single parent family situations. Shift work and family mobility have decreased the support systems for families. At present, there are concerns that our youngest citizens are at increased risk.

The increase in problem behaviour and violence among young people has brought more attention to the importance of these early years. The school system is concerned about the increase in the number of children with a variety of learning, emotional and behavioural problems. It is not sufficient to wait until a child reaches school age to assess issues and to address needs. In addition, the expanding information regarding brain development has spurred efforts to pay more heed to early childhood needs. Countries that have invested more resources into young children and their parents are experiencing better outcomes in their children in some measurable parameters such as literacy, school achievement, etc. (McCain and Mustard, 1999). The commitment to put more resources and effort into this developmental period of life is being made by government, professional groups, communities and parents.

Primary healthcare providers are in an ideal position to create links that support and improve parenting. Recent information on the importance of the early years to neurodevelopment makes it imperative that primary healthcare providers provide all families with information and services about parenting. Parents provide the major and most important environment for a child in the first few months and years. Therefore primary healthcare providers who naturally encounter children, parents and families need to learn as much as possible about the parenting process during this critical period of life. Primary healthcare providers can also take advantage of parenting experts in the community both to increase their own knowledge and for the benefit of their patients. Physicians and other primary healthcare providers can be a catalyst of improvement for children. A catalyst does not do the work but facilitates the action. The ongoing, trusting relationship with families during the prenatal period, at birth and during the early period of life puts the family practice team in an important position to contribute to this task.

A. Parents Poll

"Invest in Kids" sponsored a national survey in 1999 of 1,645 families with at least one child under six. This group was representative of Canada by region, language and income. The purpose of the poll was to determine what parents know about the importance of the first five years of life, the pivotal role parents play during that time and whether parents feel confident in their ability to care for their children. Most importantly, the parents poll showed that 61% of mothers turned to their child's doctor as the top source of information on parenting.

Results

- -92% believed the parent's role to be very important
- -85% believed babies learn from birth
- -50% believed nurturing influences development
- -Parents had low levels of knowledge about physical, emotional and social development

- -Parents believed they had the most influence over emotional development and the least influence over the development of knowledge
- -Parents felt most insecure around the birth of their first child
- -Parents wanted to improve their parenting skills
- -55% of fathers and 70% of mothers tried to prepare for parenting by reading, asking advice, etc.
- -Only 52% of parents had enough emotional support
- -Only 56% had enough practical support
- -40% believed that Canada values parenting

From this poll it seems that many parents feel unprepared and unsupported in their role. However, parents may be disturbed by a recommendation to participate in parenting programs. Instead of seeing this as an opportunity to improve skills, they may feel that the healthcare provider is suggesting that they are inadequate parents. In our society, prenatal classes are considered routine and helpful for everyone. It is hoped that this same attitude toward education about parenting will be the norm in the future (see website #5, page 51). Primary healthcare providers can facilitate this attitude by making parenting training part of the routine recommendations for new parents.

B. Goals of Parenting

How many parents sit down and consider their long-range goals as parents? Many parenting programs encourage parents to do so. Parents often have specific dreams or expectations for their children that may be unrealistic or burdensome to the child. Examining their goals may help parents to delineate realistic and supportive goals for their parenting. They may recognize the dangers of short-term goals and plans that make the parent's immediate life easier. Instead they may develop strategies to achieve more long-term child-centred goals.

One parenting program sums up parent goals, reflecting on the nurturing as well as the training role of parenting and alluding to the fact that parenting takes place in a cultural context:

> "The purpose of parenting To protect and prepare children To survive and thrive In the kind of society in which they live" Active Parenting

Parenting is Difficult

Parenting can be challenging. No other job is really fulltime. The nurturing of a young child is demanding emotionally, physically and socially. Most new parents find that their world is completely changed and the child dominates the scene. As the child grows and starts to move around, the need for parental supervision and the ability to set and enforce reasonable limits becomes increasingly important.

Nurturing and Setting Limits

These two sides of parenting are both important. Without nurturing, caring and support, the child withers. Without positive discipline, the child's behaviour may become increasingly problematic. Parenting provides many opportunities to practice and improve this balancing act. Parenting styles reflect differences in the balancing of these two poles and are reflected in outcomes. Consistency within and between parents is important.

Figure 18: Parenting – A Process



Stimulating and Encouraging Development

Stimulating and encouraging development is another important part of parenting. The parent needs to learn to pick up the child's cues, to be sensitive to the child's learning style and to be stimulating without overwhelming the child. Singing, talking, reading and playing with a small child provides both nurturing and stimulation. Helping the child learn to do gradually more complex tasks increases the child's sense of self-esteem and accomplishment. Parents can help a child deal with the frustration of struggling to master skills and tasks by being patient and encouraging (Dwivedi, 1997).

C. Parenting Style

Types of Parenting Styles

- -Authoritarian Parenting: This style of parenting tends to be controlling and rigid. Parents are less sensitive to the child's perspective. They set firm limits and do not negotiate rules. They value obedience and respect, but show low levels of nurturing, warmth and empathy. This parenting style often leads to rebellion.
- -Permissive Parenting: This style of parenting can be more nurturing or can be disinterested. The child has the control. Parents have trouble setting limits. Often this style can lead to conflicts as a child becomes older and increasingly demanding. Setting limits at that point becomes very difficult.
- -Permissive Irrational Parenting: This style of parenting is unpredictable. It is at times supportive, at other times not. Parent-child interactions are not related to the child's need but to the parental mood or need. It may be associated with parental substance abuse, parental psychopathology or violence in the home. The incidence of child problems is close to 50% in this style of parenting. Of course child abuse or neglect is a frequent concern in such a situation.
- -Authoritative Parenting: Parents are responsive to their child's needs, and nurture and support their child. Parents have realistic goals and rules for behaviour and communicate these expectations to children. They set age appropriate limits and demands. In addition they support the adherence of these behaviours in consistent, positive ways. These parents acknowledge their children's thoughts and feelings but do not give in to demands. They listen and give explanation for the limits but do not engage in endless discussion about limits. This approach helps to establish a warm, mutually positive basis for interaction. Such interaction is linked to secure attachment and self-esteem. Children feel valued and loved, but can delay gratification and acknowledge responsibility for their behaviour. It also fosters the perception that people deserve respect and teaches empathy. This style is considered optimal. This style of parenting is associated with higher levels of child cooperation.

In the National Longtitude Study (see Figure 19), one third of parents had an authoritative style, one quarter was authoritarian and one quarter was permissive. About fifteen percent were permissive-irrational. Children seemed more affected by parenting style than by socioeconomic status. Other studies support this conclusion (AAP, no date; Shonkoff and Meisels, 2000).

Figure 19: Parenting Style Outcomes – Adapted from McCain and Mustard, 1999





Parenting Styles

D. Enhancing Parenting Skills

There is a wide range of parenting programs and services, ranging from informal playgroups to formal instruction on parenting techniques. Some programs provide general parenting information, others enhance specific skill areas, or are designed with a specific audience in mind, such as new fathers. Parenting programs and services have many things in common, including principles and techniques.

Principles of Intervention and Parent Support

- -Respect for parents
- -Sensitivity regarding cultural issues
- -Improving social supports
- -Increasing parental confidence
- -Increasing parental pleasure in children
- -Supporting and improving parenting skills "adding to the toolbox"
- (Baron-Cohen et al., 2000)

Parenting Prerequisites

- -Motivation: Most parents want to be good parents as indicated by the parents poll. However sometimes parents have other problems that need to be acknowledged and addressed before their parenting ability can improve. Parents may need additional support and resources if they have a mental illness such as depression, bipolar disorder, schizophrenia, personality disorders or post-traumatic stress disorder, or if there is conflict between partners or other problems are present. Concern for their child's well being may provide the motivation for some parents to tackle certain problems. Parents may be prepared to try to solve problems for their child's sake when they might not do it for themselves. If parents are so troubled or burdened that they are not able to be concerned about their children, then intensive intervention may be needed. Are the children at risk? Should child protection services be consulted?
- -*Resources:* In assessing parent's needs, consideration of physical, emotional, financial, social, family, spiritual, socio-economic, housing and cultural resources is important. If a family has limited resources, then assistance in these areas may be most important to enable parents to perform their task.
- -Opportunity: Parents need time and opportunity to perform their parenting role. If a parent has limited ability to expend much effort with a child then this parent may feel unable to fulfill suggested activities. Then such information may add further burden to this stressed parent. Extra responsibilities, illness, or other situations may severely restrict a parent's opportunities. Different kinds of support may be needed for a child in this type of family situation. Childcare or respite services may bring the child more support and bring relief for the parent.
- -Knowledge: In the poll, parents indicated that they needed more information about parenting especially regarding emotional development. They also needed education about issues such as development, childcare, safety and health.

In order to assist parents, physicians and other primary healthcare providers need to consider these issues in order to determine what kinds of supports will assist parents to do their job at any given time (Baron-Cohen et al., 2000; Shonkoff and Meisels, 2000).

Parenting Programs

Parenting skills can be improved through:

- -Home visiting programs, e.g. HBHC Program
- -Parent support groups, e.g. Baby Talk
- -Parent training programs, e.g. Nobody's Perfect
- -Family Resource Programs e.g. drop in programs for parents and children (Ontario Early Years Centers)
- -Books, videos, websites etc.
- -Peer support e.g. self help groups

Parenting enhancement and support can occur in a variety of ways depending on the needs of a family. All parents can benefit from some of these programs. Many of these efforts have been started in order to help high risk families, however enhancing the skills of all parents provides a more positive focus in a community and enables parents to help each other without the stigma of labels. These options will vary from one community to another. Some may be community programs, others may be offered through professional services. It is helpful to know about options that are available in your community.

Some of these programs are specialized to deal with specific risks or problem areas. Home visiting may be provided to a new mother who has risk factors identified during pregnancy or at the time of delivery. For example, in Ontario, the Healthy Babies Healthy Children program provides a trained visitor to support the mother/family in caring and bonding with the baby in their home. Such intense programs have been shown to decrease the incidence of abuse. Other home visiting programs may help parents learn the extra parenting skills needed to help a child with a developmental delay or a behavioural problem.

The same is true of parent support groups and parent training programs. These types of groups may be general and provide support or training for all parents. Other groups may be specialized for parents with special concerns such as autistic spectrum disorder, attention deficit hyperactivity disorder or the adolescent parent.

The venue through which parents can achieve their goals may vary as well. Some parents would enjoy the support of a group, while others are not prepared to participate in a group. More than one venue may be used at once, for example a parent may take their child to a parent-child play group and may also have an infant development worker coming to provide training in the home. Healthcare providers who know their families well may consider which venue may suit a particular family.

