When not all is well

Outcomes of
Singaporean Chinese Very Low Birth Weight children
in mainstream primary schools

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by

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ABSTRACT

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Advances in perinatal care in the past decade have resulted in the increased survival of very low birth weight (VLBW) infants. These are children born with a birth weight of less than 1500 grams. The mortality and immediate morbidity, that is clear neurodevelopmental deficits such as cerebral palsy, of these infants are well documented. However, less is reported about the VLBW children who may not be obviously neurologically or intellectually deficient but experience various problems in mainstream primary schools nonetheless.

Underlying this study is the concern that some of the difficulties faced by local VLBW children were obscured during the period of follow-up and that they were viewed as progressing "well" based primarily on apparently normal outcomes such as average test scores.

In her capacity as a psychologist involved in the multi-disciplinary follow-up of VLBW children from two to eight years old, the author has gathered information on a sample of 107 Singaporean VLBW children of ethnic Chinese origin. Using methodological as well as investigator triangulation, quantitative and qualitative results are reported. The survey method was used to obtain the former while the latter were elicited by the case study approach. In addition, the case studies of seven VLBW children with different experiences were included.

Whilst the findings are in general agreement with the published literature, the limitations of the study coupled with Singaporean factors at play meant that they may not be entirely representative of the local VLBW population at large. It is anticipated, however, that the findings will provide the reader with a deeper understanding of how Singaporean Chinese VLBW children in mainstream schools are functioning on the whole. It is also hoped that this study will serve as a signpost for future VLBW follow-up work in Singapore.
ACKNOWLEDGEMENTS

This thesis reflects the efforts of many people who have, in one way or another, supported me through its development.

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It is to the loving memory of one of the first lady paediatricians in Scotland and a gracious friend, the late Dr Jean Maclennan (1907-2001) that this work is dedicated. Her lively account of ‘Forceps’ a VLBW chicken whose development she had followed up in the days of her youth had cheered me along the way. Above all, I thank my Sovereign God for her inspiring life and for causing our paths to cross in that beautiful ‘land of my adoption’, Scotland.
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Chapter One
INTRODUCTION

1.1 Background

Advances in neonatal medicine over the last three decades have resulted in more survivors among premature infants born with a very low birth weight (VLBW) of less than 1500 grams. Very few of these survived in the 1950s and 1960s and of those who did, only a small number would be without major disabilities. These would usually take the form of developmental setbacks mingled with multiple complications. Given their unheralded and often unexpected beginnings, the medical implications and developmental consequences of this group of tiny survivors nowadays have drawn much albeit disproportionate attention in the medical world. In other words, the focus on developmental consequences has only recently increased as professionals begin to take a more holistic view of the developing child. Furthermore, developmental deficits are gradually being viewed as a continuum ranging from neurological dysfunctions where there are clear handicapping conditions such as cerebral palsy to subtle dysfunctions such as learning difficulties at school age. Coupled with this awareness comes the recognition that there are long term sequelae even after medical complications have been resolved. This is in itself a good reason why VLBW children should continue to be followed up even after their discharge from the hospital.

Whilst the issues of mortality and initial morbidity like major neurological impairments are well documented, comparatively less is said about the ‘hidden’ problems of VLBW children who may not be clearly neurologically or intellectually deficient. Several studies have identified areas of these subtle
developmental deficits as we shall see later on. In the 1980s, the focus in the majority of studies on this particular group of children had been on the assessment of intellectual competence (e.g. Kopp, 1983). The consensus at that time was that difficulties arising from intellectual competence usually become apparent only after a child had entered primary school and then performed poorly. It was during this period that reviews on the outcomes of VLBW children (e.g. Hoy et al., 1988) raised concerns about relatively high rates of school difficulties among these school-aged children without severe handicapping conditions. In addition to neurological dysfunctions, areas such as language delay, specific language deficits, poor concentration and short attention span and borderline intelligence have been identified (e.g. Hille et al. 1994). More recently, there have been an increasing number of studies towards this end of the spectrum, that is, subtle VLBW problems. These range from investigations into psycho-educational outcomes (Sandieson et al., 1998, Boyce et al., 1999) and behavioural difficulties (e.g. Pharoah et al, 1994, Sommerfelt et al, 1996) to studies on self-perception and quality of life (e.g. Saigal et al., 1996). In addition, more of these studies have focused on older VLBW children (e.g. Szatmari et al., 1993, Botting et al., 1998, Peralta-Carcelen et al., 2000) beyond the primary school years. Barsky and Siegel (1992) summed up this paradigm shift by stating,

"the previous struggle for maintaining the survival of VLBW infants is giving way to determining what the possible sequelae for these infants in terms of long range functioning are. The subsequent development of the VLBW infant is a question that concerns both parents and the professionals who work with them" (page 275).
The sentiments and implications of this quote appear to be reflected in one issue of *Seminars in Perinatology*, which has its focus on the developmental outcomes of VLBW infants. In the introduction, Kaplan and Mayes (1997) presented the findings from developmental outcome data in terms of three areas of ‘methodologic advances’. These are summarised (page 161) firstly, that birth weight is consistently one of the most important variables in determining outcomes: “the greatest proportion of the variance in developmental outcome for preterm infants is largely carried by birth weight ...this relationship holds whether outcome is measured as medical morbidity, cognitive ability, behavioural regulation, or social competence”. Secondly, whilst acknowledging that on average, most VLBW children fare well even when followed up till school age, they cautioned that in a “small but significant proportion of low birth weight infants, functional disabilities of varying degrees of severity appear through the first 5 to 7 years of life.” On this note, Kaplan and Mayes highlighted the consensus among the more sophisticated follow-up studies that long-term follow-up was a necessity and that functional impairments later in a child’s life were a reality. A third area of methodological advancement they presented was “the addition of domains of study beyond global IQ or neurological functioning”. This included areas such as parenting behaviours and impact of intervention or therapy on developmental outcome. It is on the foundations presented thus far that the conceptual framework for this thesis is built. This chapter moves on to define the terms and abbreviations used (1.2) throughout the thesis. 1.3 gives a flavour of VLBW research within the local context followed by a statement of the aims as well as the research questions (1.4). These sections should lead us to a better understanding of ‘The importance of the study’ (1.5).
1.2 Abbreviations and definitions of terms

Throughout this thesis, the standard terms and abbreviations are used in accordance with World Health Organisation (WHO, 1977) guidelines. The definitions of the medical terms used are taken from various medical sources:

