

## CHAPTER ONE

### INTRODUCTION, PROBLEM STATEMENT, AIM AND RESEARCH METHOD AND PROGRAMME

#### 1.1 INTRODUCTION

##### 1.1.1 Reasons for and importance of the study

Low Birth Weight (LBW) premature babies have been shown to present with learning, developmental, behavioural and emotional maladjustment some years after their birth (Breslau, 1996 p.927 and Chapieski & Evankovich, 1997 p.221). This reality has motivated other disciplines (for example speech-, occupational-, and physiotherapy) to apply a preventative strategy by implementing early intervention programmes. However, no early intervention programme addressing LBW premature babies from an educational psychological perspective has been implemented in South Africa (or Africa). The educational psychologist can play an integral part in prevention. Educational psychology will therefore form the foundation of this research into the development of an early intervention programme for parents of LBW premature babies.

##### 1.1.2 The importance of the early years of life

Child development theorists on child development, such as Lerner (1993 p.43), Freud (1991 p.103), Gesell (1925 p.3), Erikson (1995 p.69), Piaget (1971 p.300), Bloom (1969 p.410) and White (1975 p.98), all emphasize the fact that the first five to six years are the most important developmental period in a child's life. During this period there is particularly great potential for growth in the physical, sexual, perceptual, emotional, linguistic and cognitive abilities. At conception a new life receives various characteristics from the mother and father. The child inherits potential intellectual ability, but this potential has to be realized through interaction between the child and the people and things around him (his environment). A person has to develop and actualize the potential with which he is born throughout his life, but the first five to six years of life is a crucial time for this self-discovery in terms of cognitive and emotional development (Leonard & Piecuch, 1997 p.246).

Every baby is born with a certain number of neurons. These neurons (which are the principle cells of the brain) are irreplaceable. Each neuron develops protrusions, or dendrites, which

connect it with other neurons. The more active the brain is, the more dendrites develop. The more the brain does, the more integration takes place between the neurons. This integration process is maximal in the first five or six years, but the speed and intensity with which connections are formed decrease steadily, and by the time the child is about five or six years old (Brierley, 1994 p.30; and Anastasiow & Havel, 1993 p.173), the process has slowed down considerably. The importance of the first five or six years of a child's cognitive development is thus clear. Cognitive development is a result of people's interaction with their physical and social environments, and through social interaction, both positive and negative, children begin to realize that they have a perspective on the world that is uniquely their own (Ndandani, 1997 p.10).

Development is an orderly process, and this applies to both cognitive development and affective development (Cooper, 1991 p.7). Both affect and cognition influence and help determine the child's behaviour.

The well-known Danish psychologist Erikson (1995 p.251) classifies the emotional development of the human being into eight stages. The first stage starts with birth and the last ends with death. According to Erikson, the newborn baby is born without any attitudes, feelings or beliefs. These develop in due course. The first important step (stage one) in this direction concerns basic trust in his parents, himself and eventually the world surrounding him. If he does not develop an attitude of basic trust, he develops a basic mistrust in himself and everything else. Whatever develops at this stage will greatly influence all further emotional development. In the first two years of life the baby has to develop a feeling that there is hope, that everything is not hopeless. This learning process starts, according to Roos and Vlok (1988 p.8), when the baby is hungry, cold or uncomfortable. He communicates this need to the world by crying. If his mother responds positively towards the baby each time this happens, he learns that she can be trusted to help him if requested. He also starts trusting his own abilities to achieve certain goals. If a child is left to cry without parental response and later stops crying by himself, he may learn that it doesn't help to cry or to reach out to people. The perception that the world, people and he himself cannot be trusted may develop. This perception may lead to a feeling of helplessness, a feeling that no matter how hard he tries, he cannot achieve a goal. He may then stop trying and withdraw. The first three stages of emotional development (as classified by Erikson), basic trust versus mistrust, autonomy versus shame and doubt, as well as initiative versus guilt, should be realized within the first six years of the child's life. This developmental progress requires increasing social competence, which has an important influence on all perceptions about himself, others and the world surrounding him.

Initially the baby is emotionally, as well as physically, reliant on the parental figures. Gradually he is able to tolerate greater distance from them and develop towards independence. The path from dependence to relative independence is accompanied by an increasing ability to care for himself and an increasing interest in relating to others. Adequate experiences of attachment during the first sensitive years encourage a healthy self-esteem and a sense of confidence, as well as the ability to negotiate later separations from important figures. The parents also facilitate the development both of empathy for others and of a desire for mutual give and take in their relationships with their babies (Reder & Lucey, 1995 p.58).

According to Bremner (1994 p.177-201) and Schaffer (1996 p.100-202), the newborn baby is not born with a self-concept. This develops with time. The child first develops an idea of his body, or a body image. Sickly or disabled children can easily feel inferior. The child discovers who he is from his parents and others' responses to, treatment of and attitudes towards him. There is a correlation between the quality of children's primary social relationships and the nature of their self-concepts. The better the relationships, the better the self-concept. Physical cuddling is one way a parent can show affection towards a child. Nurturing such as this (cuddling, holding, rocking, et cetera) from the moment the baby is born should have a positive effect on the development of his self-concept. Maltreated children are known to manifest a wide variety of more or less profound psychological disturbances. These disturbances include the development of the self-concept in deviant ways.

Along with other facets of his emotional development, a child's self-image will continue to develop and be modified throughout his life. However, it appears that the self-image that he develops within the first five to six years remains a determinant for the rest of his life (De Witt & Booyesen, 1994 p.164). If, therefore, a child has a predominantly positive self-image when he starts school, he will be self-confident, show initiative and frequently experience the achievement of success. This reinforces his self-confidence and establishes a positive cycle. Precisely the opposite will apply to a child with a predominantly negative self-image: because he believes he cannot be intelligent or successful, he will not really try and will frequently fail, reinforcing his initial negative self-image. The child's self-image impacts significantly on his view of reality.

It should be clear that the first five to six years of a child's life is the most important phase for development. It has been shown that developmental delay during this phase (caused by various factors, such as prematurity or poor parental care) may lead to long-term negative effects (for example, emotional or behavioural problems). Early intervention with children and parents is therefore important to prevent possible developmental delay within the first five to six years.

LBW premature babies are at risk for developmental delay, and they are therefore considered as a target group for early intervention. (Ballard and Peabody, 1996 p.103) states that there are

Even if development during the infancy period is normal, it cannot be assumed that all will continue to go well for the rest of the infant's life. Indeed, Ballard (1991 p.138) caution against overemphasizing the importance of the early years, arguing that early experiences, which are sure to be modified by later experiences, will not necessarily have long-term effects. They argue that infancy is only important in terms of its function in the developmental chain. All development is important, and much effective therapeutic work has been done in the stages beyond early development.

Though these arguments are valid, there is no reason for postponing intervention with high-risk babies (especially LBW premature babies), who are known to have a high prevalence of developmental delays, as well as behavioural difficulties.