Parenting programs may involve:

- -Small groups of parents
- -Group of parents and children, with child centred activities
- -One to one with or without the child
- -In the home with parent/s and child
- -One to one with parent and child

Parenting Program Goals

Although parenting programs vary in their focus, the following encapsulates the goals of most parent programs. The overall aim is to increase parent's satisfaction in their role and enjoyment of their children as well as their skill in managing and supporting their child's development. Most parenting programs are designed to:

- -Increase Knowledge about Development: Parenting programs work to increase parent's knowledge, especially in the areas of developmental stages, care and protection, aiming to reinforce the importance of stimulation and parenting in brain development.
- -Foster Secure Attachment: Parenting programs strive to increase parent's sensitivity and understanding of the child's perspective, empathy for the child and awareness of the child's cues, needs and temperament. The programs help parents become more responsive to the child, explore a wider range of response options and increase self-awareness in difficult situations.
- -Examine Parenting Styles: Parenting programs share information about the positive and negative consequences of different parenting styles, including the impact on children's emotional and behavioural outcomes. The possible outcomes of increased confidence and control in dealing with their children's behaviour as well as increase in compliance and

decreased conflict from their children can provide the motivation for trying out changes in style.

- -Improve Parenting Skills: Parenting programs address a wide range of parenting skills including:
 - -Discipline techniques such as setting limits and following through
 - -Communication skills, including positive listening and clear messages
 - -Problem solving skills for prevention of problems and teaching responsibility
 - -Stimulating development in an age appropriate manner
 - -Teaching values by sharing family tasks and beliefs
- -Foster Parental Self Care and Support: Parenting programs aim to improve parent self-care and support by sharing information on parental boundaries, fostering parent's relationships, and community supports for parents and their children.

Parenting Program Techniques

Parenting training can use a variety of techniques to facilitate learning and to make the process interesting, understandable and pleasurable. Some techniques are as follows:

- -Discussions about parental issues
- -Videos
- -Role playing
- -Problem-based discussions
- -Modeling
- -Additional resources such as literature and websites

If physicians and other primary healthcare providers are personally involved in their own parent training, it provides a good basis to recommend the same experience for patients.

Key Points - PARENTING

- -Be knowledgeable about parenting.
- -Encourage all parents to take advantage of opportunities to enhance parenting skills.
- -Assess parent-child interaction.
- -Be aware of risks to parenting and consider proactive intervention.
- -Advocate for parenting needs.
- -Be trained for parenting yourself.

Improving the Odds: Healthy Child Development



IMPROVING THE ODDS - Clinical Strategies

Introduction

What role do physicians and other primary healthcare providers play in "improving the odds" for optimal neurodevelopment in children? As part of the team, what can we do to ensure the child has the chance to reach optimal potential? Although there are many unknown factors regarding neurodevelopment and factors over which we have no control, there are interventions that can make a significant difference.

Parents and society provide the environment in which children are conceived, delivered and nurtured. Young women frequently attend clinics seeking advice and treatment for birth control to avoid pregnancy. These visits provide opportunities to share preconception information that can improve outcomes. The prenatal visit allows the health professional to continue this process, monitoring for risk factors and encouraging healthy practices to foster fetal health and future infant care. The process continues through careful monitoring of the mother and infant through labour and delivery. The ongoing assessment of infant and family continues through the well baby examination program. Physicians and other primary healthcare providers may have substantial contact with parents during these critical times of infant development. Hence it is important that primary healthcare providers are knowledgeable and apply evidence based practices in their work with infants/families. In addition, it is incumbant on physicians and other primary health care providers to become familiar with local resources that foster healthy child development.

Families with different cultural backgrounds and parents whose first language is not English may require additional services including translation, or may benefit from referral to culturally specific services. The parent's cultural beliefs about child development and child rearing and the degree of parent-child interaction may impact the healthcare provider's interaction with the client. Additional client intervention may be necessary to ensure that the parent is aware of the determinants for healthy child development.

A. Important Roles for Primary Healthcare Providers

Level of Intervention -Society	Target Groups -All children -Children at risk -Children with delay
-Community -Individual family/child	
Interventional goals in neurodevelopment may be described as	may not be to prevent a specific outcome but to reduce the
risk reduction and developmental enhancement activities.	influence of a particular negative risk factor. Intervention may
Although there are some clear-cut prevention issues such as the	target a community rather than an individual child. Some
treatment of PKU with a restrictive diet or thyroid insufficiency	interventions (risk reduction) aim to decrease the effect of those

with hormone replacement therapy, most developmental issues are not simple. Because neurodevelopment has so many interrelating factors that can affect outcomes, the aim of intervention interventions (risk reduction) aim to decrease the effect of those factors known to negatively affect development. Other interventions (developmental enhancement) promote factors that are known to support better outcomes.

The major focus of these efforts varies, based on local needs. In developing countries maternal and infant health, nutrition or safe water could be major concerns. Parents may need help with basic infant and child care. In a developed country, there are social factors affecting individuals and families that may create different kinds of problems that impact children. Although as primary healthcare providers we usually treat individual children, we need to be aware that development is contextual, taking place within a family, within a community, within a larger society. Thus, in order to improve the situation for children, the patterns of their development, both positive and negative need to be understood within a broader context. Interventions need to be contextual as well. At the societal level, it may be a decision to increase maternity benefits or provide a media campaign regarding safe sex. At the community level, it may be the decision to build a playground. At the family level, it may mean teaching parents to help their child with speech or it may be removing the child from an abusive home.

As a primary healthcare provider functioning in a community, it is important to know what other professionals, agencies or community activities, may be available to contribute to reducing the risks and enhancing development. Active communication and referral between all these participants will improve the interventional efforts and aid in assessing their effectiveness (Shonkoff and Meisels, 2000). Risk reduction and developmental enhancement can be aimed at different levels or target groups:

Specific Examples of Risk Reduction

Risk reduction aims to decrease the impact of those factors known to negatively affect development. Folic acid is a simple example of risk reduction:

- All women are recommended to take 0.4 mg of folic acid prior to pregnancy and in the early stages of pregnancy.For women at higher risk due to diabetes or epilepsy, or a
- prior child with a history of neural tube defect, the recommendation is to take 4 mg of folic acid.

Risk reduction can also have a role in reducing the risk of further problems in a child:

- -For children born with spina bifida, risk reduction involves assessment of the extent of the defect and the investigation for the hydrocephalus that may complicate the problem. This problem may need treatment to prevent further neurological damage (Hack et al., 2000).
- -Risk reduction for children with special needs may include

support for the family to deal with the physical needs of the child and the emotional/social effects on the family unit. The child and family may need special help to access school, community and other supports.

Development Enhancement

Developmental enhancement promotes factors that support better outcomes, and is important for all children and their families, not just those with known risks. For example:

- -All children will benefit from good early childhood educational experiences and opportunities to interact with other children as well as nurturing experiences with one or both parents.
- -For children at risk because of limited supportive stimulation, early childhood educational experience and play may be even more important.
- -To enhance the development of children with delays, more specialized early childhood experiences may improve their outcomes.
- -Enhancement efforts with children who have special needs may focus on any special abilities they have and also the family to enhance their coping skills (e.g. respite care).

Clinical Opportunities for Primary Healthcare Providers

There are many times in practice when there are specific opportunities to screen, assess and act. During these critical periods primary healthcare providers (i.e. midwives, obstetricians, family physicians, pediatricians and nurses) see women, infants and families and are in a position to promote optimal development. A planned approach for specific developmental periods will make these activities thorough, efficient and practical in the practice setting.

Roles for primary healthcare providers include:
Screening
-Identification of risk
-Identification of developmental problems
Risk reduction
–Education/Support
-Treatment/Referral
Monitoring/Ongoing care
Advocacy and Developmental Enhancement
Education
-Community awareness and interaction
-Community involvement and advocacy

Many screening opportunities are shared. Communication and collaboration are important in sharing information, in complementing each other's scope of services as well as in reducing duplication of services.

Screening opportunities include:

- -Well female visits/contraception counseling visits
- -Preconception visits
- -Prenatal visits
- -Peripartum visits
- -Well Baby Visits

B. Preconception

All women of childbearing age (from 16 to 45 years of age) should be screened for problems that might cause a concern for a future pregnancy and infant. If a young woman is asked about childbearing as an anticipated life goal, she may consider how her lifestyle and health may affect her future children and not just herself. The knowledge regarding early brain development needs to be available prior to conception. Women need to know that brain development is well underway by the time that a woman realizes that she is pregnant. A preconception perspective can be built into the annual health examination that many women have for birth control. For example, the risks of alcohol to the fetus are ideally covered in a preconception visit, rather than a prenatal visit several weeks into the pregnancy. All topics need not be covered completely at one specific visit, but can be covered over several visits (see Appendix A).

Planned pregnancies are predictive of better adjustment to parenthood and provide the opportunity to assess and reduce risks prior to conception (Cefalo and Moos, 1995). In the preconception period, there are many areas that are worthy of review:

-Genetic Background: Are there any genetic or other health problems in the family such as Down syndrome, cystic fibrosis, Tay Sachs disease, haemoglobinopathies, muscular dystrophy, haemophilia, neural tube defects, etc.? Discussing these issues may help a woman to consider in advance if she and her partner may need further advice prior to becoming pregnant. Woman may have questions about these issues but may be uncertain as to when it is appropriate to discuss them.

- -Health Problems: Women with health problems, such as diabetes, hypertension, heart disease, epilepsy, thyroid disease or mental health concerns, should be aware of the need to discuss pregnancy issues and plan healthcare during pregnancy. For example, changes in medications such as anticonvulsants, antipsychotics, antihypertensives, etc. should be discussed and initiated prior to pregnancy.
- -*Immunization:* If there is any doubt about immunization or immunity, then titres for rubella and hepatitis B etc. can be done and appropriate immunization given.
- -STD/HIV Screening: Screening for STD/HIV gives an opportunity to discuss safe sex and assess risk. Discovering if the woman is comfortable discussing use of condoms with her partner and if he is willing to use them will give some insight regarding the patient and her relationship.
- -Nutrition: Does the woman have eating patterns or an eating disorder that may affect her childbearing? Assess all women for nutritional status and ask about folic acid supplementation. The desire to have children may assist in motivating change. Women should be given information about the risks to future pregnancies.
- -*Violence Screening:* Asking about a woman's history of abuse at this time may facilitate her gaining any needed support, before she is dealing with a pregnancy. Sometimes women seek pregnancy believing that having a child will improve the relationship. It may be helpful to have her recognize that abuse often gets worse during pregnancy and puts a child at risk. See Appendix B for the ALPHA tool.

Preconception evaluation may include the following:

- -Haemoglobin testing and blood typing, further testing for haemoglobinopathies if indicated
- -Rubella titre, Hepatitis B, and HIV testing
- -STD testing
- -Other testing indicated in the individual situation

Anticipatory Guidance should include information about taking folic acid when pregnancy is a possibility. Woman should be encouraged to eliminate tobacco and alcohol prior to conception and to avoid other possible toxic environmental substances either in the home or workplace. Information about prenatal care and the timing of their first prenatal visit is appropriate.