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<td>Normal Birth Weight</td>
<td>NBW</td>
<td>Baby born over 2500 grams</td>
</tr>
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<td>Low Birth Weight</td>
<td>LBW</td>
<td>Baby born under 5 pounds, 8 ounces, or 2500 grams</td>
</tr>
<tr>
<td>Very Low Birth Weight</td>
<td>VLBW</td>
<td>Baby born under 3 pounds, 5 ounces, or 1500 grams</td>
</tr>
<tr>
<td>Extremely Low Birth Weight</td>
<td>ELBW</td>
<td>Baby born under 2 pounds, 3 ounces, or 1000 grams</td>
</tr>
<tr>
<td>Premature or Preterm birth</td>
<td>-</td>
<td>Birth before 37 completed weeks of gestation</td>
</tr>
<tr>
<td>Very Premature or Very</td>
<td>-</td>
<td>Birth before 32 weeks of gestation</td>
</tr>
<tr>
<td>Preterm birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Small for Gestational Age</td>
<td>SGA</td>
<td>“An infant whose weight is below the 10th percentile for gestational age, whether premature, full-term or postmature” (Berkow et al., 1992, page 1976).</td>
</tr>
<tr>
<td>Appropriate for Gestational</td>
<td>AGA</td>
<td>An infant whose weight is appropriate, that is, between the 10th percentile and the 90th percentile for gestational age.</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retinopathy of Prematurity</td>
<td>ROP</td>
<td>“A bilateral ocular disorder of premature infants that disrupts the normal maturation of the retina, occurring mainly in those of lowest birth weight ranging from normal vision to blindness. It is an additional risk factor for neurosensory impairment. The lower the birth weight, the higher the incidence of ROP and the greater the severity of the disease”. (Phelps, 1995, page 50).</td>
</tr>
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</table>
Bronchopulmonary dysplasia (BPD) "A chronic lung disorder in infants who have been treated with intermittent mandatory ventilation. At 28 days of age, they will have respiratory distress, characteristic x-ray changes, and an ongoing need for oxygen" (Berkow et al., 1992, page 1992). This condition is often seen in VLBW who have received mechanical respiratory support in the neonatal period.

Intraventricular haemorrhage (IVH) "Haemorrhage or bleeding in the ventricles of the brain. The severity of IVH is usually graded from 1 to 4, with Grade 4 the most severe. The higher the grade of IVH, the more likely that neurodevelopmental problems such as cerebral palsy or mental retardation may occur" (Aziz et al., 1995, page 325).

Morbidity A medical term representing a diseased condition or state, the incidence of a disease or of all diseases in a population.

### 1.3 The Singapore scene

This section seeks to look at the Singapore situation concerning VLBW children and their follow-up. The clinical picture is first presented followed by a brief contextualisation of local factors such as the diversity of spoken languages and the impact of these on outcomes as well as the process of follow-up. More of this aspect will be seen from Chapter Three onwards.

The quote from Barsky and Siegel in section 1.1 Background (page 2) can be used in part to describe the Singapore scene clinically. Despite advances in medical technologies over the years, the focus on this growing number of
children continues to be on medical outcomes such as retinopathy of prematurity and bronchopulmonary dysplasia. Undeniably, the inclusion of medical factors in outcome studies is important as this provides contextual information on psychological and educational outcomes.

To date, most VLBW researchers acknowledge that prematurity with very low birth weight has an effect on at least early developmental outcome through their association with medical complications. They continue to differ however, in their perception of contributory factors in outcomes. Miceli et al. (2000), for example, concluded that by 36 months, developmental outcomes are more closely related to aspects of early social environment than early physiological factors. Others focused on the significant impact of gestational age on outcomes (Ulvund et al., 2001). To assert that there is an absence of interest in the impact of non-medical factors on long-term developmental outcomes may not be a fair description of the local scenario. It may be true to say on the other hand, that long-term non-medical outcomes are not often the top priority in local clinical research.

A noteworthy attempt (Loke, Miu and Tan, 1993) in the ‘earlier’ days of VLBW follow-up in Singapore may give the reader some idea about the situation. The paper, co-authored by a clinical psychologist (Miu) reported on the neurodevelopmental outcomes on a cohort (1988-1989) of two-year-old VLBWs based on multidisciplinary assessments. Whilst medical outcomes were inevitably investigated, developmental concerns were concurrently and proportionately voiced. The authors concluded with the recommendations that “each perinatal centre should have its own audit on the results of neonatal intensive care and the quality of the survivors” (page 154). Another local study looking into developmental outcomes was carried out by Yeo and Ho (1996). Like the
previously quoted study, these authors sought to describe the short-term neurodevelopmental outcomes and evaluate the clinical factors associated with adverse outcomes in two year olds. Their findings, from "medical, psychometric, developmental and neurosensory motor assessment" were comparable with those of Loke et al. Taking a different perspective in their recommendations, they concluded that parents whose infants were at high risk for handicapping conditions should be "informed and counselled on the need for long-term follow-up with the view for early intervention and support so as to minimise morbidity arising from prevailing impairments" (page 10). Further work was recently carried out in the same centre (Ho, Yeo and Ho, 2001). This comprised a retrospective review comparing VLBW children by gestational age and weight. They reported that whilst premature VLBW children are already at risk, those classified as 'small for gestational age' or SGA have poorer long-term outcomes. Published in the Singapore Medical Journal for the Malaysian VLBW Group, a similar study to the preceding one was carried out in neighbouring Malaysia. A total of 116 SGA infants in twenty centres were studied (Ho, 2001). Their outcomes were however, reported solely in medical terms concerning the risk of mortality as compared with the Singaporean study that evaluated morbidity and long term outcomes of the SGA sub-group. From yet another neonatal care centre in Singapore, Tan and Malathi (1997) reported on the trend in perinatal mortality, major short term morbidities and early (two-year) neurodevelopmental outcomes of VLBW infants born between 1990 and 1994. The main focus of their paper was on major short-term morbidities. These constituted medical conditions such as intraventricular haemorrhage (IVH), retinopathy of prematurity (ROP) and bronchopulmonary dysplasia (BPD). The neuro-developmental outcomes were described in terms of
mental retardation, cerebral palsy, sensory impairments, that is, auditory and visual
deficits, as well as multiple handicaps. The significant absence of these conditions led these authors to conclude that “close to 90% of the VLBW cohort were free from major impairments with no visually impaired children.” (page 39). Their recommendations were promising:

“Neonatal outcome data of this nature are of use in the implementation and evaluation of policies...these results provide data for research to be undertaken in the relevant areas. Outcome data are also of relevance when counselling parents and in allowing obstetricians to make informed decisions antenatally. There is a need for multi centre or national data collection, especially for the high-risk infants. This would allow for inter centre comparison of mortality, morbidity and long term outcome on a national basis and could provide the foundation for the planning and evaluation of proper neonatal care.” (page 45).