### **1.1.3 Long-term effects associated with Low Birth Weight premature infants**

More than a decade has passed since the Newcastle research team (Neligan, Prudham & Steiner, 1976 p.113) published their data, showing that children born "too soon" or "too small" in 1960-62 had behavioural, emotional and intellectual impairments five to seven years later. There is an increasing body of literature supporting the Newcastle research, describing a high prevalence of developmental, learning and emotional maladjustment as well as behavioural difficulties in LBW premature babies when they later attend school (De Róiste & Bushnell, 1996 p.41). According to O'Callaghan, Burns, Gray, Harvey, Mohay, Rogers and Tudehope (1996 p.917), Sommerfelt, Troland, Ellertsen and Markestad (1996 p.927), Breslau (1995 p.97-104), Deshler (1996 p.69-71) and Dusick (1997 p.164), many LBW premature babies who appear motorically and cognitively normal prior to school entrance develop more subtle problems when faced with formal educational demands. Poor visual-motor skills, visual integration problems and impaired performance on tasks assessing spatial relations and memory, occur with greater frequency among LBW premature children than among matched control groups of normal birth weight, full-term birth classmates. Behavioural and social problems are also to be found more commonly in children of LBW than normal birth weight (as a result of developmental problems, as well as social influences and family factors). Behavioural problems (including hyperactivity, aggressiveness, low tractability, conduct disorders, anxiety, depression, shyness, passivity, and impaired social skills) as well as attention deficits have been reported.

However, follow-up studies of the Newcastle research, performed by Hawdon, Hey, Kolvin and Fundudis (1990 p.943) and Brambring, Rauh and Beelmann (1996 p.393), show that there are few significant long-term consequences for most LBW children, given present standards of antenatal care and perinatal management. They argue for an awareness that social influences and family factors (for example over-protective attitudes of parents) have a much more profound influence on a child's subsequent development than the biological factors which resulted in the child's being born with LBW. According to Kang, Barnard, Hammond, Oshio, Spencer, Thibodeaux and Williams (1995 p.172), as well as Ndandani (1997 p.9), compromised developmental progress is also related to poor social interaction between LBW premature infants and their parents. Ensher and Clark (1994 p.83), Hawdon *et al.* (1990 p.943) and Kang *et al.* (1995 p.172) argue that there should be a renewed commitment to investigating these important postnatal influences.

The possibility of generalizing from the above-mentioned studies is influenced by a number of factors (Lukeman & Melvin, 1993 p.839-840). These include the biological factors of the severity of neonatal illness and the immediate medical care that a LBW premature baby receives after birth. Social and environmental factors can also determine and influence long-term effects. While the fundamental causes of LBW are, as yet, only partially understood, many associated conditions, such as poor nutrition, small stature, obstetrical complications, and less than adequate maternal health, are all more common among poor women, as is reduced access to prenatal care. Sommerfelt *et al.* (1996 p.928) confirm that prematurity remains disproportionately a problem of the poor, with the incidence of LBW some two to three times higher among women who are socially disadvantaged. They further maintain that a significantly larger number of parents with LBW premature babies are single, a family factor which might lead to environmental factors such as poverty and loss of security. Other factors, such as parent-baby interaction, the parents' ability to deal with the crisis of unexpectedly having a LBW premature baby, and the stimulation of or intervention with the baby, may influence the nature of the long term effects which may follow the birth of a LBW premature baby. There are, however, findings which challenge the widespread belief that premature birth and miscarriages are only common among women from lower socio-economic groups. Career women run an increased risk of premature labour (Di Renzo, 1998 p.14). In addition, workplace stress is also blamed for many premature births. Premature babies born with LBW and presenting negative long-term effects, as well as possible ways to prevent such negative outcomes, must therefore be seen as an integrated, complex field of study. The social, ethnic and educational backgrounds of mothers may be only some of the factors which influence the prevalence of prematurity, and which may result in learning difficulties. These influences may also have an effect on the type of early intervention and support provided.

According to Chapieski and Evankovich (1997 p.221), premature births may have secondary effects on behaviour by changing parental perceptions and attitudes, thereby distorting normal parent-child interactions and relationships. Premature births are often associated with long hospital stays, and there has been concern that the extended separation of parent and infant may interfere with normal attachment. In addition, premature births can be associated with real or perceived life-threatening medical conditions and resulting parental anxiety may lead to an overprotective parenting style. A multi-aetiological model is undoubtedly necessary to explain the behavioural maladjustment in infants and children born prematurely. The impact of both biological and social risk factors must be understood, if those infants most at risk are to be identified and effective interventions designed and implemented for them.

#### **1.1.4 Early intervention for LBW premature babies**

##### **(1) Introduction**

Prematurity is often preventable, according to Luke (1995 p.17), whose intervention programme succeeded in lowering the French prematurity rate by 52% (from 8.2% in 1972 to 3.9% in 1989) and the French early preterm rate (births before 34 weeks of gestation) by 50% (from 2.4% in 1972 to 1.2% in 1989). It seems that prevention of prematurity is the most successful way of dealing with the problems that LBW premature babies may experience.

Research on early intervention in infancy seems to be divided into two main approaches (Cooper, 1991 p.32). One approach deals with those wanting to enrich the environment, to encourage early learning or to optimize childcare and education within the framework of normal infant development. The other approach is based largely on a deficiency model, and deals with early intervention that is aimed at providing compensatory stimulation to infants who are deprived of a normal environment, such as premature infants. Strategies used to achieve these goals vary in whether the intervention focus is primarily the child, a parent (usually the mother), or the parent-child relationship (Spiker, Ferguson & Brooks-Gunn, 1993 p.755). This thesis will be founded on the first approach, although the second will be integrated where it is appropriate.

Over the past twenty years, early intervention for LBW premature babies has been emerging rapidly as a discipline in its own right in both hospital and community settings. It has drawn professionals from a wide variety of specialized fields (education, including health education, special education, child development research, et cetera), and has generated its own literature, which is in turn expanding rapidly, as can be seen in the work of Dudley, Gyler, Blinkhorn, and Barnett (1993 p.74), Lukeman and Melvin (1993 p.837-849), McCollum and Yates (1994 p.54-

63). The importance of parental involvement with premature infants during the hospitalization period is well-documented (McCluskey-Fawcett, O'Brien, Robinson & Asay, 1992 p.152). Because the immediate needs of the infant are of prime concern to nursing staff in the Neonatal Intensive Care Unit (NICU), and these needs are more efficiently handled by trained staff than by parents, parents usually have to be assertive and persistent to assume a major caregiving role. Intervention programmes, therefore, need to focus on providing parents with the information and skills necessary to assert their right to be involved successfully. Parents who are well-informed about the functioning of the NICU, are realistic and can provide care for their children. Parents who know how to negotiate good working relationships with the staff will be more likely to feel empowered rather than powerless, and be more active in the early days of their children's lives. In turn, these parents will be better-prepared to provide appropriate care when their babies come home.

The major challenge facing neonatal health care, according to Lawhon (1996 p.48), is to combine the necessary technological intensive care for the newborn baby with a sensitive and individualized approach, to facilitate neurobehavioural development while acknowledging and supporting the parents of these infants in their role as primary and long-term caregivers.

## (2) Positive effects of early intervention

Studies by Spiker, Ferguson and Brooks-Gunn (1993 p.760) as well as Bacharach and Baumeister (1998 p.197), show the positive effects of early intervention for LBW premature infants, on outcomes lasting beyond the first year of life (e.g. maternal interactive behaviour and children's social competence and cognitive development).