SALLY AND BRAD'S CASE

Sally, age 24 years has come for a visit with her fiancé, Brad. They are planning to get married in the next few months and want to discuss future pregnancies. Susan has been diabetic since age fourteen and although she had a rough time adjusting to her illness, she now follows her diet fairly well and checks her blood sugars once a week. She admits that maybe she should do it more often. She takes 30 units of NPH insulin in the morning and 22 units at suppertime. She uses regular insulin at times.

QUESTIONS TO PONDER: What special care might Sally need before and during pregnancy? What are the risks to the fetus and how can they be reduced? How can you introduce the option of delaying pregnancy until her blood sugar levels are controlled? How can you foster support from Brad?

DISCUSSION: Recognition of preplanning as a strength is important. Exploring both their family histories for any genetic problems, diabetes or other family illness may be an important part of the discussion at this visit. Sally needs a review of her diabetes because of her rather high insulin dose and her fairly lax attention to her blood sugars. Any complication of diabetes should be investigated prior to proceeding to try to become pregnant. She needs to learn of the importance of tight control of her blood sugar before and during pregnancy and for the need for folic acid. She should be advised about a plan for prenatal care regarding obstetrical and medical consultations. She now may be willing to go to a diabetic clinic for retraining. Of course other issues related to HIV, HepB testing etc. should be discussed with them both as well. If Brad has come because he is motivated to encourage Sally and support her in her care, the positive outcome of a pregnancy will be enhanced for this couple.

C. Prenatal

The goals of prenatal care are a healthy term infant and a healthy mother. Prenatal roles include antenatal care, prevention, risk detection, intervention to reduce risks and treatment of intercurrent problems. The Society of Obstetricians and Gynaecologists website provides valuable information about prenatal care: www.sogc.org.

Antenatal Visits and Records

- -Forms such as the Ontario Antenatal Record can be very helpful aids in providing care if they reflect evidence based practice, are easy to use, comprehensive and updated to reflect current practice. The Ontario Antenatal Record is used almost universally (Beck et al., 2000; Schuurmans et al., 1998). See Appendix C for more information about the Antenatal Record.
- -The Antenatal Record reminds the primary healthcare provider to follow the physical developments and concerns of the pregnancy and also to assess the psychosocial risks for the mother and the expected infant. If intervention is initiated prior to delivery for some problems, there is the potential to improve the outcome for the infant.

- -The Antenatal Psychosocial Health Assessment (ALPHA) can supplement the enquiry. There is a provider version and a patient self report questionnaire. If psychosocial risks are present, extra supports and interventions can be sought ahead of time. The early neonatal period is a critical time for the infant-parent interaction. It is no longer reasonable to wait until problems arise and waste valuable time (Wilson et al., 1996). See Appendix B for more information about ALPHA.
- –Involving the father as much as possible in prenatal visits and classes is associated with less anxiety and more involvement after the birth. Encouraging his active participation may facilitate his partner's recognition of his role and facilitate communication between partners during this period. Special prenatal classes or sessions for expectant fathers provide the opportunity to review and discuss common issues and unique perspectives (Watson et al., 1995).
- -The prenatal period is the optimal time to promote prenatal education, and to review infant feeding plans, community supports and parenting adjustments with both partners.
- -Prospective parents who need additional support would benefit from a referral to the Healthy Babies Healthy Children Program early in the pregnancy, particularly teen parents.

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MARY AND CARL'S CASE:

Mary comes in for her first prenatal examination late in the first trimester of pregnancy with her husband Carl. This is Mary's first pregnancy and while it was unexpected, the couple appears delighted at the prospect of having a child. Everything appears routine except for an extended discussion around alcohol use. Mary and Carl indicate that they party with their friends on a weekly basis. When questioned about alcohol use, Mary mentions that she usually has 4 or 5 drinks at each social event. She also indicates that during the week she will have a drink or two in the evening to unwind. Mary wonders if this is OK, or if she should cut back. She also asks if it is OK to drink wine coolers since they are "mild drinks".

QUESTIONS TO PONDER: Is Mary's level of alcohol use a risk to the fetus? Are some types of alcohol safer than others? How can you provide accurate advice about the risks to the fetus, without raising undue fear in the couple?

DISCUSSION: It is a priority to address Mary's current alcohol use and to assess the risks to the fetus. The healthcare provider should keep in mind that alcohol use may be under reported due to comfort levels or lack of knowledge about standard drink sizes. Mary could contact Motherisk for accurate personalized information about her risks. Mary and Carl will then need support in making decisions based on this information. Mary may also need support and advice during the process of addressing her alcohol use. Ask her how confident she is of her ability to stop drinking. Carl can play an important role in assisting and encouraging her through this process. Mary should be informed that the safest choice is not to drink any alcohol and that coolers are not "mild drinks".

D. Perinatal

Maternal/ Family Assessment

Assessment of the mother-infant dyad begins at delivery and should be reviewed prior to discharge and within the first week after birth. These early encounters should provide time for exploration of problems and creation of solutions in areas such as breastfeeding, fatigue, family stresses, or worries about the baby's neonatal behaviour. Early strategies may prevent developing problems and enhance parental confidence.

- -Review the mother's/parent's perception of the delivery and the infant. Does either parent have any concerns about the infant? If there are infant problems, what is the parent's understanding of the problem? Do they need help in coming to terms with the infant's difficulty?
- -Review the progress of breastfeeding and respond to questions regarding care. Is a lactation consultant needed? Assistance with breastfeeding may help prevent premature cessation of breastfeeding. The support may also help allay depressive tendencies by aiding early maternal competence.
- -Review mother's health and supports at home. Assess the resources that will foster a healthy interaction between

mother/parents and the infant. This early period is a critical time. The presence of the father at labour and delivery as well as in discussions about the baby may improve bonding of the mother and infant (Wilson et al, 1996, Wilson et al, 2005).

In Ontario, Healthy Babies Healthy Children uses the Larson Prenatal Screening Tool during pregnancy and the Postpartum Screening Tool (Parkyn) following delivery. These tools are used with the mother's consent and can alert staff to risk factors for future problems including concerns related to the child, the mother, the labour or delivery, the bonding or the social situation. The screening tools can identify women who would benefit from an assessment by a public health nurse. For detailed information on these tools, see Appendices D and E.

Public Health nurses follow up with a postpartum phone call to all consenting mothers within 48 hours of discharge from the hospital. This call is an important marker of the need for further assessment and intervention/support. All at risk mothers are offered an initial home visit. Ongoing visits may be offered if sufficient risk is indicated. Early intense visitation programs have been shown to decrease the incidence of child abuse, increase parental support and increase infant development measures (Shonkoff and Meisels, 2000). Referral to these programs can be made if concerns arise after the initial postpartum period. Such programs are designed to help support the mother, encourage positive childcare and help both parents enjoy the infant. Ongoing communication between Healthy Babies Healthy Children staff and the family physician, obstetrician or pediatrician is important. Additional services can be accessed as needed. See Section 5 for more information about the Public Health Programs.

Neonatal Assessment

A detailed physical exam at each well baby visit in the first month

of life including a neurological exam is very important in establishing a baseline of postnatal development. As described in Section 2, prematurity, illness or abnormality in the newborn can be risk factors inhibiting the early bonding process. Coupled with the presence of other risks, careful monitoring or intervention may be indicated. Public Health visitation as well as more frequent reviews by a physician could be important to support and/or detect the need for further help. See Appendix G for information on Neurological Examination of the Newborn.

SUSAN'S CASE:

Susan is two months old and in your office for the first time. She was discharged from hospital one week ago. She was born by Caesarean section at 33 weeks gestation. Her mother had an abruptio placenta in a twin pregnancy that precipitated the Caesarean section. Twin A was a stillbirth. Susan had a separate placenta but required resuscitation and intubation after birth. Within two days she was extubated. Her birth weight was 1250 grams. There were no other major complications during her stay and she was discharged at 2500 grams at seven weeks and was breastfeeding. Her hearing was screened in hospital and she has an appointment for followup with the Infant Hearing program audiologist. Susan's mother already has had a call and a visit from the public health nurse. Susan's mother understands that immunization starts at two months of age.

QUESTIONS TO PONDER: What further information or investigation would you pursue? What feelings or issues regarding Susan might her parents be facing? How might you go about addressing their concerns and discussing a plan for Susan's ongoing care? What services and support systems might be available in your community to assist Susan and her family?

DISCUSSION: At this visit, the family doctor needs to be sure that all the records regarding Susan are obtained and a clear picture of the follow up recommendations and plan from the neonatal unit is forthcoming. A thorough physical and neurological examination is needed for a base line knowledge of Susan. Some discussion with the parents regarding their understanding of the problem and their present comfort level caring for Susan is appropriate now. Exploring the stress of the difficult beginning for Susan and the loss of the other twin may help to bring out any depressive or anxious symptoms as well as provide support. Both parents should be encouraged to attend visits as much as possible. The normal Well Baby Visit plans and immunizations as well as modifications to accommodate Susan may be discussed. The importance of attending the audiology assessment should be stressed because of the importance of identifying hearing loss as soon as possible. Support for the role of Healthy Babies Healthy Children is warranted so that parents understand how this program can assist in obtaining optimal care for Susan through further early intervention, assessment and guidance. After the visit, communication with Healthy Babies Healthy Children and other professionals will be important to be sure that Susan's care is well coordinated. If Susan is found to have a hearing loss, a referral for medical investigation will be made. The family doctor should expedite the process so Susan can receive all of the Infant Hearing Services as soon as possible. A referral to the Infant Development Program for early intervention is also warranted as Susan is at high risk for developmental delays. Susan is at risk for early childhood hearing loss, even if her hearing is normal now. She will be followed by the Infant Hearing Program, but should also be monitored at visits for signs of hearing loss. Susan might be at risk for visual problems due to prematurity and consideration given to a referral to the Blind and Low Vision Early Intervention Program. If breastfeeding difficulties present themselves, consider early referral to a lactation consultant. The parents may also benefit from support for dealing with their grief through local bereavement services

E. Infant/Child Health Surveillance Using the Rourke Record

After the baby goes home, in most situations, ongoing care continues at regular infant visits and as deemed necessary. These visits usually are frequent in the first months and gradually spaced farther apart as infant development proceeds. Because of the scope and depth of the issues to be addressed at these surveillance visits, a systematic approach is needed for efficiency and comprehensiveness. The Rourke Record provides both age appropriate screening reminders as well as a convenient record for charting early child development.

During the early visits particular attention needs to be paid to the infant-parent-family adjustment. A family check as well as an infant check is vital. Specifically inviting fathers to attend well baby visits and parent groups may give added incentive. Support groups for new fathers are available in some communities and have been deemed helpful by participants.