With multidisciplinary VLBW follow-up programmes being set up in the main hospitals in Singapore over a decade ago, the cohorts are understandably comparatively younger than those of other developed countries. A standardised system among the centres has yet to be more effectively established. Although local studies appear piecemeal and centre-dependent, there is agreement among the centres that “the outlook is (therefore) optimistic” (Loke et al., page 159).

Looking at the Singapore scene from a different perspective, one needs to understand that non-medical outcomes such as educational and psychological outcomes are in many ways culturally as well as linguistically bound. Take for example the variety of languages spoken locally. She has four official
languages, English, Mandarin, Tamil and Malay and for a Singaporean to be at least bilingual is a cultural norm. The definition of bilingualism continues to be a subject of debate internationally. In Singapore, it is defined along the lines of “.having proficiency in English and one other official language, specifically one’s ethnic mother tongue” (Tay, 1984, page 5). In addition to learning English which has a central role in education and communication, children in mainstream schools learn an additional language, their own mother tongue. Thus it is Mandarin for the Chinese, Malay for the Malays and Tamil for the Indians. The sample in this study constitutes a group of children who are exposed to two languages in mainstream primary schools but are primarily from Mandarin speaking homes. For assessment or clinical judgement to be comprehensive and for outcomes to be representative, one will need to take into consideration the influence of local factors introduced in this section.

1.4 Aims and research questions

This study seeks to investigate the developmental outcome of a group of Very Low Birth Weight children born during 1990 and 1991 at a specialist hospital in Singapore. The three aims of this study are firstly, to give an overall picture of how Singaporean Chinese VLBW children are performing academically at primary school and secondly, to investigate their levels of cognitive functioning and overall development. More specifically, the prevalence and profile of impairments in these areas are described with the support of case study reports of individuals. A third aim would be to identify and address issues in the process of following up this group of children.
Based on these aims, the research questions that are to be answered are:

1. a. How are Singaporean Chinese VLBW children performing academically, that is, in their Mother Tongue (Mandarin), English and Mathematics?
   b. What is the status of their psychological development in the domains of cognitive ability and overall functioning?

2. What is the prevalence and profile of needs and impairments in this group of children?

3. What are the issues involved in the process of VLBW follow-up in Singapore?

Throughout this thesis, reference will be made to studies that investigate low birth weight infants (LBWs i.e. birth weights ≤ 2500g) if their samples also contain VLBW and ELBW infants. It has to be borne in mind that within these groups heterogeneity rather than homogeneity usually exists. In other words, despite the fact that low birth weight can be reliably quantified, it does not represent a homogeneous condition. For example, some of the VLBW infants may be premature and have weight appropriate for their gestational age (AGA) whilst others may be small for their gestational age because of intrauterine factors such as inadequate nutrition. Paneth (1995, page 25) described the possible reason for a baby being of low birth weight hence small “..either because it was born too soon, because it grew too slowly in utero, or because of some combination of the two.”

1.5 The importance of this study

In her capacity as a psychologist involved in the follow-up assessments of VLBW children, the author has collated information on a group of such children whose problems or the severity of these have somehow remained
‘hidden’ or undetected during the period of follow-up. These problems in turn affect the children’s functioning during their early mainstream primary schools years.

Underlying this study is the concern that VLBW children are all too often discharged from follow-up as being “well”, that is, without any obvious problems. The decision to discharge a child is also based primarily on apparently normal outcomes such as average test scores. These children are unjustifiably expected to follow normal paths of development despite increasing evidence of latent impairments or difficulties in primary school and beyond. There is mounting evidence (Kaplan and Mayes, 1997) that functional impairments may be obvious only when a child is older and faces greater demands of complex tasks. Within the Singaporean context, little is documented on how well or poorly this group of children is doing in mainstream primary schools. It is envisaged that the findings of this study will serve as a signpost in the right direction for VLBW follow-up services in Singapore.

1.6 The structure of this thesis

Following this introductory chapter, the thesis proceeds to review the literature on VLBW children with greater emphasis on non-medical or developmental outcomes (Chapter Two). These include the areas of special education as well as the hidden handicaps VLBW children in mainstream schools experience. The chapter culminates in looking at research issues, namely, the difficulties and directions in VLBW follow-up. Chapter Three aims to give the reader insight into the methodology adopted with methodological triangulation as its cornerstone. Assessment issues with a uniquely local flavour can be seen in this
chapter. The results are then dichotomised into quantitative (Chapter Four) and qualitative (Chapter Five) findings. The latter chapter purports to take the reader, as it were, through a picture gallery of the lives of seven VLBW children from their toddler days to lower primary school life. Chapter Six provides not only a discussion of the findings but also gives a critique of the process of follow-up and the issues surrounding it. The concluding chapter (Chapter Seven) ends with a recapitulation of the study, looks more specifically at its limitations and seeks to make recommendations for future studies.
Chapter Two

LITERATURE REVIEW

2.1 Introduction to the problems of VLBW children

The implications of increasing numbers of VLBW survivors cannot be underestimated. This phenomenon has resulted in "greater numbers of those children who carry the highest risk of impairment entering the pre-school and school education system" (Hall et al., 1995, page 1037). The impact of this on research can also be seen in the shift of research foci. As with the trend in medical practice and perception, researchers are gradually moving away from investigating mortality and clear handicapping conditions to subtle dysfunctions. Indeed, there is a growing agreement among professionals working with this unique group of children that such dysfunctions are long term despite the gradual and progressive resolution of those medical complications.

To date, studies on pre-school and younger school-aged VLBW children seemed better documented than work on their older school-aged counterparts and adolescents. Not many studies have gone beyond middle childhood (e.g. Hunt & Tooley, 1988, Smedler et al., 1992, Hall et al., 1995, O'Callaghan et al., 1996). Comparatively less work is to be found on adolescents, with a few exceptions (e.g. Levy-Shiff et al., 1994a, Botting et al., 1998, Walther et al., 2000). In a study on a group of 19-year-olds, Ericson and Kallen (1998) carried out a retrospective cohort study examining medical and psychological variables in a group of Swedish VLBWs. With a sample size of 260 boys, they were able to find not only an association between birth weight
and their stipulated variables, but a "clear cut effect" of birth weight on mental development.