The focus on parental support is well-founded in research (Thurman & Gonsalves, 1993 p.177), which suggests that mothers who are more active in the NICU are also more actively involved with their babies during the first three months at home. Without some early intervention aimed at supporting the relationship between the mother and the baby, it is likely that this relationship will suffer (Thurman & Gonsalves, 1993 p.177). Such support could start within the first few days of the baby's hospitalization, while the mother is still in the hospital recovering from the delivery. The research shows the positive effects of early intervention on outcomes such as overcoming the mother's anxiety and fear regarding the NICU. It is important to help mothers understand their baby's condition, while minimizing their feelings of guilt.

Studies done by Bennet and Guralnick (1991 p.1513) show that LBW premature babies who receive personal care have reduced oxygen requirements, a shorter hospital stay, and improved performance on infant development tests.

Most interventions for LBW premature infants have taken place in NICU (Bradley, Whiteside, Mundfrom, Casey, Caldwell, & Barrett, 1994 p.531). There is, however, been increasing interest in interventions, for infants with LBW and their parents, that continue after discharge from the NICU, because children's long-term health and development appears to be closely tied to the quality of care that they receive throughout the early years of life (Bradley *et al.*, 1994 p.531). The long-term results, according to Seitz and Apfel (1994 p.677), suggest that changes in the caregiving environment, resulting from early family support, lead to benefits for all the family's children. Parent-focussed programmes thus appear to provide a particularly efficient strategy for intervention efforts. Van Den Boom (1995 p.1811) shows that children who receive early intervention continue, three years later, to be more secure in their relationships with their mothers, to exhibit less behaviour problems, and to be better-able to maintain a positive relationship with their peers than the children who do not receive intervention. Another important result of such intervention may also be to alleviate parental anxiety, and thus free the parents from distortions of their perceptions, enhancing their ability to confront the baby's situation as realistically as possible.

It is preferable for help to be offered during the crisis, rather than much later when the traumatic evidence of failure may be a battered child or one who fails to thrive. According to McCluskey-Fawcett *et al.* (1992 p.154) and Miles and Holditch-Davis (1997 p.259), intervention programmes that (a) provide parents with the information and skills they need to feel competent and empowered as parents and (b) address the unique emotional needs of these families, are likely to alleviate many of the negative factors that are associated with the difficult experience of LBW prematurity.

Lawhon (1996 p.52) concludes that the most successful interventions involve the parent's understanding the infant's developmental needs, reading the infant's behavioural cues, and deriving satisfaction from caring for and interacting with the infant. Interventionists should therefore create an atmosphere in which parents feel supported in a difficult experience, and yet respected for their knowledge and concern for their child.



### (3) Reasons for early intervention for LBW premature babies

The vast majority of babies discharged from neonatal units can expect a healthy outcome, although an irreducible minimum of babies with varying degrees of developmental delay is likely to remain. Many characteristics of LBW premature babies put them at risk of developing less than optimal patterns of social interaction with their parents. These babies are less active, initiate fewer interactions with other people, and provide less feedback to their parents than their full-term peers. Furthermore, they maintain less eye-contact with their mothers, avert their gaze more, smile less and are more difficult to cuddle and console than their full-term peers. Mothers and their LBW premature babies may fail to form a bond of attachment, because of the separation resulting from the baby's protracted hospital stay, the baby's inability to interact with the mother for the first several weeks of life, and the lack of a clear parenting role for the mother during the baby's hospitalization (Bennett & Guralnick, 1991 p.1514). Whether delayed or not, the emotional impact of the time spent in hospital may have long-lasting effects on the family's adjustment, and the baby's emotional development, which includes his self-image and the powerful influence it may have on the rest of his life. Early intervention may therefore prevent problems with regard to relationships (parent-parent, baby-parent, sibling-baby, parent-sibling, et cetera).

For LBW premature babies, intervention programmes may help them to gain a higher level of functioning, which could possibly not have been accomplished without early intervention. According to Lerner (1993 p.49), one of the strongest arguments for early intervention is that it can eliminate many problems (e.g. delayed development) which may become entrenched if they persist into later years. The goal of early intervention, then, is to prevent or reduce the severity of a handicapping condition (e.g. delayed emotional development), so that the child is able to function adequately and is able to actualize his full potential. Developmental intervention (including tactile, vestibular-kinesthetic, auditory, and visual stimulation) has been advocated for LBW premature babies, and the importance of informing their parents about the increased risk of behavioural problems is recognised. According to O' Callaghan *et al.* (1996 p.918), parents may feel equipped to deal with the possibility of developmental delay, as well as possible behaviour and social problems, if they are adequately informed.

According to Roos and Vlok (1988 p.15), the parents' skill in dealing with the baby (how promptly the mother changes a nappy, how hygienically she cares for his bottles, or whether she follows a well-established routine) is not of prime importance to the child's development of trust and self-esteem within the first two years of his life. They point instead to the parent's underlying emotions, motives and attitudes. A child senses these, and is influenced primarily by them,

rather than by outward acts of skill. There is a wide range of possible parental reactions to having a LBW premature baby. On the one hand, the mother may feel anxious and guilty, or even fearful of becoming attached to a baby who appears to have a tenuous hold on life. This may translate into overprotection and/or rejection. On the other hand, parents may accept and encourage. They may choose to emphasize their child's delays or limitations, or they may prefer to concentrate attention on their child's normal development, et cetera. Another possibility is that of denial of their baby's situation.

Many parents are in need of emotional care themselves, but not all staff find themselves able to adopt a nurturing attitude towards them. In the environment of the NICU the conditions for getting to know one's baby are far from ideal. Parents find it hard to watch while painful medical procedures are performed, and indeed many withdraw from the situation completely, often feeling helpless and guilty about doing so. Those that are present, unless they are unusually detached, feel upset at not being able to prevent these things from happening to their baby, and at not being able to comfort the baby sufficiently and alleviate the pain. The inability to carry out the normal caring role makes many parents feel frustrated. According to Varma (1993 p.85), a measure of balance is required in the rearing of the LBW premature baby, and this can be addressed in an early intervention programme.

#### (4) The implementation of early intervention for LBW premature babies

Early intervention can be implemented in the form of a preventative programme if it is individualized, functional, modifiable, and sensitive to the autonomic and neurodevelopmental status of individual babies (Bennet & Guralnick, 1991 p.1515). Most successful programmes designed to optimize the development of LBW premature babies have utilized a comprehensive combination, not only of child development, but also of family support and parent education, improving the quality of parent-child interactions. Parental involvement is the cornerstone of many early intervention programmes (Reynolds, 1998 p.508), as evidence is accumulating that parental involvement helps increase the likelihood of their long-term effectiveness.

According to McCollum & Yates (1994 p.128), families, not intervention programmes, provide continuity in a child's life. They are, by definition, the primary physical and social settings in which a child's development occurs. Interactions with persons with whom the child has strong emotional ties have important implications, not only for the continuity and health of the particular relationship involved, but also for the predispositions that the child will bring to future interactions, and relationships with other persons. The development of a sense of self-efficacy, mastery and competence with regard to the expectation that one can control one's environment,

is influenced by parent-baby interactions that support the child's emerging emotional sense of self. Thus, the feedback that a baby receives from emotionally salient individuals early in life appears to be critically important to development. Conversely, parents' sense of self-efficacy as parents depends on the responses of the baby to their efforts in play and caregiving (McCullum & Yates, 1994 p.133).