Process of Infant Health Visit - This Follows the Rourke Record

Goals of the Infant Health Visit:

-Address parental concerns

- -Monitor physical growth and development
- -Assess parent-child interactions and family health
- -Counsel about development, safety, nutrition and community resources
- -Encourage parents
- -Provide immunization and other preventive care
- -Identify risks/problems for action

-Parent's Concerns: Parents should be specifically asked about their concerns about their children and these concerns need to be taken seriously. Common parent concerns relate to sleeping and nutrition. Parental concerns related to developmental problems have been shown to be accurate. It is also clear that unless the parental concerns are addressed, other information or guidance may not be heard. If the background of parent's questions or problems is probed carefully, more information about the infant, family problems or parental stresses may be gleaned. Such discussions can help in understanding family values, parental expectations and cultural issues. This information will be helpful in addressing the parent's real concerns and in tailoring other information and advice to the family situation.

While asking parents about their concerns encourages parents to discuss the issues that they are finding difficult, parents are not necessarily aware of a wider range of issues that may apply to their child. Parents are usually the best and most reliable sources of information regarding their child's development.

Parent questionnaires or screening tools regarding their child's development and behaviour can assist parents in reviewing their child's progress. Such questionnaires can be quite precise in asking about specific behaviours and tasks and can help parents to clarify difficulties in each developmental area. Using such tools to screen all children for difficulties is shown to be more reliable than relying only on clinical judgement. In addition, they are not reliant on the cooperation of a child who is tired, afraid or ill and can be filled out when the parent has time to focus on the questions (Glascoe, 2000). They can help identify areas for further evaluation by the primary care professional.

One such parent tool is the Nipissing District Developmental Screen[™]. This screen provides the basis of the developmental screening portion of the Rourke Record and is described in detail in the next section on monitoring growth and development.

The Rourke Record:

- -Addresses parental concerns
- -Provides evidence-based guidelines and record
- -Covers birth to age six
- -Incorporates developmental screening "red flags"
- -Serves as a reminder of age appropriate issues to cover in enquiry and advice
- -Is easy to use
- -Will soon be computerized

The Rourke Baby Record is used to document preventative infant care. Developed originally the mid 80's, the most recent revision was made in 2009. It incorporates the most current evidence based recommendations for infant/ child health surveillance. It can function as an aide-memoire to foster efficient, comprehensive well baby/child care. As such it is an ideal teaching tool as well a clinical record. To date it has been widely adopted by primary health care professionals (family physicians, nurse practitioners). See Appendix H for the Rourke Baby Record 2009 (available in English and French). www.rourkebabyrecord.ca

The Healthy ABC's, a health maintenance guide for Well Baby Visits, was developed at the University of Montreal. It is similar to the Rourke Record and has been used in the province of Quebec since 1997. This tool is available in English and has undergone recent revisions. (available in English and French)

-Monitoring Growth and Development: Recommended physical screening procedures for specific ages are included in the Rourke Record. Developmental screening can be done through interview or by having the parent check the developmental screening tool (Nipissing) prior to the examination and then reviewing their responses during the examination. The goal is to review all the areas of development:

-Physical - including height and weight

- -Vision (<u>see www.cps.ca/english/statements/CP/cp98-01.htm</u> for vision screening tools)
- -Hearing (see chapter 5 for more details on hearing concerns)
- -Motor gross and fine
- -Communication including speech and language (See Appendix K for more information)
- Cognitive e.g. looking for a dropped object, naming colours
- –Socio-emotional e.g. smiling, eye contact, pointing (see Appendix J and K for more information)
 (see appendix M and N for more information on ASD)

-Nipissing District Developmental ScreenTM: The Nipissing District Developmental Screen[™] is a series of age appropriate developmental checklists (13 different age levels) designed for use by parents with children between the ages of 1 month and six years. The questions cover seven areas of development: vision, hearing, speech-language, gross motor, fine motor, cognitive and self-help skills. Evidence-based indicators for autism have been incorporated into the screen. It is sensitive to the varying cultural values in child-rearing and allows for alternate experiences. The skills in each screen are expected to be mastered by most children by the age shown. Any NOS on the screen require further inquiry and further followup including continued attentive surveillance, health teaching and/or referral for assessment (ARC, 2002). A "wait and see" approach only further delays appropriate intervention. The forms can be filled out by parents in the waiting room or can be sent home with parents to be completed for the next visit. The Nipissing can also provide a conversation template to highlight ways to provide quality experiences that can support development either in the home or in childcare situations as it includes suggested activities designed to encourage a child's overall development at specific ages. See Appendix I for more information about the Nipissing District Developmental Screen[™] or http://www.ndds.ca/Pages/evaluation.html.

It is important to be aware of "red flags" that may indicate risk for developmental problems. For more information on developmental monitoring see Appendix J. For an additional case of an older child with developmental delays, see Appendix O.

-Assessing Parent-Child Interactions

-Observation: How comfortable does the parent seem to be with the child? If upset, how easily does the infant settle? Observing the mother feeding can be helpful. Is the parent responsive to the infant? Is the infant difficult to handle? The nursing and other staff may provide valuable information from their encounters with the parent and child. How does the mother appear? Does she look excessively tired? Tearfulness is frequently a sign of postpartum depression.

MARTIN'S CASE

Martin is in for his six month checkup and his mother mentions that other members of the family are concerned. He is a cheery responsive baby but he does not sit up alone and still seems to have trouble holding up his head. He feels like a "sack of potatoes" when you pick him up. He is beginning to coo and imitate sounds and reach to grasp things. On reviewing his history you have noted that he was full term and with normal apgars. His mother was treated for hyperthyroidism during her pregnancy. He has tended to be a floppy baby and was delayed in holding his head up well. Otherwise there were no concerns.

QUESTIONS TO PONDER: What would be your approach to this developmental delay? What specific concerns might you have regarding the infant? What further investigation would you pursue? What referrals or interventions would you instigate?

DISCUSSION: Martin is lagging in motor development and has persistent hypotonia. Further inquiry into family history for developmental problems is needed. A number of genetic problems may need to be considered. You learn that there is no specific family history except that his father, a lawyer, did not walk until 16 months. A neurological assessment and planning for further developmental assessment would be warranted. A full workup for the causes of this child's motor delay is important. Education for the parents and referral for early intervention can be initiated in the meantime. Some inquiry into daily care and stimulation opportunities for Martin may be useful. In addition to assessment, early intervention in the form of physiotherapy (accessed through Infant Development Programs) could be taught to Martin's caregivers to stimulate his muscle development. A careful follow up plan is important to monitor his progress.

- *Expectations:* A gentle exploration of the parent's expectations of the young child, parenting and "how things are going" may facilitate the discussion of problems. Mothers may have a difficult time admitting negative feelings about the parenting experience. Excessive concern about the baby may also be an indicator of depression. Comfort with caring for the baby can also be checked.
 - -Support systems: How is the mother caring for herself? Is she eating and sleeping well? How is the family adjusting to the baby? How are the partner and other members involved? Are there outside supports? Are there other family stressors?
 - -Parental Mood: Indicate that there are often difficult feelings around this transition time. Direct questions about depressive symptoms including suicidal ideation are important if the mother's mood is affected.
 - *–Siblings:* Discussing other children and their reactions to the infant is also an important part of looking at the family system.

Postpartum psychiatric disorders are important problems to identify during the early neonatal period. It can be difficult because the early signs of fatigue and insomnia are hard to distinguish from the normal effects of caring for a neonate. A new mother may find it difficult to admit to her feelings and thoughts or may under report her depressive symptoms due to shame, fear or confusion.

Routine screening for postpartum depression using the Edinburgh Postpartum Depression Screen (EPDS) at six weeks is recommended and repeat screening is encouraged as up to twenty percent of women become symptomatic during the first six postpartum months (see Appendix R). This screening tool has been validated for use in pregnancy, with fathers and has also been translated into many languages for use in multicultural populations.

Some preventative tactics include targeting women who are at risk and educating woman in advance to monitor themselves for symptoms. Women can be educated about the early signs of postpartum depression and what they should do if they have any symptoms. However it may still be difficult for women to recognize the symptoms. Over-concern for the child may be a sign to consider. See Appendix S for a PPMD Desk Reference to assist with diagnosis and management of post partum mood disorders.

BRIAN'S CASE

Brian is in with his mother for his 2 month well baby visit. Mother states that she stopped breastfeeding two weeks ago because she is arranging to go back to her office manager job much earlier than she originally planned and because she did not feel that the breast-feeding was going well. Brian's examination is normal and he looks well cared for. Upon further assessment of the mother it is learned that she is finding it hard to be at home. She misses the contacts at work. Her husband works long hours and has little time for her or the baby. She has no contact with her family. Her parents live in another city; her mother has had some mental health problems and her father is an alcoholic. She is alone, isn't enjoying the mothering experience and feels that a babysitter could look after the baby better. The baby is easygoing and content to sit in the swing most of the time.

QUESTIONS TO PONDER: Do you have any specific concerns this situation? Is a return to work likely to provide an adequate solution to this mother's problem? Do you have any concerns for the infant? Are there any "red flags" in the situation to pursue? What further steps will you plan at this visit?

DISCUSSION: There are a number of concerns in this situation. The mother isn't happy and the baby may not be getting much positive interaction with his mother both because of his temperament and his mother's mood. There is the need to question the mother regarding depressive symptoms including thoughts of self-harm or negative thoughts regarding the baby or her care of the baby. If these symptoms are severe, then urgent measures may be needed to address a postpartum depressive/psychotic problem, including emergency psychiatric intervention. If the father is out of town and no reliable family members are available, then consideration for calling child protection services may be necessary to ensure the safety of the infant. If the symptoms are less severe, then a complete assessment of the mother's physical and emotional status is warranted as soon as possible. Her partner ideally should be included in this assessment. Together with the patient and her partner, further treatment decisions including assessment regarding the need for antidepressant medication and psychotherapy will be important. A referral to a lactation consultant, Healthy Babies Healthy Children and early parent programs may help mom to get some outside support immediately and some ideas as to how to engage with the baby. Involving the father may help him recognize the important role he can play for the baby and his wife. Some communities may have a fathers' program to aid this process. If she continues her plan to return to work, then some guidance in choosing adequate childcare may be important stimulate his muscle development. A careful follow up plan is important to monitor his progress.

Ask women about their mood, coping ability, family supports, eating, sleeping and getting out. Problems in these areas warrant further investigation. It is not usual in the postpartum period to have consistent difficulty getting back to sleep after the baby has settled. More common "postpartum blues" should pass in the first 2 weeks. Be on the lookout for feelings of confusion and for thoughts regarding harm to the baby. Involvement of patient and family is most important in planning treatment of depression, and attention to attachment issues for the baby (Chokka, 2002a; Chokka, 2002b; Yonkers and Steiner, 1999).

-Counseling Parents

Counsel parents about:

- -Development anticipatory guidance
- -Parenting concerns
- -Safety
- -Nutrition
- -Community resources

Parents need information around all of these issues. For many topics it is useful to have printed information to review with parents so they can read it again at home.