Despite the gradual emergence of published work on birth weight concerning older and adult subjects, reported outcomes tended to be secondary in nature. In other words, these studies did not purport to measure the relationship between specifically very low birth weight and for example, cognitive functioning. That such outcomes were relegated to secondary status could in part be due to the fact that these studies tended to have a wider focus, for example, the association between birth weight in general and cognitive function (Sørensen et al., 1997, Richard et al., 2001).

Paradoxically, investigations carried out during the earlier years of a VLBW child's life may underestimate the prevalence of less obvious conditions such as learning difficulties as he progresses into primary school. This scenario may have prompted some authors to suggest that outcomes, even at school age, cannot be considered as conclusive (e.g. Zubrick et al., 1988). Another possible reason for such statements of caution is that children's abilities do change over time and are affected by their experiences in school and at home. Notwithstanding this, the number of studies on the subtle consequences of being born VLBW has been on the increase. Added to the many investigations into medical outcomes (e.g. Hack et al., 1993, Singer et al., 1997) are studies that are more directly and specifically concerned with educational and psychological outcomes (e.g. Wolke, 1994, McCormick et al., 1996). There are also a small but growing number of studies that address the issues of VLBW follow-up (e.g. Wolke, 1995, McCormick, 1996, Wocadlo & Rieger, 2000, O'Shea, 2001, Vohr, 2001).
The purpose of this review is to firstly, obtain a profile from the literature on how VLBW children are functioning as a whole before moving on to secondly, evaluate the deficits and difficulties those in mainstream schools face in different aspects of development. The third goal would be to take a closer look at issues pertaining to follow-up as reflected in the literature. It is anticipated that this literature review would provide the insight into some of the consequences of being born with a very low birth weight. It is also hoped that it would give an idea of the significance of the problems on a child's life especially when these or their severity tend to remain hidden, unidentified, overlooked or underestimated.

2.2 Developmental deficits in VLBW children

Most researchers attribute increasing occurrence of developmental deficits to corresponding decrease in mortality. In other words, there is growing concern that the survivors are getting younger and lighter but burdened with undesirable consequences. Moreover, intervention programmes seem to exert little long-term effects. Whilst Hack et al. (1994) acknowledged that programs of early childhood intervention might have some compensatory influences on the development of these children, they concluded that these have little influence on what they termed "structural deficits" (page 758). Along similar lines, Halsey et al. (1996) identified "a continuum of morbidity" and concluded that "even with adequate to optimal environments; school problems are common, and objective testing pinpoints weakness on all conventional measures of functioning compared with matched peer groups" (page 793). Both...
studies imply that whilst deficits may vary in kind and severity, they are long lasting if not permanent.

2.2.1 Major handicaps and special educational needs in VLBW children

In comparison with those who were born with normal birth weight, VLBW children have more educational needs (e.g. Saigal et al., 1991). For example, studies on school aged VLBW children have concluded that they are at a higher risk or more disadvantaged in the skills required for primary school. In the 80s, reports from the United States (e.g. Eliers et al., 1986) indicated that more VLBW children needed remedial help and/or special education than did their normal birth weight peers. This trend continued in the 90s (e.g. Hack et al., 1994). Hall et al. (1995) reported that at 8 years old, 15% of their sample of VLBW children was attending special schools and more than half of those in mainstream school were in receipt of remedial support. In an observation study, Halsey et al. (1996) found 50% of the ELBW children in regular classrooms with no special services. Comparing their sample with a matched control group, they also found that 20% of ELBWs had significant disabilities including cerebral palsy, mental retardation, autism and low intelligence with severe learning problems. They further highlighted the need for the provision of more special educational services for these children. At least two issues arise from these reports.

Firstly, there is a difference between the outcomes of ELBWs and VLBWs with the degree of disability being inversely proportional to the weight and gestational age of the child at birth. In a study comparing 7 to 8 year old ELBW and VLBW children with a matched group of NBW children, Hack et al.
(1994) found the group with the lightest birth weight (< 750g) to be at a serious disadvantage in the skills required for adequate performance in school. Higher rates of handicapping conditions such as mental retardation (IQ < 70), severe visual disability and cerebral palsy were also found. Whilst these rates are comparatively less for the heavier group (i.e. <1499g), they are still inferior to the matched group of NBW children. Literature on outcomes in children born small for gestational age (SGA) presented conflicting results. Some did not find any differences between the outcomes of this group and their appropriate for gestational age (AGA) peers (e.g. Hadders-Algra et al., 1988, Grantham-McGregor, 1998). Others found marginal differences (e.g. Sommerfelt et al., 2000) and then there were those (e.g. McCarton et al., 1996, Larroque et al., 2001) who found greater risk in SGAs for difficulties with association between specific areas of outcomes such as cognitive functioning and school performance. Closer to the issue at hand, Smedler et al. (1992) looked at the psychological development in VLBW-SGA children and reported risk of developmental problems, even in the absence of disability and pathology during the first years of life. Similarly, Kok et al. (1998) reported poorer long-term outcome in terms of neuromotor, cognitive and school performance in premature SGAs when compared with their AGA peers.

Secondly, definitions of special needs and educational provision vary between and within countries where studies have been carried out. For example, Eliers et al.'s study may have looked at regular or mainstream schools but these included special, self-contained classes. Their school-aged sample therefore included children who were physically, mentally or emotionally handicapped and who needed the assistance of specially trained and certified
teachers. Whilst not always categorically stated, many American studies were noted to adopt frameworks similar to the following standardised eligibility classification of special needs: "physically impaired, sensory impaired (SI), profoundly mentally handicapped, trainable mentally handicapped, educable mentally handicapped, specific learning disabilities, emotionally handicapped, and speech and language impaired (SLI)." (Resnick et al., 1998, page 308). The degrees of severity in mental deficiencies are usually encompassed under the umbrella term 'mentally handicapped'. In the United Kingdom,

"a child has special educational needs if he or she has a learning difficulty which calls for special education provision to be made for him or her. A child has a learning difficulty if he or she:

a) has a significantly greater difficulty in learning than the majority of children of the same age
b) has a disability which either prevents or hinders the child from making use of educational facilities of a kind provided for children of the same age in schools within the area of local education authority
c) is under five and falls within the definition at a) or b) above or would do if special educational provision was not made for the child.