"Parents are the best-placed people to help their children fulfill their potentials" (Anonymous, in Bernbaum & Hoffman-Williamson, 1992 p.35). The development of parent-infant relationships can be accomplished through parent support groups, one-to-one parent support contacts, or a combination of the two interventions. According to Roman, Lindsay, Bogar, DeWys, Beaumont, Jones and Haas (1995 p.383), however, little is known about the efficacy of such programmes.

The implementation of early intervention, and ways of dealing with developmental delay, are influenced by a number of factors. The social, ethnic and educational backgrounds of mothers may influence the prevalence of learning and behavioural difficulties and the early intervention and support provided. The social disadvantage of many of the families into which such children are born must be taken into account when considering ways to support them. According to Dudley *et al.* (1993 p.76), it is particularly difficult to involve poor women in programmes designed to facilitate intervention, because of lack of transport, the need to care for older children at home, and other crises of daily living. An effective approach to early intervention implementation, that would appear to be suited to rural communities, is collaboration with other community assets, such as volunteers and extended networks of families and neighbours (Doctoroff, 1995 p.346).

Blanchard's research (1991 p.133) provides strong evidence that a comprehensive, high-quality programme of early intervention, implemented with parents of LBW babies, can reduce, by the age of three, the number of LBW babies at risk of developmental impairment. It also appears that some subgroups of LBW children benefit more than others. Of particular importance are the findings from the same study, which indicate that babies born to mothers who are under-educated demonstrate cognitive gains when they participate in high-quality early intervention programmes, if they attended these regularly (Brambling, *et al.*, 1996 p.396).

The system of services for young children who are at risk and disabled has been characterized by a lack of interagency co-ordination (Rossetti, 1993 p.2). Minimum transitions during early childhood years are as follows: birth of at risk baby, hospital services (neonatal intensive care unit, follow-up clinic), transition, home or community (infant/toddler services), transition, public or private preschool services, transition, primary level school. Although families face transition

issues along with at-risk children from infancy to adulthood, transition practices have been directed towards the child, with little attention devoted to the family. The question that now concerns professionals is that of how early intervention personnel will shift from a more traditional, child-focussed model to a family-focussed model that includes transition planning as an integrated part of service delivery. Family-focussed transition activities (for example focussed interviewing and collaborative goal-setting) require new roles, new skills, and new ways of interacting that extend beyond the expertise of a single discipline (Rossetti, 1993 p.3).

Traditionally, early interventionists have assumed that parents of infants and toddlers with special needs are not ready to begin thinking about the future because of the multitude of immediate concerns regarding their child's medical or developmental status (Rossetti, 1993 p.6). Rather than speculating on whether a parent is ready or not, it may be more effective to ask parents to describe their own strengths, concerns, and needs for support as parents during the intervention process. Family support models are based on the assumption that parents have differing needs at different times, and that effective intervention is tailored to meet individual needs (Niemeyer & Proctor, 1995 p.315).

Liebenberg (1993 p.266) recommends that further studies should focus on developing communities, establishing the type of support which can successfully be implemented in them. According to her the support should start while the baby is still in the NICU, and fathers should also be involved. She emphasizes the point that medical staff working in the NICU should be trained in dealing with parents of premature babies.

##### (5) Current situation of early intervention for LBW premature babies in different countries

Although advances in medical technology have improved the LBW premature baby's prognosis for survival, other aspects of neonatal care should also be considered, in order to ensure the best possible early intervention to facilitate optimal development of babies within their families (Gatten, Arceneaux, Dean & Anderson, 1994 p.167). With the development of high-risk perinatal centres all over the world (Davis, Richards & Robertson, 1983 p.89), a number of mothers have begun to be admitted to the maternity division of hospitals with a NICU just prior to delivery or shortly thereafter. This trend could be helpful to both parents, since it prevents extra complications, owing to having family members in two different hospitals, for the father. If there is not sufficient time to arrange for her transport prior to giving birth, it is recommended that the mother be moved during the early postpartum period. The situation, however, varies in different countries.

According to Ensher and Clark (1994 p.94) and Dudley *et al.* (1993 p.75), the majority of mothers living in Australia deliver babies in hospitals where maternal and neonatal problems can readily be identified and addressed. India, in contrast, is the prototype of the crowded, overpopulated developing nation. There is a wide variety of impediments to adequate critical care. While advanced technology may be available, it is often reserved only for those who can afford to pay. The vast majority of babies are born at home or in a neighboring house, and local midwives attend to the mothers. Babies with anomalies or of low birth weight usually are not even taken to the few critical care facilities that do exist. The mother should remain hospitalized for the duration of her premature baby's hospital treatment, because she acts as the baby's food supply. Most intensive care nurseries have very limited technology, and it is not uncommon to see more than one baby receiving ventilator care at a time. Often several babies share a heating unit or even a bed. There are many well-trained physicians in India who are capable of caring for the critically ill newborn, but resources are limited.

According to Ensher & Clark (1994 p.94), the situation in China and Egypt is similar to that in India. In a developing nation, an intense effort must be maintained to ensure progress toward high-quality health care. In the former Union of Socialist Soviet Republics (USSR), there has been little change in the care of critically-ill neonates. Babies born at or near term with mild infections or readily-correctable surgical problems receive care. Infants with more complex malformations and very low birth weight are routinely allowed to die. Since this society has chosen not to fund intensive neonatal care, there are few medical and nursing personnel well-trained in this field, technology is limited, and no standards or expectations exist on a national level. However, the Soviet citizens value their healthy children and invest vast amounts of time and money in education, preventative health care, and sport training.

The United States of America continue to be at the forefront of early identification and intervention (Michelsson & Byring, 1997 p.133). According to Michelsson and Byring (1997 p.133), Finland also has a high standard of medical care when compared to the rest of the world. For the most part, early intervention services are available, free of charge, for all Finnish children. Intervention for developmentally-delayed children is considered part of ordinary medical care.

### 1.1.5 The current situation of early intervention for the LBW premature baby in the South African context

In South Africa, as a developing country, many medical problems arise as a result of the high birth rate in a population which is poorly-nourished, has limited resources and education, and limited health services. Infant mortality remains high, and is contributed to by the excessive number of births, poor maternal care and malnutrition. There is, however, both modern equipment and expertise available, but it is costly and is found only in the larger cities. The rural communities therefore have to travel far, after being referred by a doctor at a clinic or peripheral hospital. Those who can afford private medical care and those who have reached the government-subsidized tertiary hospitals in time, can be sure of excellent service.

The Chris Hani Baragwanath Hospital, a government-subsidized tertiary hospital in Johannesburg, provides a model of successful premature infant caretaking. Mothers of premature babies reside in a room adjoining the premature nursery, and each feeding time they enter the nursery to feed and handle their babies. According to Davis *et al.* (1983 p.262), the modern unit has been run in this way since 1976. The lying-in arrangement was originally instituted because of a shortage of nurses, but has multiple benefits. It allows the mother to continue lactation, permits her to take on the care of the baby more easily, reduces nursing time and allows mothers time for mutual discussion and support. Davis *et al.* (1983 p.263) found that parents in this care situation touched, talked to and looked at their babies in the *en face* position, and rated themselves as competent in baby care measures. These mothers continued to show involvement with their babies during feedings, and were concerned about their general development three months after their discharge from the nursery.