-It is important to have information about local parent support resources. Parental supports can improve parenting skills and improve outcomes for children. Know what is available in your community, including parenting programs, and where parents

JOANNE'S CASE:

Joanne is 1 year old and comes in with her mother for a regular check up and to have her 12 month shot. The Nipissing Screen indicates that Joanne has met all her milestones and in a few cases, exceeded them. The Rourke Record does not indicate any concerns. Joanne is growing well, seems content, interested and healthy. She responds to her mother's requests and uses a few words while in the office. She is not quite walking on her own, but pulls to a stand and moves around, steadying herself on the furniture. When Joanne is given her shot, she whimpers a bit, but is quickly comforted by her mother. Mom indicates that she started back to work on a part-time basis 3 weeks ago. Childcare has been arranged with Joanne's grandmother.

QUESTIONS TO PONDER: Do you have any concerns for this child? Is the visit over, or is there further information that you could provide? Are there any ways you can support early neurodevelopment?

DISCUSSION: Joanne appears to be a healthy, happy child who is developing well. With no health concerns to act on, it may appear that there is no reason to continue the appointment. However, the early years are a period of rapid neurodevelopment. Advice and information should be given to all parents, not just the parents of children with medical concerns or developmental delays. Joanne is at an age where physical and social skills are developing rapidly. Suggest ways that the parents and the grandmother can increase stimulation and interaction with other children. This family could be linked with programs such as an Ontario Early Years Centre, that include drop in services, parent support and activities for children. Grandma could use the program to meet other parents and caregivers and to provide additional opportunities for Joanne. Ask Mom how the return to work is going and suggest that she inquire about parent groups that might meet at hours that accommodate her work schedule. Because of Joanne's increasing mobility and interest in her surroundings, you may also want to provide information for the family and grandmother on general safety and child proofing measures. You can also ensure that the grandmother has the number of the doctor's office so she can call if she has any questions or concerns. An information sheet about the 12 month should be given to the mother, as well as information about the upcoming 15 month immunizations. The healthcare provider could also encourage the mother to involve the father and/or the grandmother at her next visit.

can call for suppport, information or recorded messages about common parenting concerns.

- -Encourage parents to enjoy their children, to watch their development, and to play, talk, read and sing with them. Parents can be encouraged to recognize that the baby can give them cues as to what he/she is ready to do.
- -Monitor psychosocial issues experienced by parents, including changes in the relationship. Parents may benefit from referrals and support. Marital satisfaction can drop between six and eighteen months for the mother and after eighteen months for the father. An infant with difficulties may aggravate this trend. Some studies find that 15% to 20% of couples are separated or divorced by the time the first child is four years old (Watson et al., 1995).

-Advice on optimizing development can be given for all children, even those that may be advanced or developing typically. Every child can profit from early educational experiences and all parents can benefit from participation in parenting supports that enhance parenting skills. Parents should be encouraged to use community resources such as:

- -Ontario Early Years Centres
- -Parenting groups
- -Books, tapes, phone lines, websites
- –Play groups
- -Library programs
- -Toy lending programs
- -Healthy Babies Healthy Children

-Encouraging Parents: Parents need encouragement in their job. Recognizing positive interactions and positive aspects of their infants is appreciated and supportive. They also need understanding regarding the difficult aspects of parenting. Building up the parent's confidence to care for the child is known to improve their parenting.

-Providing Immunization

Recommended immunizations include:

- -Pertussis (acellular), Diphtheria, Polio, Tetanus vaccine (aPDT)
- -Haemophilus influenza B vaccine (HIB)
- -Measles, Mumps, Rubella vaccine (MMR)
- -Varicella vaccine
- -Hepatitis B vaccine if indicated
- -Pneumococcus, Meningococcus
 - -The schedule of immunization for each child should follow the most current public health recommendations. The (2009) Rourke record edition provides a separate immunization record sheet.
 - -Please note that providing immunization also means providing information about vaccines. When counselling parents it is important to give information about the risks and side effects of the vaccines as well as the benefits of preventing the diseases. Strategies to reduce pain and distress at the time of injection can be provided to parents.
 - –Pneumococcus streptococci, varicella and meningococcal vaccines have been added to the Ontario provincial immunization plan as of January 2005. Specific recommendations and availability information can be obtained from the local public health department as for other vaccines.
 - -Parents must be informed about the risk of not having their child vaccinated.
- -*Identifying Risks and Problems:* When problems are detected, the help of other professionals, agencies and groups may be needed to assess and provide specific interventions. Access to different services can be confusing for parents. In Ontario, many regions have central numbers that provide information to help find appropriate services. The Public Health department is always a good place to enquire regarding regional children's services. See Section 5 for information about other services.

One example of new research in this area is the Early Development Instrument (EDI) which is a measure of children's early development at school entry. This instrument is administered in the second half of the senior kindergarten year of school. This is a population-based measure that reflects the impact of community services such as preschool play programs on the children's "readiness to learn". The EDI can be integrated with other health and developmental indicators to measure the impact of new programs on the community.

Identified risks or problems:

- -Failure to thrive
- -Developmental delays/behaviour problems
- -Attachment problems
- -Family, social problems including abuse, neglect,
- deprivation
- -Hearing loss
- -Vision problems

In the past, there has been a tendency to take a "wait and see" attitude toward some developmental problems rather than look for early interventions. In view of the new understanding about brain development, physicians and other primary healthcare providers will need to be more proactive in instigating interventions. Referrals and intervention can be started even before diagnosis, as parent education can often help the situation. For example, a referral to the Infant Development Program can occur before the cause of the delay has been determined. Suggestions for interim action on the part of parents while waiting for a visit often can be obtained from the service. For some specialized assessments, a long waiting period may be the reality. This fact makes a proactive response all the more important.

See Section 5 for more information about some of these services:

- -Pediatric Services (Developmental or other)
- -Healthy Babies Healthy Children (Public Health Early Childhood Services)
- –Infant Developmental Program (IDP)
- -Ontario Early Years Centres
- -Preschool Speech and Language Program
- -Infant Hearing Program
- -Physiotherapy and occupational therapy may be accessed through IDP
- -Family and Children's Services (FACS)
- -Community Care Programs
- -Blind and Low Vision Program

MICHAEL'S CASE:

Michael is in for his 18 month checkup. His father indicates that he is a little concerned because he thinks that Michael isn't doing as much as he used to do. Michael is using fewer words than he did a few months ago. The father assumes that it is related to the birth of their second child two months ago. The mother indicates that she is also concerned, but she has been very busy with the new baby. However, in filling out the Nipissing District Developmental Screen[™], the parents note that a number of other issues may be important. Michael does not bring things to show his parents and uses few gestures to communicate. The parents have trouble getting Michael to look at them. Tantrums are frequent if Michael is interrupted in his activity.

QUESTIONS TO PONDER: Could the change in Michael's behaviour be due to the arrival of the new baby? Is this degree of regression typical of older siblings? Do you have any concerns about Michael? Would you address them now or would you wait until you see Michael at the next regular checkup at age 2? What do you do next?

DISCUSSION: Regression is always important. While minor behavioural changes can occur with the birth of a new baby, a thorough evaluation is required before reassuring the parents. A review of family, prenatal and developmental history is indicated along with a physical and neurological examination. Hearing tests and referral to Preschool Speech and Language may be initiated while awaiting specialist consultation (developmental pediatrics-autism spectrum disorder needs to be considered). Early intervention could be enlisted now through an Infant Development Program. This home-based program will give the parents support as well as suggestions to help them start some strategies to engage Michael. In the meantime, suggestions on the Nipissing activity side and visiting a parent-child program such as an Ontario Early Years Centre may also provide support and other stimulation for Michael. Michael and his parents should be seen again soon to review his progress, the assessment process and the family's coping with the situation. If Michael is diagnosed with Autism Spectrum Disorder, referrals for the new baby to Public Health and Ontario Early Years may also improve the odds and prevent delay in the younger sibling (see Appendix L).

- -Women's Shelters and programs
- -Autism Intervention Services
- -Many local services such as nursery schools and toy lending programs that may also help children and parents

F. Early Intervention

Early Action for Delays/Risks/Behaviour Issues

Early action for concerns can involve:

- -An in depth family assessment
- -Further assessment/monitoring
- -Early infant/child intervention programs
- -Speech and language referral
- -Referral to paediatrician and/or developmental paediatrician
- -Audiology referral
- -Ontario Early Years Centre
- -Informal play groups etc.

- -It may take time to determine the basis of delays; however by acting early, it may be possible to help parents adapt their pattern of interacting with the child. This intervention may help the child, even before a specific diagnosis has been made.
- -Healthy Babies Healthy Children can help connect families to appropriate early intervention (i.e. home visiting).
- -If families are not involved in playing or reading with their children, then suggestions regarding these activities may help while waiting for referrals, which often take some time. Referral to nursery school, library, play groups or a parentchild program may also help.
- -These early measures may prove to be all the interventions that are needed for some children and can be instigated while waiting for further consultations to occur.
- -Have printed suggestions to give parents available in the office. Websites, infant development programs and public health can provide suggestions or materials.

- -Communication and social development are areas where primary healthcare professionals may be reluctant to label a child prematurely. In the past physicians especially have tended to take a "wait and see" approach. However there is increasing evidence that delays of language and socialization are important and can be detected earlier than expected in the past. More importantly, there is solid evidence that early intervention can make a difference and can alleviate some common secondary problems. Parents can be educated regarding this approach.
- -Even mild forms of Autism Spectrum Disorder may be detected by eighteen months. Clues are delays in communication skills such as eye contact, response to name, joint attention, pointing to share interest and language delay. Failure to develop social skills such as pretend play or showing something of interest may be early signs. Regression in these skills at any time is also cause for concern. It is important for primary healthcare providers to become more aware of the developing skills of communication,

language and social behaviour. Some physicians and primary healthcare providers may be willing to do further investigations themselves. The M-CHAT (Modified Checklist for Autism in Toddlers) is a screening tool for toddlers, eighteen months old that can be done in the office and is fairly simple to complete. However, it is not a diagnostic tool (Baron-Cohen et al., 2000; Ho, 2001; Kagan-Kushnir and Zwaigenbaum, 2001). See Appendices L and M for more information on Autism Spectrum Disorder and MCHAT. MCHAT: Robins, Fein and Barton, 1999

-Behavioural problems also warrant early referral. Children with Oppositional Behaviour and Attention Deficit problems often have preceding histories of being difficult toddlers. Parents may benefit from early help to develop firm, calm but nurturing approaches to the behaviour. This may abort the escalation of problems and help prepare these children for school. Unfortunately these issues are not often addressed before school. Lack of a specific diagnosis does not preclude intervention and supplementing parenting skills.