A child must not be regarded as having a learning difficulty solely because the language or form of language of the home is different from the language in which he or she is or will be taught. Special educational provision means:

a) for a child over two, educational provision which is additional to, or otherwise different from, the educational provision made generally for children of the child's age in maintained schools, other than special schools, in the area
b) for a child under two, educational provision of any kind."
(The Department for Education, 1994, page 5)

Whilst special education is not compulsory in Singapore, the categories of children with special needs are standardised among the Voluntary Welfare Organisations who run the 17 (to date) special schools with financial & professional support from the Ministry of Education. Special needs children are described as "having a distinct disability and unable to benefit from mainstream schooling." (Ministry of Education, Singapore, 1999). There are presently seven broad categories: Educationally Sub-Normal, Intellectually Disabled, Hearing Impaired, Visually Handicapped, Spastic (cerebral palsy) and Multiply Handicapped. Whatever the source of definitions, the terms ‘Impairment’, ‘disability’ and ‘handicap’ are often used to describe the classifications of developmental deficits. The World Health Organisation (1980) defines these terms as:

"Impairment. An impairment is any loss or abnormality of psychological, physiological, or anatomical structure or function. A child was regarded as impaired in the overall outcome if he or she had an impairment in an area of examination that did not lead to any disability.

Disability. A disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being. A child was regarded as disabled in the overall outcome if he or she had a disability on an area of examination or if a multiplicity of impairments caused loss of function or activity."
Handicap. A handicap is a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for the individual.

A child was regarded as handicapped if he or she had a handicap in an area of examination or a multiplicity of disabilities caused a social disadvantage."

(in Kok et al., 1998, page 167)

Amidst varying definitions adopted by different groups and countries to delineate outcomes and needs, Halsey et al.'s (1996) "continuum of morbidity" (page 793) offers an apt description for the complex variation that exists. Applying this notion to the VLBW situation, a child's position on the spectrum seems clearer when he or she has obvious handicapping conditions than when these are absent. In the former, special education is deemed necessary whereas in the latter situation, the child is found to be performing poorly despite being apparently 'normal' and attending a mainstream school. In other words, this variation in outcomes and needs is in part due to the various types of developmental deficits VLBW children may have as well as the subtlety therein.

2.2.2 Hidden Handicaps and mainstream education

The terms 'hidden', 'subtle' and 'latent' have been used to describe the deficits found in non-handicapped VLBW children. One reason for the use of these terms is that many of these problems may not be detected until school age (Den Ouden et al., 1993). Some authors reason that a minor disability will remain 'hidden' if the criterion for normality is merely the absence of major neurological impairment (Zubrick et al., 1988) or 'lack of
frank disabling conditions’ (Schendel et al., 1997). Other authors have moved on to address such subtleties as ‘often evidenced in learning problems’ (Ross et al., 1991) or as the areas of difficulties in ‘cognition and neuromotor function’ (Klein et al., 1989, Pharoah et al., 1994). An increasing number of studies have sought to identify these obscure types of developmental deficits. Hack et al. (1994) for example, found that school aged VLBW children were more likely than their normal birth weight (NBW) peers to have mild learning disabilities, attention disorders, developmental impairments and breathing problems such as asthma. They noted that educationally, VLBW children have more learning problems and lower levels of achievement in reading, spelling and mathematics than their normal birth weight counterparts. Similarly, Hille et al. (1994) identified areas such as language delay, specific language deficits, poor concentration & short attention span and borderline intelligence. Horwood et al. (1998) succinctly summarised the findings:

"In particular, VLBW infants tend to have higher levels of behavioural problems - specifically, increased attention deficit and hyperactivity; poorer performance on tests of cognitive ability and academic achievement; higher levels of learning problems; increased likelihood of need for special education or grade retention; poorer language and social skills; and poorer psychomotor skills." (page F12)

It is in the light of the abovementioned areas that a good proportion of this literature review is to be structured. Having gleaned from the literature on how VLBW children are functioning as a whole, we now proceed to evaluate the deficits and difficulties those in mainstream schools face in different aspects of development.
2.2.2.1 School performance

Reporting on children born prematurely (32 to 35 weeks gestation), Huddy et al. (2001) gave the percentages of poor outcomes in certain areas of education: 32% in writing, 29% in Mathematics, 19% in speaking, 21% in reading, and 12% in physical education. They concluded that up to a third of their cohort may have school problems. This appears to be a fairly consistent picture over the years.

A closer look at Hille et al.'s and Horwood et al.'s studies informs one that both are population based cohort studies that have documented school-aged outcomes for a relatively large sample of VLBW children. The former, carried out in the Netherlands, did not have a control group but constituted a longitudinal study that followed a group of children from the age of two to nine years old. Horwood et al.'s, a New Zealand study, had a control group comprising NBW 8 year old children taken from yet another study. This particular group of children was however, born approximately nine years earlier than the VLBW cohort. Despite consistencies in the instruments and process of data collection, the use of 'historical controls' constituted a potential weakness in the study. Hille's sample was categorised into four groups of varying degrees of school failure. These were: "children in mainstream education at the appropriate level for age without special assistance (group 0), children in mainstream education at the appropriate level for age but with special assistance (group 1), children one or more grades below the appropriate level for age, either with or without special assistance (group 2), and children in special education (group 3)" (Hille et al., page 427). Horwood et al. sought to investigate the difference between ELBW and VLBW children and compared
these as one group with the controls. Unlike the other studies evaluated earlier on (e.g. Hack et al., 1994), they found that in general, there was little difference between the two groups. Although both studies included children with disabilities within the category of special needs, Hille et al. took further notice of the group that did not respond. They found that this included more children with disability on various functions at five years of age or with lower socio-economic status or SES. This may have underestimated their findings in terms of prevalence of school failure. Unfortunately, the difference in the Dutch educational system meant that their findings may not be comparable to those carried out elsewhere, for example where children remain in the special units of mainstream schools. Despite their differences, both Hille's and Horwood's investigations yielded similar results namely, VLBW children experience more school difficulties and failure than their NBW counterparts. In short, they are at greater risk educationally. Whilst this is the general agreement, findings on the degree and nature of the impairments vary. Inconsistencies can also be attributed to methodological differences, such as the presence or absence of subgroups in birth weights, that is, ELBW and VLBW groups as well as diverse stages and types of assessment during the preschool and school years. Methodological differences may be illustrated by two studies investigating reading skills in school-aged VLBW children. In assessing school progress, the psychologists in Rickards et al.'s (1993) study administered a reading test, the Neale Analysis of Reading Ability – Revised, to their sample of 8-year-old VLBWs (which included ELBWs). This measure, together with a teacher's questionnaire on general academic and social aspects of school life comprised their educational outcomes. They did not find any significant difference
between their sample and the Normal Birth Weight controls in this area. Saigal et al. (1992) on the other hand, propounded the need to further investigate differences in the predictability and presence of Learning Disabilities in general and specific terms separately. Relying on an instrument different from Rickards et al. in their assessment, the Wide Range Achievement Test – Revised (WRAT-R), they looked the presence of reading disability in a group of ELBWs. They were careful to note that the high reading disability rates were general in nature as compared with a lower prevalence of specific reading disability. Like Rickards et al., they did not address other learning problems such as “poor comprehension in face of good word recognition (reading) or those with difficulty in maths or writing” (page 360). Nevertheless, their study highlighted the importance of distinguishing between children with general learning problems because of lower IQ scores and those children who have normal intellectual function but perform poorly on achievement measures i.e. those with specific learning problems. Examples of these impairments are dyslexia (reading/spelling), dyscalculia (numeracy) and dysgraphia (handwriting skills).