Early intervention at the Pretoria Academic Hospital, also a government-subsidized tertiary hospital, includes an inter-disciplinary focus (speech-, occupational-, and physiotherapy, dietetics and paediatrics). These therapists monitor the babies' physical and language development. The babies are identified in the labour room and treated at the NICU. Treatment is followed up at the baby clinic, and thereafter at the early intervention clinic, to ensure that the necessary therapeutic programme is implemented. Many therapists are involved, but only 4-5 babies can be seen per clinic day. The focus is primarily on each individual baby. The clinic is not readily accessible to the disadvantaged population, on account of its position.

Although professionals working with premature infants have come to recognize that the experiences of parents during the infant's hospitalization and homecoming are stressful and difficult, the predominant focus in most NICUs continues to be on the acute care needs of the

infants (Parette, Bryde, Hoge & Hogan, 1995 p.243 and McCluskey-Fawcett, *et al.* 1992 p.148). Because parents will ultimately assume care of the infant, and will strongly influence the child's developmental outcome, NICU procedures and early intervention need to include psychological interventions for parents. According to McCluskey-Fawcett *et al.* (1992 p.149), such interventions will be effective only if they are endorsed by the concerns and perceptions of the parents.

In light of the possible long-term effects of LBW prematurity on babies, the following must be kept in mind. Previously, in South Africa, learners with special educational needs were accommodated in separate, special schools or classes. However, since 1997, South Africa has been one of many countries which have made significant progress towards adopting an integrated education model ("inclusion policy"), where all learners are accommodated in the so called "main stream", and not in separate schools or classes (South Africa, 1999 p.14 and Baker, Labon & McGovern, 1995 p.18). The new Curriculum 2005 will effect a shift to a curriculum which is based on outcomes, i.e. where the learners will be actively responsible for their own learning, and the teachers will have additional roles as facilitators (South Africa, 1997 p.3). Each learner will therefore have a prior set of outcomes to achieve, as will have been discussed with the parents of the specific child. A majority of parents with LBW babies come from a lower socio-economic, as well as an educationally-disadvantaged, environment (Brambring *et al.*, 1996 p.394). It is therefore necessary, from before the learners begin with formal education, to educate and inform these parents on child development, goal-setting, et cetera, so as to ensure that they will be able to set realistic outcomes for their children when these are needed. Parents must, however, receive more than information. They need emotional support, understanding and compassion as they cope with their own emotions and behaviours (Webster & Ward, 1993 p.4). The parents also need to be informed about their role in the new education policy of South Africa.

An early intervention programme offers parents support (individually and by means of support groups), information (for example on child development), as well as skills (for example problem-solving techniques). This study may lead to the inclusion of the educational psychologist as a vital member of the early intervention team. The input from the educational psychologist may provide continuity in the support available to the parents of LBW premature babies.

### 1.1.6 The Educational Psychological Model

According to Mwamwenda, (1995 p.7), educational psychology is comprised of understanding human behaviour in relation to the problems involved in educating children. According to this author, the areas of concern to educational psychology are the following:

- *The learners* - their growth and development, their needs, their individual characteristics, their abilities and achievements, their nutritional state and the childrearing approaches adopted by their parents.
- *The learning situation* - the size and structure of the classroom and the school buildings. A child is not likely to learn adequately if the classroom is poorly ventilated, too hot or too cold, or lacks proper equipment such as proper seating, books, blackboards, et cetera.
- *The learning process* - the methods employed by teachers, their personalities, their understanding of and responses to their pupils' behaviour, all of which will determine to a large extent how children will learn.

According to Woolfolk (1995 p.11), educational psychology focusses on the psychological study of the everyday problems of education, from which are derived principles, models, theories, teaching procedures and practical methods of instruction and evaluation, as well as research methods, statistical analyses, and measurement and assessment procedures appropriate for studying the thinking and affective processes of learners, and the socially and culturally complex processes of schools. Essentially educational psychology is seen as the discipline concerned with teaching and learning processes.

In a similar vein, Gage and Berliner (1988 p.11) view educational psychology as being concerned with helping to solve those problems found in all phases of teaching - pre-instructional, instructional and post-instructional - and in all parts of the instructional process - setting objectives, understanding student characteristics, appreciating the nature of the learning process, selecting and using teaching methods and evaluating learning.

What most of the aforementioned delineations of the educational psychological terrain (Pretorius & Pienaar, 1997 p.1; Woolfolk, 1995 p.11; Gage & Berliner, 1988 p.11) have in common, is that they focus to a greater or lesser extent on the study of the behaviour of people (learners and teachers) in instructional settings. The focus, in these perspectives on educational psychology, tends to fall on the secondary educational situation (school), whilst the holistic educational psychological perspective (defined in section 1.8.1), aims to take into account the total spectrum of circumstances of a person's upbringing, starting from the primary educational



situation (family), and including both the secondary educational situation (school), and the tertiary educational situation (society).

As soon as the child is identified as having a developmental problem, which usually manifests itself as either an emotional, a behavioural or a learning deviancy, and the question of how the symptom(s) can possibly be addressed is asked, then the terrain of the professional educational psychologist is entered (Van Niekerk, 1991 p.41).

Educational Psychology is therefore a profession which requires both knowledge and skills (Roux, 1997 p.16). This means that it must fulfil the requirements of science as well as practice. Being theoretically-orientated, both psychology and pedagogics, as disciplines, focus on personality development. On the other hand, orthopedagogics and clinical psychology, being practice-orientated disciplines, focus on problems in human development and design actions to address these problems. In order to practice their science, it is necessary for educational psychologists to embrace both psychology and pedagogics, which aim to explain the child's development as a phenomenon. Although it is mainly pedagogics and psychology that are consulted in this regard, other disciplines (for example sociology) can also be incorporated in an accountable interpretational model (Van Niekerk, 1991 p.43).

The educational psychologist aims to explain impediments to and/or deviancies in the development and behaviour of children, and design techniques and methods to address these impediments and/or deviancies, from a personality-developmental perspective. The discipline of educational psychology is thus one of converging scientific perspectives, and its task is to select and detail theories and practices relevant to its involvement with the child in need (Van Niekerk, 1991 p.43), in order to harmonize the educational dynamics within the child's unique educational situation.

### **1.1.7 The role of the Educational Psychologist in Early Intervention Programmes**

As the LBW premature baby consistently falls in a high risk category with regard to physical, psychological and educational development, the educational psychologist's field of expertise includes preventative strategies and guidance for parents and other relevant role-players in the upbringing, education and development of such a child as a person (Van Niekerk, 1991 p.34). Family centered care includes appropriate and timely interventions that help parents deal with their own needs and distress, and that help them move from parenting a very sick infant to parenting a child with both normal and special needs. Such interventions can make a difference in the development and health outcomes of the child, as well as in those of the entire family.