BRITTANY'S CASE:

Brittany, age three, has come in with her mother to have stitches removed. The emergency department had stitched a small cut on her knee after she fell when running on the ice. This family is new to the community and this is their first visit to your office. After removing the stitches, you ask basic questions regarding Brittany's past health and immunization record. You notice that Brittany is running around the room looking into everything. She is interrupting constantly during the discussion. Brittany is offered toys but she just scatters them and does not play with them. Brittany's mother comments that she is often frustrated by Brittany's behaviour.

QUESTIONS TO PONDER: Would you do anything at this point or just be glad when they leave? What issues might you want to pursue in the future regarding this child and her family situation?

DISCUSSION: Plan a follow up well child checkup (initial assessment and 3 year checkup) to review Brittany's behaviour and development and to indicate your concerns to Brittany's mother. Give the mother the Nipissing screen for 3 year olds to complete before the next visit. At the next visit it will be important to learn more about the family constellation and interaction. It may be useful to identify Brittany as challenging (as opposed to the mother lacking parenting skills) and explore mother's experience with the child. If she is finding Brittany difficult to manage, then being supportive and helping her connect with added resources may be well received. It would be important to suggest that routines and rules might help to prepare Brittany for school and to learn to focus on a task. Early educational opportunities such as Ontario Early Years Centres, nursery school or other peer programs could be suggested. Brittany would benefit from some structured programming and Mom may learn from other mothers. Parenting training may help Mom to add more structure and learn ways to gain Brittany's attention and cooperation, in addition to providing some support for herself. An exploration of the pregnancy history (any illness, alcohol or drug use), family history (psychiatric illness, learning disabilities, Attention Deficit Hyperactivity Disorder), Brittany's past history of injuries (any fractures or unusual injuries) and whether any psychosocial risks are present (domestic violence) is important. If you suspect abuse or dangerous substance use, child protection services must be informed.

ALICIA'S CASE:

Alicia is in for her two-year old checkup with her parents. Her mother expresses concern that she is not talking as well as the other children in the play group, who are stringing words together. Although Alicia has about twenty words that the family deciphers, they are not clear. She uses lots of gestures and grunts to make her needs known and is very interactive with parents and peers. When not understood, she has tantrum behaviour, which is frustrating to her parents. They feel she understands well but cannot get out what she wants to say. The parents also noticed that their nine-month old daughter is already babbling, mimicking and making sounds, something Alicia did not do although her birth history and other milestones were normal. Alicia's father thinks that she is just a late talker as he was, but wanted to be sure that there was not a problem.

QUESTIONS TO PONDER: If "late talking" is a family characteristic, does it need to be addressed? Or will it resolve in time without intervention? What plan of action might you pursue?

DISCUSSION: Audiological testing confirmed Alicia's hearing was normal and referral was made to the Preschool Speech and Language Program. All areas of communication were assessed by a speech language pathologist, including language comprehension and expression, nonverbal communication and speech production. Assessment indicated that Alicia seemed to have a specific speech production disorder (possibly Developmental Apraxia of Speech). Although she seemed to have no other problems related to oral musculature (i.e. no drooling or feeding problems, etc.), further neurological testing may be indicated to rule out specific neurological problems. Referral to appropriate pediatric specialist (developmental, neurological) should be made. The speech language pathologist will involve the parents in therapy, teaching them to support her speech development through play and everyday routines. Parenting training may be recommended to help parents better understand and cope with Alicia's communication problem, such as dealing with her tantrums of frustration. Individual or group treatment may also be recommended. Early intervention with speech and language problems is most important; in fact, it's never too early to start. The family may benefit from participation in a parent-child program, and this may stimulate the speech development of the younger sister as well.

Early Intervention for Children with Specific Disabilities

There is growing evidence that early intervention has a positive effect on development for children under the age of three who have disabilities (Shonkoff and Meisels, 2000). Effective programs include both parents and children. Specific structured programs work the best. Parents can become trained in special techniques to help their children. Research is limited, needed and ongoing.

Collaboration and partnership between families and a broad network of professionals (from education, social services and health care) is important for all children. When children have specific disabilities, there is a need for smooth transition between the preschool years to the education system. When special assistance or therapy is required, it is hoped there will not be any disruption of required support services and programs. Liaison work involving reciprocal sharing of information will identify students' needs prior to the start of the school year. Families will need to be supported as they become familiar with school requirements. Individual teachers and school administrators are encouraged to take a proactive role in developing good relationships with parents. Healthcare professionals in the community are encouraged to support and build on such strategies with local school boards.

G. Special Needs

Children with Special Needs and their Families

A major concern for children with special needs and their families is secondary problems that put the child and family at further risk. Therefore, there are still preventative interventions as well as treatment interventions to consider for these situations (OCFP, 2000).

Children with special needs may require:

- -Ongoing monitoring, collaboration and case management
- -Intervention for psychosocial concerns
- -Encouragement
- -Resources
- -Advocacy

- -Because these families may need the help of several different services, no one service may keep the whole picture of the child and family in view. Collaboration and communication between the professionals and agencies involved is essential for the child/family. It is important to review the total picture on a regular basis and to determine if the needs of the whole family are being considered. Service coordination meetings including all professionals and the family are an important mechanism to identify specific roles, to review progress and future plans, to reduce duplication of service and to ensure that all necessary services are in place.
- -Wraparound Care is a style of service coordination for families who have complex care needs and are involved with multiple service providers. Informal providers (i.e. faith community, neighbours, friends and cultural groups) can be integrated into the long term treatment plan alongside the therapists and social workers involved in the case. A Wraparound facilitator works with the community service providers and informal supports to help meet the needs of the family. The family is encouraged to be part of the planning process and to take an active role in learning to coordinate their own treatment teams. This process can help empower parents and often reduces the confusion that can develop with poor communication among different agencies.
- -If the family is overwhelmed, the child too is at further risk. These families need encouragement for the efforts they are making. It may be difficult to see their efforts in a positive light when problems are ongoing. The need for recognition and support is real.
- -With the stress of caring for a child with special needs, the use of respite services may provide a parent with relief. Parents may need encouragement to seek or use respite services.
- -The family of a child with special needs has many stresses that can affect the immediate and extended family. The burden of care can be heavy and may lead to isolation, depression, relationship problems, sibling problems, etc. It is important to assess the needs of the whole family. Children with special needs may require periods of separation from caregivers due to hospitalization. Parents may need to be at home with their other children. While this often cannot be avoided, care

should be taken to ensure that when the caregiver is present, they are well supported by healthcare professionals in their efforts to nurture their children with special needs.

- -Siblings often end up assisting with care giving, carrying more responsibility and receiving less care themselves. The outcomes of this responsibility can be positive but there are risks for these siblings. Their own needs may not be met and they may not have optimum stimulation for growth and development.
- -Social isolation is a risk because of care requirements. Special training is needed for anyone staying with the child, so therefore disabilities may limit the socialization opportunities for the family.
- -Parents are at risk for medical as well as psychological illness because of inadequate sleep, poor nutrition and inadequate self-care.
- -Physical and financial needs are often increased. Parental ability to work may be hampered by the child's care, etc. Anticipate needs, ask families and know where to look for help.
- -Unfortunately children with special needs are at particular risk for abuse and neglect, often because of the extra family burdens. Health professionals need to be alert to this possibility and to act proactively. Sometimes a positively planned approach with child protection services for temporary foster services may provide a much needed break for parents and families. This process would be preferable to an emergency situation.
- -Completing forms, making calls and supporting a family may be part of an advocacy function.
- -The Association for Community Living, Public Health or a social worker from the Community Care Access Centre (CCAC) can be consulted about financial resources and strategies that may be available for families. For additional resources and services, see page 51 as well as Appendix Q.
- -Once parents become more knowledgeable, they can become advocates for their children and the children of other parents.

-Enhanced 18 Month Well Baby Visit (Rourke 2009): An

"enhanced" eighteen month well baby visit is a critical and timely strategy for helping parents and caregivers to identify children who may not be meeting developmental milestones, and to take steps to help them with developmental skills they will need when they enter school. In Ontario, the enhanced 18 Month Well Baby Visit refers to:

- -a consistent, focused, developmental review and evaluation at 18 months of age completed by the primary health care provider (usually a family physican or nurse practitioner), in collaboration with parents.
- –use of standardized tools. These tools include a parent tool, the Nipissing District Developmental Screen[™] (NDDS) and a professional tool, the revised Rourke Baby Record (RBR).
- -a process to support discussion with parents on healthy child development, providing information on parenting and community programs that promote healthy child development and early learning and when needed, provide referrals to specialized community services for those children identified with potential issues, needs and risks.
- -See Appendix N for information on the 18 Month Visit and a suggested flowchart for evaluation and management of specific types of developmental delay. www.18monthvisit.ca

Useful websites

-www.machealth.ca

- Resources available here include the Ontario Rourke Baby Record, the Nipissing District Development Screen[™] and the Early Child Development and Parenting Resource System Pathway, which lists community services.
- -Ontario Rourke Baby Record: Available at www.machealth.ca , www.cps.ca , www.cfpc.ca and www.rourkebabyrecord.ca
- -Nipissing District Developmental Screen[™]: www.ndds.ca, www.machealth.ca
- -Ministry of Children and Youth Services: www.ontario.ca/child
- Ministry of Health and Long-term Care: www.ontario.ca/healthMinistry of Health Promotion:

www.ontario.ca/mhp

-Ontario Early Years Centres: www.ontario.ca/earlyyears

Reports

- -Getting It Right at 18 Months, Making It Right for a Lifetime, Report of the Expert Panel on the 18-Month Well-Baby Visit. www.children.gov.on.ca/htdocs/English /topics/earlychildhood/gettingitright.aspx
- -Final Report to the Ontario College of Family Physicians for the Evidence to Support the 18-Month Well-Baby Visit. www.ocfp.on.ca. This report includes clinical practice recommendations that have been incorporated into the enhanced visit.

Key Points - IMPROVING THE ODDS

-Look for opportunities to reduce risks and offer enhancement of neurodevelopment for all children.

- -Assess for factors that may pose risks to child neurodevelopment and for developmental delays.
- -Do not take a "wait and see attitude"!
- -Be proactive by informing parents, initiating further investigation, providing referrals and continuing to monitor both child and family.
- -Learn about supports available in your community.
- -Incorporate a plan to encourage all parents to seek training and support for their task.
- -Stress the importance of early childhood educational experiences for all children.





WORKING TOGETHER - Interdisciplinary Teams

Introduction

A wide range of provincial programs and services have a profound influence on healthy child development and the early years in Ontario. Family physicians and other primary healthcare providers offer valuable contributions to the health of children and families. However, they are not able to meet all needs or address all concerns. Knowledge of available programs and services can help primary healthcare providers support families. Some programs and services such as Ontario Early Years Centres may benefit all families. Others, related to developmental, mental health or speech issues such as Infant Development Programs, Children's Mental Health Programs or Preschool Speech and Language, are designed for children with special needs or concerns. Public Health programs, such as Healthy Babies Healthy Children, deliver important services for families, including the postnatal screen, the postpartum phone call, home visits and linking families to needed services. In addition through Ontario's Best Start strategy every community in Ontario has formed a Best Start network that is working toward bringing services together in a comprehensive, flexible, integrated and seamless way so children and parents can access them at familiar neighbourhood locations. Physicians and other providers are encouraged to link with their local Best Start network and support the planning and development of the comprehensive services for families; and to understand how their services fit within the broader system of supports and service for families.