The variation in the studies reviewed thus far serve as a poignant reminder to VLBW researchers that there is more than meets the eye in appraising school performance or educational outcomes in VLBWs. It appears that more precise areas are being unearthed as research into outcomes progress. Taylor et al. (2000) for example, evaluated a relatively unexplored domain that affects learning: Verbal Memory deficiencies in ELBWs. Reporting on the prevalence of such deficits, they recommended strategies for educational intervention and highlighted the importance of assessing multiple memory skills. This principle of assessing multiple facets within an area could be further generalised, for
example, to assessing multiple skills of learning to obtain a more comprehensive profile of educational achievements.

2.2.2.2 Motor skills

In a study that appears to have similar characteristics to some of the above studies (e.g. Hille et al., 1994, Horwood et al., 1998, and Rickards et al., 1993), Hall et al. (1995) focused on the three areas of difficulty previously identified in another population based study (The Scottish Low Birthweight Study Group 1992b). These were school attainment, cognitive abilities and motor function. Their sample was a large sample of 324 children which was geographically defined, that is, within Scotland. They differentiated between ELBW and VLBW and provided matched controls for all except for twenty four children who were in special schools. Armed with a more detailed assessment protocol, their findings fell into similar categories as Hille’s i.e. levels of school failure. Whilst these were in agreement with Horwood that ELBWs and VLBWs are significantly poorer in the areas investigated, Hall found higher rates of failure in the former group. In addition, they discovered that the area of motor skills was weaker in comparison to the skills of NBWs.

Writing on a group of children who may not be VLBWs but have what is commonly known as the ‘clumsy child syndrome’, Losse et al. (1991) stated that the problems “are of interest not only because they are directly distressing to the children themselves, but also because they are thought to be associated with a high incidence of learning difficulties, school failure and psychological problems.” (page 55). In the light of this statement, it should be of concern to VLBW researchers that motor clumsiness has been found to be twice as common among children with low birth weight as compared to those
with normal birth weight (Sommerfelt et al., 1996). Marlow et al. (1993) concluded that motor skills in turn affect the school performance and found these to be good predictors of the latter. According to Leonard and Piecuch (1997), it is at school age that parents begin to judge the refinement and accuracy of their children's motor skills, both fine and gross. Studies have revealed conflicting evidence as to whether motor problems resolve over time. Powls et al. (1995) for example, found that whilst there are signs of early improvement, motor problems do persist into adolescence and affect learning and hence academic achievement. They concluded that "the deficit remains".

Commencing with pre-school VLBW children without clear handicapping conditions, the Scottish low birthweight study group (1992a) has reported poorer neuromotor performance as assessed by tests of motor function. Furthermore, this deficit has been shown to continue when the children enter mainstream schools and are presented with greater complexities in the classroom situation. Two studies with diverging aims and designs, Marlow et al. (1993) and Pharoah et al. (1994), looked at eight-year-old low birth weight children and arrived at similar conclusions. The former was a longitudinal study that sought to obtain a profile of outcomes whilst the latter investigated the prevalence of these. Pharoah looked at a more heterogenous group of children with birth weights below 2000 grams. Marlow studied those below 1250 grams which would have included more ELBWs, a group known to be at greatest risk among low birth weight children. Moreover, theirs was a hospital-based study which meant susceptibility to bias in variables associated with an institution. This, however meant that the researchers had the advantage of following this group of children over a period of time and would have led to more in-depth findings in the course
of the children’s development. Marlow et al. were able to, for example, ascertain that motor testing at six years of age was the best predictor of school problems at eight years old. Pharoah et al.’s study comprised a geographically defined and therefore larger sample which they categorised into ELBW s, VLBWs and LBWs. Their overall findings concurred with Marlow’s in that among school related difficulties, weak motor functioning in these children was most evident. The inadequacies in the motor skills of VLBWs are aptly described by Hall: "They performed poorly on motor tasks, many of which are part of everyday life for children" (page 1045).

2.2.2.3 Cognitive ability

Cognitive development is possibly the most investigated area from without the medical arena in VLBW research. The general trend of the literature supports that view that VLBW children are at risk in their cognitive skills and that the relationship between these and birth weight is a linear one. However, due to its relationship with other factors such as visuomotor skills and subsequently school performance, cognitive ability as such cannot be addressed in isolation. It is particularly important to bear in mind that difficulties arising from cognitive incompetence often become apparent only after a child has entered primary school. This is because increasing demands on the expanding range of skills that is required, for example, linguistic maturity, visual memory, language processing, and visuomotor skills accentuate the problems. These are usually long-term and presents as a worrying trend. On the other hand, studies (e.g. Pearl et al., 1995) have shown that whilst parents expect cognitive delays in the early years of their VLBW children, they anticipate a catch-up sometimes to ‘normality’ by school age. Attempts will be made in this section to address
various issues pertaining to intellectual competence in mainstream VLBW children. Aylward et al.'s (1989) review of outcome studies suggested that VLBWs without major neurological impairment have normal but lower ($< \frac{1}{2}$ SD) IQs for studies without controls and between $\frac{1}{2}$ to 1 SD for those with controls. Some researchers have taken a step further to look at different categories of VLBWs in relation to cognitive development. Hutton et al. (1997) for example, investigated the relationship between gestational classification i.e. small for gestational age (SGA) and appropriate for gestational age (AGA) and cognitive ability. Taking the opportunity to investigate infants who would not have survived during the time of the work of Nelligan et al. (1976) entitled, 'Born too Soon or Born too Small', they assessed the children's cognitive ability, as measured by IQ and reading comprehension, among other functions in school aged SGA premature children. They found cognitive ability to correlate with the degree of fetal growth retardation. They concluded that infants born too early and too small are at an even higher risk than AGA infants for cognitive deficits. In the light of Nelligan's and Hutton et al.'s findings, Lagercrantz (1997) wrote his medical recommendations in *The Lancet* with the captivating title, 'Better born too soon than too small'.