## 1.2 THE ASSUMPTIONS OF THE RESEARCH

In terms of the preceding orientation, the theoretical assumptions of the programme to be designed and developed can be stated as follows:

- LBW premature babies are at high risk for physical, intellectual, emotional and/or social delays capable of interfering with normal growth, development and learning capacity (O'Collaghan *et al.*, 1996 p.917; Sommerfelt *et al.*, 1996 p.932; Breslau, 1995 p.927; Deshler, 1996 p.73).
- Early childhood is a unique developmental phase (Lowenthal, 1996 p.325).
- Parenting skills are enhanced through knowledge of all areas of normal development and childrearing (Bennet & Guralnick, 1991 p.1513).
- An enriching home environment improves a child's development and social adjustment (Dudley *et al.*, 1993 p.74).
- Intervention programmes (focussing on the parents, baby and family context) may help LBW premature babies to develop normally (Thurman & Gonsalves, 1993 p.177; Bennet & Guralnick, 1991 p.1514).
- Supplying information and knowledge on upbringing and education, as well as on the acquisition of parenting skills, can minimize or prevent infants' later developing developmental, learning, behavioural and/or emotional problems. The educational strategy is not, however, a guarantee for avoiding all problems. The aim is rather to narrow the spectrum of problems which may develop, to minimize the intensity and escalation of problems, and to prevent some problems (Reynolds, 1998 p.508).

## 1.3 PROBLEM STATEMENT

The premature birth of an infant is a life crisis (McCluskey-Fawcett *et al.*, 1992 p.148). The experience of the parents includes high levels of anxiety related to dealing with complex medical terminology and technology, as well as separation from the infant. These experiences, as well as anxiety about the long-term consequences of a premature birth, may cause parents concern for a long time to come. They are concerned about the effects of the experience on the baby, and about the effects of the separation on themselves and their relationship with their child. The implications of the possible developmental delay of LBW premature babies means, further that the question of early intervention needs to be addressed.

Early intervention for parents of LBW premature babies by means of a macro-level educational parent guidance programme, developed or adapted for South Africa from an educational psychological perspective, does not exist. A programme of this nature would include emotional

support, information and skills training for parents, focussing on issues such as dealing with the emotional reactions of having a LBW premature baby, parent-infant interaction, and infants' social and emotional development.

The problem statement of this study is contained in the following main research question: How could a programme designed from an educational psychological perspective serve as a preventative strategy, and thus contribute to an early intervention for the parents of LBW premature babies?

The following further sub-questions are implied by this main question:

1. What are the specific risks, needs and care requirements of LBW premature infants which their parents can address?
2. What is the nature of the emotional reaction which parents of LBW premature babies experience within the first few months after the baby's birth, and in which way(s) can the educational psychologist assist parents to work through these feelings?
3. Which criteria should be met by an early intervention programme for parents of LBW premature babies in order to fulfil the parents' needs?
4. What should an early intervention programme for parents of LBW premature infants encompass in terms of its objectives, components, design, content, format, and implementation?

#### **1.4 AIM OF THE RESEARCH**

The primary aim is to develop a cost-effective early intervention programme for parents of LBW premature babies, as a means of providing support and counselling for parents on a macro-educational level. The programme will be developed within the South African context, but in such a way that it can be adapted to be implemented in other developing countries in Africa as well, using Egypt as an example. The focus will be on support and counselling for parents as a preventative educational psychological strategy, and not in a rectifying dimension. Those psychological and educational factors for which parents may require guidance will be identified and integrated with the parents' other individual experiences, needs and concerns (for example, difficulties in parental-infant relationships).

The study aims to develop an early intervention programme in liaison with other relevant disciplines (speech-, occupational- and physiotherapy, dietetics, paediatrics and nursing), which can successfully contribute to the educational psychological perspective as research focus.

The programme will be developed in individual session as well as group session format, on the basis of relevant research findings and theory. Ten sessions will be developed, to attend to both individual parents and support groups of 4-5 pairs of parents. To ensure parental empowerment, knowledge, feelings and skills will be addressed. Family support will already have been provided within the first few days of the baby's hospitalization, while the mother was still in hospital recovering from the delivery.

The programme, when developed, will have clear, precise and measurable objectives, which will be put into practice. These objectives will help parents who find themselves in the circumstances of having a LBW premature baby to face the problems that may lie ahead with much greater calm and understanding. They will supply information and knowledge on upbringing and education, as well as on the acquisition of parenting skills which can minimize or prevent infants' later developing emotional, behavioural, developmental, and/or learning problems. The programme will target not only literate, but also semi-literate and illiterate parents.

## **1.5 THE RESEARCH METHOD**

### **1.5.1 Introduction**

The choice of methods used in this study will take the ethical issues into consideration, to ensure research beneficial to all role-players.

An exploratory study (including interviews and questionnaires) will be used to identify specific parental needs. The collaborative programme development follows integration of the information gained from a review of the literature, as well as the interviews and questionnaires.

Data analysis occurs throughout the data collection process (Mertens, 1998 p.350). The analysis process is systematic and comprehensive.

The researcher will include reflective activities that result in a set of notes that record the analytic process, thus providing accountability.

### **1.5.2 The researcher**

In qualitative research, the researcher is the instrument for data collection (Mertens, 1998 p.175). The qualitative researcher decides which questions to ask and in what order, what to observe and what to write down. In general, qualitative research text recognize the importance

of researchers' reflecting on their own values, assumptions, beliefs, and biases and monitoring those as they progress through the study to determine their impact on the study's data and interpretations (Denzin & Lincoln, 1998 p.3). The researcher of this study ensured monthly debriefing sessions. These sessions were held with an African educational psychologist in service with The Department of Education.

### 1.5.3 Gaining permission

Before the data could be collected, the researcher had to follow appropriate procedures to gain permission from the gatekeepers of the Pretoria Academic Hospital as well as The Mataria Teaching Hospital. The research proposal had to be evaluated by various ethical committees to ensure the outcome of ethical principles as follows:

- Beneficence: maximizing good outcomes for science, humanity, and the individual research participants and minimizing or avoiding unnecessary risk, harm and wrong.
- Respect: treating people with respect and courtesy, including those who are not autonomous (for example the LBW premature babies).
- Justice: ensuring that those who bear the risk in the research are the ones who benefit from it; ensuring that the procedures are reasonable, non exploitative, carefully considered, and fairly administered.

A consent form has to be developed and handed to each participant to sign, ensuring confidentiality and anonymity.

The following research activities will be carried out in this study, in accordance with the stated aims:

### 1.5.4 Literature review

The theoretical issues concerning the LBW premature baby's needs and care, the emotions that parents may experience after their baby has been born preterm and of LBW, parent-infant interaction and infant development will provide important directives for developing an early intervention programme for parents of LBW premature babies, from an educational psychological perspective. These issues will be examined by means of a review of the relevant literature. Factors to take into consideration when developing an early intervention programme for parents will also be explored.

### 1.5.5 Situation analysis

A situation analysis needs to be conducted in order to understand the situation of parents of LBW premature babies. It is necessary to explain and specify their situation in terms of their culture, the support they have, the implications that the LBW premature baby has for their family and community, their biographical details, as well as the hospital's infrastructure, in order to be able to design appropriate programme objectives which will meet their specific needs. A situation analysis will be done at the Pretoria Academic Hospital, by means of observations and interviews with relevant staff members.

In striving to adapt the early intervention programme so that it will be appropriate for parents of LBW premature babies in other developing countries in Africa, a situation analysis will also be done at the Mataria Teaching Hospital in Cairo, Egypt. The applicability of the programme can be assured by an understanding of the specific situation of the parents of LBW premature babies in Egypt. An early intervention programme will therefore be formatively developed for the South African context, but the programme will be adapted for the context of Egypt as an example of another developing country.