A. Public Health Programs

In Ontario, public health programs obtain their legal authority from the Health Protection and Promotion Act. The Ontario Public Health Standards are guidelines for the provision of mandatory health programs and services by the Ontario Ministry of Health and Long Term Care through public health units. The Family Health Program Standards outline the mandatory health programs and services for Reproductive Health and Child Health for all Public Health departments across the province. This Public Health program provides a range of health promotion programs across all age groups, from preconception to the end of adolescence. Strategies include disease and injury prevention, health promotion and health protection. The Reproductive Health and Child Health mandates use population health approaches to promote preconception health, healthy pregnancies, proper nutrition, healthy child development and parenting. Multiple health promotion strategies include: increasing awareness through media campaigns and workshops, promoting healthy child and family public policy, collaborating with community partners and services, and providing small group interventions such as prenatal and parenting classes.

Prenatal and early childhood experiences have a profound effect on health and well being in later life. The Family Health Program is directed toward children, youth, parents, caregivers and people in their reproductive years who are making choices about future family life. The program is intended to protect and promote the health of families, prevent disease and assist in the attainment of an optimal level of health. The focus of Reproductive Health is on planning for a healthy pregnancy and promoting healthy behaviours and environments before and during pregnancy. Child health is focused on promoting healthy development through parenting practices and supportive environments. Another standard program under Infectious Diseases is Sexual Health. The primary focus of Sexual Health is on the establishment of healthy sexual relationships and personal responsibility. Many health and social service providers work collaboratively to implement public health programming. For more information, contact your local public health unit at

http://www.health.gov.on.ca/english/providers/program/pubhealt h/oph_standards/ophs/progstds/pdfs/ophs_2008.pdf

The components of the program are <u>Sexual Health, Reproductive</u> <u>Health</u> and <u>Child Health</u>. The primary focus of Sexual Health is on the establishment of healthy sexual relationships and personal responsibility. The focus of Reproductive Health is on planning for a healthy pregnancy and promoting healthy behaviours and environments before and during pregnancy. Child health is focussed on promoting healthy development through parenting practices and supportive environments. Many health and social service providers work collaboratively to implement public health programming. For more information, contact your local public health unit at <u>http:// www.health.gov.on.ca/english/public/</u> contact/phu/phuloc mn.html

Children In Need Of Treatment (CINOT) Dental Program The <u>Children In Need Of Treatment (CINOT)</u> dental treatment program is part of the Child Health Program. The objective of CINOT is to provide a basic level of dental care to children, from birth to Grade 8 or their 14th birthday (whichever is later), who have identified dental conditions requiring urgent care. Children are eligible for this program if they have no dental insurance or other form of coverage (e.g., Ontario Works, Ontario Disability Support Program, Federal Government coverage for refugee claimants, etc.) and the parent/guardian has signed a written declaration that the cost of the necessary dental treatment would result in financial hardship. NB: Parents may be asked to prove financial hardship.

To determine if a child is eligible for CINOT call the health unit, in the area where the child lives, to arrange for a dental screening. Health units will offer a screening appointment within five working days of your call. All children identified as CINOT-eligible are tracked to ensure they receive the needed care. If they do not receive the care, health unit staff will refer the child to the local Children's Aid Society for suspected (dental) neglect. Preventive dental services, including topical fluoride application and fissure sealants, will also be offered to children who would benefit from these services.

When a child is identified as CINOT eligible, health unit staff makes inquiries regarding younger siblings and other family needs. Appropriate referrals to health unit programs (e.g., to the Healthy Babies Healthy Children program, pre-natal classes, parenting classes, counseling, immunization, etc.) or other community programs are facilitated.

B. Healthy Babies Healthy Children Program

The Healthy Babies Healthy Children (HBHC) program is a prevention/early intervention initiative designed to help families promote healthy child development and help their children achieve their full potential. Introduced in 1998 by the Ontario Government, Healthy Babies Healthy Children is funded by the Ministry of Children and Youth Services and administered by Public Health Units. .

The Healthy Babies Healthy Children Program is under the Family Health Program Standards, Child Health Program. The HBHC program is about healthy child development. Early childhood experiences make a critical and long-term difference in children's development, and in their health and well being during childhood and as adults (Hertzmann and Keating, 1999). Each year in Ontario, babies are born into families where a number of factors affect their ability to achieve their full physical, mental and emotional potential. A child's ability to develop to his or her full potential is affected by factors in their social and physical environment. The Healthy Babies Healthy Children program provides targeted and universal services. The targeted component of the HBHC program focuses on a family approach to strengthen and build the capacity of parents at risk by providing parenting skills and support through a home visiting program by a public health nurse and a family home visitor. The universal component of the program is provided to all families. Due to funding it is important to note that there is a variation across the province in the extent of the implementation of the Healthy Babies Healthy Children program.

Healthy Babies Healthy Children was originally intended only to serve families at "high risk", but in 1999 it evolved into a program that offers both universal services (i.e., services available to all families in Ontario) and targeted services (i.e., services available to families who meet certain criteria). The program offers families at risk more detailed assessment services and referrals to community services. The program offers families at high risk home visiting services, service co-ordination, referrals and other supports.

The program is designed to:

- -Give children a healthy start in life
- -Provide more intensive services and supports for families with children who may not reach their full potential (i.e. at high risk).

Program components include:

- -Larson Prenatal Screen: As part of the universal program a prenatal screen (Larson tool) is completed on all pregnant women who access the Healthy Babies Healthy Children program prenatally, and may be used by other service providers in the community. The Larson prenatal screen consists of three questions designed to identify factors that are associated with parenting difficulties and problems with child development. Screeners may administer only the three required questions, or they may integrate the questions into a longer, more detailed prenatal assessment. The screen is administered as early as possible during pregnancy. It is designed to identify a small number of factors associated with low birth weight and parenting problems including:
 - -The mother's smoking habits
 - -The mother's level of education
 - -The mother's attendance at prenatal classes or effort to seek out prenatal information

The period between conception and birth lays the foundation for a child's well-being. It is the time when the child's basic neural structures are established and these structures have a direct impact on the child's development. It is also the time when the attachment between mother and child begins. For mothers at risk, the pre-

natal period is a critical time and the optimal starting point for Healthy Babies Healthy Children services. The relationship that develops after the baby's birth is often enhanced if the home visitor gets to know the mother in the prenatal period.

-Postpartum Tool, Healthy Babies Healthy Children (Parkyn): Healthy Babies Healthy Children Postpartum screening aims to reach all consenting women who give birth in Ontario, identify those who may be at risk, and link them to services. It consists of a series of questions designed to identify factors associated with risk for child developmental problems. The Parkyn postpartum screen is administered before the mother leaves hospital either by a postpartum nurse, public health nurse or by a midwife. Physicians also are encouraged to fill in sections of the Parkyn tool during visits for postpartum or newborn care. Postpartum screening is an efficient, effective way to have contact with almost all families with new babies in Ontario, and to identify those who may be at risk, early in the child's development. As part of the postpartum screen, hospital staff and midwives ask mothers for permission to share the results of the screen with the Board of Health, and whether they wish to receive a postpartum phone call and home visit from a public health nurse. Healthy Babies Healthy Children works with hospitals and midwives to establish procedures and protocols for notifying the Board of Health of all births and obtaining results of all postpartum screens, providing the mother/parent consents. The Parkyn screen can help determine whether a child and family is at risk. Brief and in depth assessments may then be completed to further assess risk for poor child development; a family with a high risk assessment may be referred to the home visiting program

-Nipissing District Developmental Screen[™]: A parent completed developmental checklist designed to assist parents, health care and child care professionals with a convenient and easy-to-use method of recording the development and progress of infants and children from 0 to 6 years of age. Age appropriate activities designed to promote



Improving the Odds: Healthy Child Development

overall development accompany the Screens. The NDDS[™] is not a diagnostic tool and it is not meant to be a formal assessment of the child's skills but rather parent self-report tool to determine any areas that may require some extra help or additional screening.

- –Areas of development covered by the screens include communication, gross and fine motor, cognitive, social/emotional, and self-help. The Screens coincide with immunization schedules as well as key developmental stages up to age six.
- -Availability: Ontario residents, programs and providers, including primary health care providers can access the NDDS[™] website www.ndds.ca to download both PDF copies of the NDDS[™] screen and the interactive online NDDS[™], at no charge.
- -Parent Education and Support: Many public health units provide a phone call about 48 hours after post delivery hospital discharge to offer support and education. Healthy Babies Healthy Children links families to parenting groups that offer information on healthy growth and development, attachment, play based learning activities, and other parenting resources in their local community. Healthy attachment behaviours are promoted in the mother-child relationship through individual intervention. Some public health units offer all new parents an initial home-visit.
- -*Referral and Service Coordination:* Families and children identified by the Parkyn as "at risk" are linked to various community resources related to parenting or child development to support and strengthen family functioning and to promote healthy child development. Referrals/ Service Coordination also may take place via information telephone line (ie Parent Talk Line, Health Connection). A collaborative management plan is developed with the family, the public health nurse, the family home visitor, other health unit staff and community services, to ensure continuity of care for families involved with the home-visiting program.

See Appendices D and E for the Larson and Parkyn tools

C. Other Services

There are many additional services and service providers that are important resources for families of young children. Public health units can help primary healthcare professionals become more aware of the range of services available in the community, providing a complete directory of local services. Some services assist all parents in their important and challenging job of raising young children, while others support children and families who face specific challenges. Services may be accessed and delivered uniquely in different communities, however central access numbers as provided by the Healthy Babies Healthy Children should simplify the situation. Healthcare professionals are encouraged to work together to improve access and communication between service in their communities and region.

Unfortunately, specialized services are not always available, or there may be a long waiting list. It is not sufficient to diagnose a concern. Diagnosis needs to be followed by appropriate interventions, supports, treatment and care. Healthcare professionals are opinion leaders who may need to take on an advocacy role. Issues and concerns about access and availability of services should be documented. All healthcare providers can and should advocate to improve service delivery and resources.