As one would have gathered from the many studies on cognitive ability, the Intelligence Quotient or IQ has been the focus of the majority of researchers seeking to evaluate the intellectual competence of VLBW children (e.g. Abel Smith and Knight-Jones, 1990, Saigal et al., 1991 & Dammann et al., 1996). Abel Smith and Knight-Jones (1990) confirmed the frequent occurrence of lower scores on intelligence scales. Using a single measure of outcome, the McCarthy scales, they compared the VLBWs' performance with matched
controls on the subtests of the scales which included skills such as motor and memory. This study differs from those that take an overall IQ score from such scales and combine it with outcomes from other measures in order to obtain a composite picture. Saigal (1991) for example, had a battery of ten measures investigating six areas of functioning in ELBWs. Abel Smith's sample was smaller and included only 2 ELBWs. In addition, they looked at younger children (mean age 60.37 months) who have had at least a term at school. Saigal's subjects were primary school aged children who had been on long-term follow-up by the team. The experience and demands of primary school would have therefore been different for the two groups and it was thus difficult to draw a comparison between the two sets of outcomes. The general consensus is that VLBW children do not perform as well as NBWs even in situations where the former appear 'normal'.

Recently, Dammann et al. (1996) studied a group of 298 VLBW children 63 of whom were ELBWs. Their aim was to examine the cognitive development in both neurologically disabled children and VLBW children without any overt impairment at pre-school age. Their study differed from previously cited studies in that they did not have a control group and included children who had already been identified with neuropaediatric diagnoses such as cerebral palsy and behavioural problems. This was on the condition that the child's disabilities were not too extreme as to affect testing. The findings from their battery of standardised developmental tests indicated that the cognitive area of memory skills was poor. This supported Abel Smith and Knight-Jones's findings of weaker memory skills or more specifically, visual memory skills as compared with auditory memory skills. Dammann suggested that the difference
in the children's performance might be accounted for by the fact that visual memory skills are tapped by tasks more related to visuomotor skills, an area in which VLBWs are known to have difficulties. With emerging and increasingly specific areas of weaknesses being identified, the stark reality remains: “as the school curriculum places increasingly heavier demands on cognitive processing, further evidence of learning difficulties may emerge” (Hall et al., 1995, page 1048). Implicit in this quotation is the close relationship between cognitive ability and educational outcomes.

2.2.2.4 Behavioural difficulties

In addition to learning difficulties, motor impairment and cognitive weaknesses, behavioural problems is an area researchers of VLBWs have been turning their attention to in recent years. Restlessness, irritability and short attention span are among the more commoner behaviours noted (Sykes, 1997). Studies have shown an increased prevalence of the problems of inattention and hyperactivity in the younger group of VLBW children (Astbury et al., 1987; The Scottish Low Birthweight Study Group, 1992a&b). Investigations of older children (Szatmari et al. 1993, Botting et al., 1997) yielded similar results. In a study (Breslau, 1988) of VLBW children at 9 years of age, boys were found to manifest more behavioural disturbance and poorer social competence than matched full-term boys of normal birth weight. The control group in this particular study was matched for social class and the sample comprised primarily of families with low socio-economic status (SES). It has to be borne in mind that social class has long been found to be an important determinant of outcome in VLBW children (Hunt et al., 1988; Ross et al., 1990). Negative associations between SES and outcomes are usually
reported. More illuminating, perhaps, are studies that have reported significant differences between the SES of VLBWs who attended follow-up and that of VLBWs who either had an outcome of clear disability or were non-responsive hence ‘lost’ to follow-up (e.g. Hille et al, 1994, Piecuch, 1997). Unfortunately, the sample in this study excludes the latter groups and therefore does not offer sufficient variation to make such multivariate analysis with respect to SES possible. Moreover, literature in this area will not be covered here as it is beyond the objectives of this thesis.

Teachers' rating scales and/or reports have recently become key measures in assessing the behaviour of this group of children. "The school setting is particularly relevant to the assessment of a child's adjustment, for behaviour can be evaluated relative to that of his/her age peers by individuals (teachers) who have considerable experience of age appropriate norms." (Sykes, 1997, page 316). The rationale exemplified in this quote is commonly adopted in studies on the behaviour of primary school VLBW children. In Zelkowitz et al.'s (1995) study for example, teachers were asked not only to rank a child's academic performance in comparison with his classmates, they were also asked to complete a behaviour inventory known as the Classroom Behaviour Inventory by Schaefer, E.S. & Aronson, M.R. (1966). Other studies use behaviour measures that included parent ratings as well as teacher ratings. Saigal et al. (1991) and Rickards et al. (1993) have both found that parents of VLBW children tend to report that their children were not coping at school. Heiser et al. (2000) affirmed that parents of VLBW infants tended to underestimate their infants' development. In a way, findings like these are 'expected' as parental variables such as their attitudes and involvement, have been known to affect the
outcomes of the VLBW child (Levy-Schiff et al., 1994a). Investigating parental factors from a different approach, Sommerfelt et al. (1995) pointed out that the parents in their study were comparatively disadvantaged in terms of parental variables related to socio-economic status (SES) e.g. child rearing and maternal well-being variables. Whilst the focus of their outcome was cognitive i.e. preschool IQ, they suggested that an IQ score “may lack the necessary sensitivity to identify children at risk of impaired neurological development, and a broader range of outcome measures, including child behaviour and personality, may need to be assessed before such conclusions can be drawn”. (page F141).