#### (1) Observation

The researcher will make use of moderate participation while observing the research setting (situation analysis), as well as the participants during the implementation of each session. The researcher will attempt to balance the insider and outsider roles by observing and participating in some, but not all of the activities. Lesser interactive observations will also be conducted to identify ethnographic factors.

The following strategies will be implemented to enhance the validity and reliability of the observational data:

- Two observers will be used, diverse in age, education and culture, including the researcher and an occupational therapist at The Pretoria Academic Hospital and the researcher and a pediatrician at The Mataria Teaching Hospital.
- Observational findings will be cross-checked with these other professionals.
- The researcher will describe the research setting in detail.
- Observations will be made over a long period of time at various times of the day, days of the week, and months of the year. At The Pretoria Academic Hospital, over a period of one year and at The Mataria Teaching Hospital, over a period of five weeks.

The situation analysis will be extended by a needs analysis, which will be conducted to secure information on the contexts of the programme (Borders & Drury, 1992 p.3).

(2) Needs analysis by means of interviews (indirect observation)

Structured individual interviewing as a method of data collection will be done, using a questionnaire (needs analysis questionnaire; Appendix 6). It will ensure that the researcher covers all the terrain in the same order for each participant (Mertens, 1998 p.321).

According to Borders and Drury (1992 p.18), the motive behind the needs analysis is not to compare different populations, but to serve a particular group. A needs analysis in the format of an interview questionnaire will be conducted with parents of LBW premature babies. Data will be gathered from two groups of parents. One group will be at the Pretoria Academic Hospital, and the other group at the Mataria Teaching Hospital in Egypt. The purpose of the needs analysis will firstly be to determine whether there is a need among parents of LBW premature babies to take part in the implementation of an early intervention programme. A further objective will be to determine if the programme content (as identified from the literature review) is in accordance with the needs of these parents.

A list of topics will be identified by a study of the literature. These topics will be recast into questionnaire format, bearing in mind both the programme's objectives and the following factors:

- The aim of the programme, which is to address the unique needs of the parent population of LBW premature babies
- The format of the questionnaire to be used (yes/no responses, rank ordering, as well as space for comments at the bottom of the questionnaire)
- Confidentiality (no names or initials will be used on the questionnaire unless the parents are interested in further participation)
- Ensuring informed consent (parents will not have to participate if they choose not to do so for any reason).

The interview technique will be used because it is flexible and adaptable. It can be used with different kinds of people, including illiterate people, and responses can be probed, followed up, clarified, and elaborated on, to achieve specific accurate responses (McMillan & Schumacher, 1993 p.238). Nonverbal as well as verbal behaviour will be noted in face-to-face interviews, especially in this study, which concerns personal qualities and information.

The questions on child rearing issues may lead to anxiety, suspicion and uncertainty, since these are very sensitive issues. If parents do not understand the context in which they have to answer these questions they could wonder what is wrong with their baby, and/or themselves as parents. The reason why they are to be questioned, and the way in which to respond to the questions will therefore have to be made clear to the parents. An interpreter will be provided to assist the researcher if the parents cannot communicate freely in English.

The primary disadvantages of the interview are its potential for subjectivity and bias on behalf of the researcher, and its high cost on account of its time-consuming nature. Making use of an interpreter may also present further complications. The interpreter may ask leading questions to support a particular point of view, or the interpreter's understanding of what is said may be inaccurate. To ensure the reliability of the interview data, the data will have to be assessed by means of an inter-rater agreement.

An analysis of the data gathered from the situation analysis (including the needs analysis questionnaire) will help determine the way in which the early intervention programme will be developed.

#### **1.5.6 Triangulation**

A way to strengthen a study design is through triangulation (Patton, 1990 p.187). Denzin and Lincoln (1998 p.46) mention types of triangulation, which will be used in this study:

- Data triangulation; the use of multiple data sources in this study will include the researcher, questionnaires and other professionals.
- Investigator triangulation; the use of several different observers and evaluators. The needs analysis questionnaire will be checked by asking other educational psychologists (one from the University of Pretoria, one from the University of South Africa and one from The Department of Education) to review the topics and suggest changes, before the organization and interpretation of the information. This strategy is known as multiple operationism (Garbers, 1996 p.83 and Mouton & Marais, 1992 p.93).
- Methodology triangulation; the use of multiple methods to study the problem will include a literature review, observations, interviews, and formative evaluation.
- Interdisciplinary triangulation; the researcher will make use of interdisciplinary teams to assist with the data collection as well as the analysis and interpretation of the data.

Qualitative data analysis is not mechanistic. The basis in a qualitative study rests on corroboration to be sure that the research findings reflect people's perceptions (Mertens, 1998



p.183). Specifically, triangulation requires the convergence of multiple data sources from a variety of participants under a variety of conditions. If all people and sources not agree, this difference in opinion will be made explicit in the report.

### **1.5.7 Audits**

The researcher will use this method to document the changes that occurred during the research and the supporting data for interpretations and conclusions.

### **1.5.8 Pilot implementation and second implementation**

A pilot implementation of the early intervention programme will be carried out with two objectives in mind. Firstly, during each session with the parents, elements that will enhance or impede the effectiveness of the programme will be identified. These elements represent the contribution that will be made by the parents, the facilitator and the programme. Secondly, during the pilot implementation, the parents' participation during each session, as well as their responses on the feedback sessions, will be recorded and analysed qualitatively from an educational psychological perspective. The outcome of these analyses will then be used to indicate those elements that should be used in the design of the early intervention programme.

The early intervention programme that has been developed will be implemented as a unit for a second time, in Egypt. Culturally-sensitive aspects will be identified, highlighted and adapted, to ensure effective implementation.

### **1.5.9 Formative Evaluation**

The development of the early intervention programme will be carried out by means of a formative evaluation. According to Ramashia and Rankin (1995 p.11), as well as Berk and Rossi (1990 p.13), the process of formative evaluation serves to clarify the direction of a project, involves collecting and sharing information for project improvement and helps to shape a project as it develops, by assessing how it could be improved. Formative evaluation typically consists of a process of consultation, sampling and data collection.

Consultation will include all major stakeholders. These will include the staff at the NICU and maternity wards, the parents of LBW premature babies and their families.

Sampling involves choosing a certain number of people who meet specified criteria. The parents to be included in the research will be parents of LBW premature infants between the ages of 0 and 24 months. The infants will already have been identified and diagnosed as LBW premature at the maternity ward of the Pretoria Academic Hospital. Either they will be treated in the NICU of this hospital, or treatment will be followed up at the baby clinic or the early intervention clinic.

Data collection will involve descriptive recording of parent involvement during an implemented session, as well as recording of the course of each session. This will be achieved by having the facilitator, co-facilitator and interpreter (if necessary) complete an evaluation form after a discussion of such a session. The results will be analysed from an educational psychological perspective. This process of analysing the course of each session will continue until the objectives which were set for each session are met, in combination with positive parental participation and evaluation.

#### **1.5.10 Ethnographic interpretation**

The parents' responses to the content and format of the early intervention programme will likewise be analysed to evaluate the cultural appropriateness of the programme, and the programme will continually be adapted to ensure that its content and format will be entirely transparent and easily grasped. To accomplish this, idiosyncratic and typical participatory patterns will be investigated, by questioning parents about the familiarity of the contents and format of the programme. This is especially important, because for the parents to participate, learn and apply new skills, they should know what is required of them, and the content should link up sufficiently with their existing knowledge structures. Therefore, nothing with regard to the format or content should be unclear to them.