Areas of Service

- -Mental Health Services and Supports: Mental health services and supports are delivered to children and youth by numerous community agencies throughout the province. Mental health services and supports range from health promotion, illness prevention and early identification, such as parent education and school-based programs, to highly specialized treatment, such as cognitive behavioral therapy and intensive home-based interventions. These services and supports are delivered by providers with specialized training in child and youth mental health, in mental health, or in serving child and youth populations.
- -Developmental Services: Developmental services can assist children who have developmental delays. The services may be accessed through a formal program such as a Child Development Centre or a Children's Treatment Centre, or through a healthcare provider such as a developmental pediatrician. Infant Development Programs and Autism Intervention Program are services of special note (see next page).
- *–Early Learning and Child Care:* Child care plays a key role in promoting healthy child development and helping children arrive at school ready to learn. It is also an essential support for many parents, helping them to balance the demands of career and family while participating in the workforce, or pursuing education or training. The early learning and care system consists of both unlicensed and licensed child care. Unlicensed or informal child care may be provided by relatives, friends, neighbours, or nannies. Licensed child care consists of private home day care agencies (also called home child care) and day nurseries (also called child care centres). Day nurseries may include nursery schools, full day programs, programs providing supports to children with special needs and their families and before and after school programs.
- -Parent-Child Services: Parent-child programs promote healthy child development and well-being of families. These include Community Action Programs for Children, Ontario Early Years Centres and Family Resource Programs. Most provide drop-in programs, toy lending, parenting classes and information and activities for children, depending on the

unique needs of the communities they serve. Some communities have family wellness clinics for parents to have on-the-spot assessments for their preschool children.

- -Speech and Language Services: Speech and language services help children with communication delays or concerns. Speech and Language Pathologists, the Infant Hearing Program, the Preschool Speech and Language Program and other community audiological services work together to maintain, develop or restore the child's highest potential for communication (see next section for a description of the Preschool Speech and Language Program and Infant Hearing Program).
- -*Therapists:* Therapy may address physical and/or cognitive issues. Occupational therapists and physiotherapists play an important role in improving children's ability to perform certain tasks. Play therapists conduct play therapy assessment and treatment with young children who do not have the language skills to benefit from cognitive therapy. Clinical psychologists can provide individual therapy, family therapy, marital therapy, group therapy, behaviour management and educational sessions for parents and families.
- -Healthcare Services: There is a wide range of healthcare services that can be coordinated to support healthy child development. Midwives, family physicians, developmental and special service pediatricians, nurse practitioners and nurses all have an important role to play in promoting and supporting health in the preconception, prenatal and postpartum periods.
- -*Child Protection Services:* Family and Children's Services (previously called the Children's Aid Society) supports families in their central role of caring for and nurturing children. It advocates for children and provides coordinated, quality services for children, families and individuals. The primary service focus is on children in need of counselling, support and protection from abuse and neglect. They often administer and run group homes and offer foster care.
- -Social Workers: Social workers counsel families, with a focus on parent training. They support the family in managing the mental health issues of their child.
- -Financial Supports: The stress of poverty can create additional challenges for parents. Families may benefit from referrals to programs that address financial concerns such as food banks and emergency shelters. Certain professionals, such as social workers may be quite knowledgeable about programs that are available in the local area. Community Care Access Centres may also be a resource, depending on the region.
- -Supports for Pregnant and Parenting Teens: Pregnant and parenting teens have specific needs and concerns and may be more comfortable if referred to programs specifically designed for adolescents. Programs may include teen prenatal classes or

teen parent support groups. In addition, Learning, Earning and Parenting (LEAP) can assist and support teen parents so that they can finish high school, obtain assistance with childcare, improve parenting skills and achieve economic self-sufficiency.

- -*Programs for Fathers:* Fathers have unique needs and perspectives on parenting, and often benefit from programs for fathers. There are many excellent programs available, including Dads Can and Focus on Fathers.
- -Informal Supports: Keep in mind that informal supports are also very important to child development. These can include parent self help groups, neighbours, the faith community, friends and extended family.

Programs of Special Note:

- -Preschool Speech and Language: Preschool Speech and Language Services provides services for children from birth to senior kindergarten entry for communication problems. Services include speech-language assessment, therapy, consultation, home programming and parent education.
- -The Infant Hearing Program (IHP): Undetected permanent hearing loss(PHL) can cause speech and language (Oral and or ASL) delays in children. Speech and language delays put children at risk for emotional and social delays, difficulties with in the family, childcare and school. We need to find these children as soon as possible. The IHP provides Universal newborn screening to all Ontario newborns in the hospital pre discharge or in a community clinic.

Children identified with a permanent (PHL) Hearing loss or at risk for developing PHL are provided audiology assessments and monitoring of a child's hearing (0-6). Children with an identified PHL are provided with communication and language development as needed. Sometimes it will be 1:1 therapy while other times it is group or parent training. Social support is provided to parents of newly diagnosed children.

Health professionals should assess whether the newborns in the practice have received the newborn screen and review the results with parents. If the child is identified as deaf or hard of hearing, the professionals should support the parents to access the IHP services the child is entitled to. If a child has been prescribed hearing technology, the professionals should encourage the parents to make use of the technology.

It is important to repeatedly assess all children in the practice for delays in speech and language development and re- refer to IHP if required. Any infant who has been cared for in Neonatal ICU or had any medical conditions that could affect hearing should have regular audiological screening according to a high risk protocol. If a baby/child stops babbling, vocalizing or stops talking consider requesting a hearing assessment. Early identification of PHL and intervention gives parents the tools to bring out the very best in their child/ren.

-The Ontario Blind Low Vision Early Intervention Program (BLV): Vision problems should be identified as soon as possible children. The Ontario Blind Low Vision Program is an early intervention and family support service for children(0-6) with visual acuity no better then 20/70 in the better eye after correction, visual field restrictions of 20 degrees or less in the better eye eye conditions such as Cortical Vision Impairment (CVI), Retinopathy of Prematurity (ROP), Optic Nerve Hypoplasia (ONH), Albinism, Coloboma, Microphthalmia, Anophthalmia.

Children with Blind or Low Vision are at risk for attachment issues, poor emotional development, fine and gross motor, social, language and communication development delays. Specialized support is available through the Ontario Blind and Low Vision Early Intervention Program. Indicators of visual impairment are, lack of eye contact, lack of visual fixation, or lack of tracking by three months, a haziness in the pupil, lack of co-ordinated eye movements, turning, tilting of the head when looking at objects.

Optometry and Ophthalmalogy are covered by OHIP with a physician referral and 3-6 months is not to early too refer. BLV Early Intervention supports parents to bring out the very best abilities with in their low vision and blind children.

- -Infant Development Program: This program provides early intervention for families with children who are developing more slowly than expected, or whose development is at risk because of birth or medical problems, genetic disorders, low birth weight or for reasons unknown. The services include developmental assessments and home visiting where the therapist recommends adaptations to the environment and teaches the parent how to use their home environment to encourage their child's development.
- -Autism Intervention Program: This is a program for children who have a diagnosis of Autism. The program provides support services and training to families, intensive behavioral intervention (IBI) to promote development and address behaviours; and transition services to help children with autism integrate into new environments.
- -Ontario Early Years Centres: These centres offer services that are accessible by all families with children from ages 0 to 6 regardless of socioeconomic background, culture, geography

or special needs. They help parents link with other organizations that provide services such as childcare, healthcare and recreation programs. Ontario Early Years Centres promote healthy child development and readiness to learn through:

- -Programs and services for parents/caregivers and children from ages 0 to 6
- -Services designed to support the early years service community
- -Initiatives designed to educate the community at large and encourage the community to play an active role in healthy child development

Best Start: Helping Young Children Get the Best Start in Life

We all want the best for Ontario's babies and children. That means making sure they get the best possible start in life. That's why the Ontario government launched Best Start. It's a plan to strengthen healthy development, early learning and child care services during a child's first years so children in Ontario are ready and eager to learn by the time they start Grade 1.

The goals of Best Start

Best Start is Ontario's Strategy to invest in children's healthy early development - all in a convenient and easily accesible system for parents and caregivers. The Ministry of Children and Youth Services is working with community partners – school boards, public health units, child care and children's service providers, and municipalities to ensure that:

- -many more children and parents have access to services and supports, regardless of individual economic or social circumstances
- -pre-school, kindergarten, quality child care, public health and parenting programs are integrated into a seamless system that supports families and children
- -early and on-going screening of Ontario's children to identify potential issues, needs and risks is strengthened
 -early learning and care hubs are centrally established in Ontario's communities to provide families with a single, integrated, seamless point of access to services and supports based on local needs and available resources.

Enhancements to Ontario's ongoing prevention and early intervention programs means we can identify babies at risk early and help families get the advice and services they need to give their newborns the best chance for healthy development and to help children with language and hearing disorders develop the communication skills they'll need to succeed in school.

Ontario is building a system of early learning and child care that will give our children the best chance at future success. That system is Best Start.

Concluding Remarks

The nature versus nurture debate is not new. What is new is the realization of the importance of the early years in neurodevelopment. While many parents are expecting a perfect healthy baby, despite our best efforts, this does not always happen. What healthcare providers can do is improve the odds. Further research is expected to provide more insights into early brain development, structure and function and how it influences behavior. Research will help us revisit and refine our approaches to support neurodevelopment, with a continued emphasis on the importance of the early years.

The "Healthy Child Development: Improving the Odds" CME workshops and this associated toolkit were designed to increase knowledge of the implications of recent information about neurodevelopment. The role of primary healthcare providers is critical to early neurodevelopment. There is extensive brain development in utero and in the first year of life. Many things influence early wiring processes in the fetus, infant and young child, including factors such as genetics, nutrition, care and nurturing. The early period of neurodevelopment has an important influence on future learning capacity, emotional regulation and risks for mental and physical disease.

Family physicians and other primary healthcare providers need to be aware of the challenges of parenting and of effective interventions. All parents need assistance, information and guidance. All children can benefit from early childhood education experiences. Primary healthcare providers can promote healthy child development by supporting parents, paying special attention to issues of attachment and parent-child interaction. Early recognition and intervention is critical in all developmental delays. Interdisciplinary coordination provides a comprehensive approach to screening, assessment and intervention for developmental delays in infants and young children. A familiarity with local resources and services will help the healthcare provider support all families, while providing extra supports for families at risk.

Key Points - Service Providers

-Primary healthcare providers do not need to provide all services and meet all needs of a family.

- -Family physicians and other primary healthcare providers should be aware of local services and referral systems.
- -The Healthy Babies Healthy Children program can help families find needed services.
- -Link families as early as possible to appropriate services to help the child have the opportunity to reach full potential.



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Additional Resources

Websites

- 1. www.motherisk.org
- 2. www.ChildTrauma.org/
- 3. www.sogc.org
- 4. www.earlychilddevelopment.ca/
- 5. www.investinkids.ca
- 6. http://www.pbso.ca/ (Perinatal Bereavement Services Ontario)
- 7. www.rourkebabyrecord.ca
- 8. www.18monthvisit.ca

Many maternal, newborn and early child development resources and services are available from:

Health Nexus, Best Start Resource Centre 180 Dundas Street West, Suite 301, Toronto ON M5G 1Z8 Telephone: 416 408 2249 / 1 800 397 9567 Fax: 416 408 2122 beststart@healthnexus.ca www.beststart.org