Safeguards will be useful for minimizing the source of cultural bias or for recognizing the influence of the researcher's own framework. The researcher will keep a journal of how her perspectives change through the study. Discussing her progress with a colleague (an African educational psychologist) can enhance her ability to detect when she acts according to cultural bias. Member checks will be conducted with participants who are members of the culture under study, which may help seeing where divergence in viewpoints may be based on culturally different interpretations.

## 1.6 RESEARCH STATEMENT

In order to evaluate the success of this early intervention programme, it will be necessary to analyse all the factors concerning its implementation which might have played a role in the success or failure of its supply of information and knowledge on childrearing, as well as on the acquisition of parenting skills, to parents. An educational psychological perspective on the situation of parents with a LBW premature baby will provide a suitable point of departure for this analysis and will also serve as a theoretical framework on which to base this research.

### 1.7.1 Low Birth Weight (LBW) premature baby

A low birth weight (LBW) premature baby is a baby who is born before the 37th week of pregnancy and weighs less than 3.5 kg (7.7 lbs). These babies are at a higher risk of health problems, including respiratory distress, infections, and developmental delays. The research will focus on the educational and psychological needs of parents of these babies.

### 1.7.2 Neonatal Intensive Care Unit (NICU)

The division between intensive and special care is a relative one, but in general, the level of care provided in a NICU is dependent upon the severity and how quickly adjustment, medical evidence and specialized services (labour and a high standard of nursing skill) such care may be said to be given to the patient when necessary (Morris 1995 p. 33)

### 1.7.3 Caregivers

In western cultures, families may care for children and young people permanently, either through biological parents, through adoptive parents or through foster parents (Recher & Jones 1995 p. 237)

Afficans have a culture of extended families (Ubuntu), where other members of the family or community may be asked (by the parents or family) to look after a child. These people take on

## **1.7 EXPLANATION OF TERMS**

### **1.7.1 The educational psychological perspective**

The educational psychological perspective of which an overview is given in this section follows from the orthopedagogical paradigm of the University of Pretoria. This paradigm concerns the relationship that the total circumstances of children's upbringings might have with the impeded or deviant development of their overall potential, and also with the attenuations of or distortions in the unique meanings with which they invest their world.

### **1.7.2 Low Birth Weight (LBW) premature baby**

The phrase "Low Birth Weight (LBW) premature babies" will be used, throughout this study, to refer to babies born with a weight of less than 2500 grams, prior to 37 weeks of gestation.

### **1.7.3 Infancy**

The word "infancy" derives from Latin roots meaning "not speaking", and infancy is usually defined as the first two years of life, or the period of life prior to the development of complex speech (Etaugh & Rathus, 1995 p.5).

### **1.7.4 Neonatal Intensive Care Unit (NICU)**

The division between intensive and special care is a rather artificial one. It is generally accepted that full neonatal intensive (tertiary) care provision is dependent upon a units having the necessary, and now extensive, equipment, medical expertise and specialized assessment facilities, and a high standard of nursing skill. Such care must be able to be given for long periods when necessary (Moore, 1995 p.33).

### **1.7.5 Caregivers**

In western cultures, families may care for children and young people permanently in three ways: through biological parents, through adoptive parents or through foster parents (Reder & Lucey, 1995 p.237).

Africans have a culture of extended families (Ubuntu), where other members of the family or community may be asked (by the parents or family) to look after a child. These people take on

the parental responsibilities. Three or more generations of blood relations and in-laws may live in the same house, according to Le Roux (1994 p.11), in an extended parent-child relationship. The composition is often determined culturally, and may include uncles, aunts and grandparents. This easy availability of substitute caregivers is typical throughout the sub-Saharan region.

For the purposes of this study, a caregiver is viewed as somebody taking on the parental responsibilities towards a child. The caregiver could be involved for only a short period of time (e.g. a visit), or permanently (e.g. adoption). Where the term “parents” is used, it must be understood to include caregivers.

#### **1.7.6 Early intervention**

Early interventionists use early intervention programmes to work with infants and young children with special needs, and their families (Lowenthal, 1996 p.145). In recent years, conceptual models for early intervention have changed from a focus on the mother and child to one that acknowledges and appreciates family dynamics and the importance of fathers, siblings, grandparents and support networks, both formal and informal, in the family’s overall functioning and adjustment process (Mahoney, Wiggers & Lash, 1996 p.295). This latter model will be applied in this study.

In this study, the early intervention programme that will be developed integrates these views, by focussing on support and counselling for parents, whilst acknowledging and appreciating other relevant role-players in the LBW premature baby's life.

#### **1.7.7 Parent counselling as a preventative strategy**

The term “parent counselling” refers to two things. First it refers to a preventative strategy on a macro-educational level (early intervention). Second, it refers to an individualized, rectifying strategy on a micro-educational level (Ferreira, 1987 p.11). This study focusses on parent counselling as a preventative strategy.

Parent counselling as a preventative strategy includes early intervention for parents. It is a preventative educational strategy, or plan of action, whereby educational information and parenting skills are taught to parents, and their knowledge and insight are developed. Educationally-orientated media, for example radio, television, computers and print, and parent support programmes implemented by a skilled person, can be used as presentation methods.

The aim of such a preventative strategy is to prevent educational problems, behavioural developmental problems, et cetera, owing to a possible lack of educational preparedness by parents, through the distribution of educational information, development of knowledge and practice of specific parenting skills (Abidin, 1992 p.409). Parent education and training may also prevent a problem from intensifying.

Primarily, a preventative strategy focuses on the prevention of educational problems, as well as having a wide-ranging, large-scale impact via a variety of presentation methods.

### 2.1.1 Introduction

Parent counselling, as a preventative strategy on a macro-educational level, is therefore an advanced strategy, because the information and knowledge gained must also be transferred to and translated into specific parenting skills (tailored and applied to a specific need and situation). According to Ferreira (1987 p.11), this process can only be realized within the context of a structured parental counselling programme, facilitated by an educational psychologist.

## 1.8 RESEARCH PROGRAMME

- Chapter 1 contains the introduction to the study, its assumptions, the problem statement, the aim of the research, the method and statement of the research, as well as the explanation of relevant terms.
- Chapter 2 deals with theoretical issues relating to the research. These issues include information on the LBW premature baby's needs and care, the emotions that parents may experience after their baby has been born preterm and of LBW, parent-infant interaction, and infant development.
- Chapter 3 focusses on what parental involvement in early intervention programmes entails.
- Chapter 4 reports on the formative evaluation of *The Gldenpfennig Early Intervention Programme*, by means of a situation analysis, pilot implementation and second implementation.
- Chapter 5 provides a summary of the research and presents the final conclusions and recommendations of the study.

### 2.1.2 Definitions

The terms *viability* of preterm infants were used (until the early 1980s) or *descent* (infants born prior to 37 weeks (less than 255 days) from the first day of the mother's last menstrual period, as well as those with a weight of less than 2500 grams (Dominguez, 1992: 109 and Kruppi & Drukier, 1995 p. 109) The appropriateness of the definition lay in the fact that birth weight was the most frequent and reliably-recorded measure for infants and that those