The intrinsic problem with investigations into behavioural difficulties is that information is often primarily obtained from teachers and parents ratings. Whilst standard formats such as the Conners Rating Scales are used, responses to the same questions vary depending on the rater’s perception of what constitutes a problem. The area of inattention and overactivity for example, is included under the general heading of behaviour problems in some studies (e.g. Klebanov et al., 1994) or separately in others (e.g. Szatmari et al., 1990). Evaluation is made the more difficult because the evidence on the relationship between VLBW and behavioural difficulties is mixed. Compounding the problem of diversity in definitions of behaviour problems, most studies have not used measures that enable closer analysis of the types of behavioural problems. Nevertheless, there is a empirical evidence that more problems exist among VLBWs than NBWs. In some studies this trend is more evident as the children grow older (e.g. Zelkowitz et al., 1995) and in boys (e.g. Ross et al., 1990). The former found that VLBW children at nine years old had more social and behavioural problems than when they were six. Theirs was,
however, not a longitudinal study which presented more confounding factors associated with their findings. Ross et al. (1990) on the other hand considered IQ, SES and parental education in relation to social and behavioural problems. The findings of the studies surveyed in this section are generally in agreement: Very Low Birth Weight children are at risk of having hidden handicaps such as learning difficulties, motor and behaviour problems which become more apparent when they enter primary school. Discrepancies among these studies are attributable in the main to definitions of study populations and measurement of outcome. Moreover, the methodological differences among these studies are 'minimal' in the sense that they are usually quantitative studies with matched control groups comprising children of normal birth weight.

2.3 Research issues on VLBW outcomes

The findings of two meta-analyses on VLBW outcomes were published between 1989 and 1990. The first, carried out by Aylward et al. (1989) analysed 80 studies over a decade (1979-1989) whilst the second, Escobar et al. (1990) investigated 111 studies from three decades (1960-1990). Both used similar statistical analyses characteristic of meta-analysis. They also had a number of common criteria for the inclusion or elimination of studies for consideration, with Escobar et al. having in their investigations exclusion criteria that were more stringent (page 205). Among these would be studies examining four broad areas: mortality statistics, those which included data on VLBW children in higher weight ranges. Thirdly, anecdotal reports and fourthly, those reporting less than ten births.
Notwithstanding the recent critique by Sutton et al. (2000) that "selection bias is known to occur in meta-analyses because studies with results that are significant, interesting, from large well-funded studies, or of higher quality are more likely to be submitted, published or published more rapidly than work without such characteristics" (page 1575), it may be of benefit of to glean from the conclusions of studies such as Alyward et al.'s and Escobar et al.'s not only in terms of the difficulties encountered in VLBW research but the recommendations for future follow-up. These are imperative as one progresses to consider the difficulties as well as the direction of this study.

2.3.1 Difficulties

Research into the outcome of very low birth weight has been both piecemeal and problematic. Drawing key conclusions for this group of children has been a difficult task for reasons such as subject and methods issues, environmental factors and outcome measurement. Aylward et al. (1989) identified the methodological problems as "inadequate description of subject population, perinatal course not considered, single-hospital samples, lack of appropriate comparison groups, excessively high dropout, no assessment or control for environment, too short duration of follow-up, global or vague outcome measures, variability in diagnostic criteria, inclusion of severely handicapped children in mean scores and no consensus on correction for prematurity" (page 516). A number of these problems were noted in this review. Hille et al. and Horwood et al. for example, included VLBW children with special needs whilst Hack et al. had their focus on ELBWs. The inclusion of these children in the studies may have depressed the overall results. On the other hand, the exclusion of non-respondents may have overestimated some of
the results. In addition, there existed a number of studies that did not involve control groups. Dammann et al. for example, relied on standardised assessment norms as a basis of comparison while other studies used standardised parents' reports (e.g. Schmit & Wedig, 1990). Throughout the comparison of studies in this review, varied definitions or inconsistent boundaries of difficulties, for example, behavioural versus attention problems, were noted. Moreover, many of the studies were hospital based. This in turn meant differences in medical procedures and therefore a lack of generalisability to other groups of VLBWs and VLBWs as a population. In fact, these limitations are highly likely to have resulted in an underestimation of the prevalence of developmental deficits let alone hidden ones.

Taking a bird’s eye view, Vohr and Msall (1995) outlined three contributory factors to differences in the reports of outcomes: “the heterogeneity of perinatal management (i.e. medical) approaches, the diversity of study populations, and the comprehensiveness and duration of follow-up assessments”. They also commented on the need to adopt a more progressive approach in terms of “comprehensive neurological, developmental, functional and health care status outcome” (page 204). Where then does one go from here?

2.3.2 Directions

Vohr and Msall’s (1995) comments on a more progressive approach appear to have been taken note of in more recent studies by various authors. Whilst Saigal (2000) moved on to investigate areas such as self-perceived health status and quality of life, others (e.g. Palta et al, 2000, Msall & Tremont, 2000) looked into functional assessments and self-care outcomes. Msall and Tremont (2000), for example, wrote on functional outcomes in self-
care, mobility, communication and learning. Whilst recognising the concept of a spectrum of impairments mentioned earlier on in this chapter, they pointed out that “… measures of impairment do not fully capture the scope of functional limitations” (page 381). To illustrate this point, they gave an example of a child with cerebral palsy who may have a gait difference but is independent in daily mobility tasks. Inferring from this, a boy with subtle deficits, for example in motor skills, might be functional in a mainstream school if he is overall cognitively intact. However, he is deemed less functional in the area of daily living skills when at eight years old, he still leans against the wall to put his trousers on at home! From this illustration, it appears as though the spectrum of impairments comprises not just breadth but also depth with different levels. The question one needs to ask here may no longer simply be ‘towards which end of the spectrum is the child?’ but ‘on which level of the spectrum is the child?’

Another important area that is gaining more recognition in VLBW follow-up is that of investigating dropouts as well as those who do not cooperate with assessments. In a paper ‘Who goes and who stays’, Aylward et al (1985) described the characteristics of mothers and infants who were most likely to drop out of programmes. A decade later, Wolke et al. (1995) wrote a letter on the importance of documenting dropouts. They cited the findings of a study by some medical professionals (Wariyar et al., 1989) that “losses in follow-up studies of very preterm children are mostly unrelated to prenatal, perinatal, or neonatal medical conditions” (page 447). This is an alarming trend as it implies that non-medical deficits in VLBW children, such as those that have been discussed thus far are not being given priority by the recipients of follow-up services. Wocadlo and Rieger (2000) looked at yet another group of
children who attended follow-up but exhibited uncooperative behaviour. Their hypothesis was that within this group of children, those who displayed mild deficits as they grew older were more at risk for non-verbal learning difficulties. Consideration of such groups in follow-up and research is important from a number of perspectives. Ethical and methodological concerns for instance, should not be overlooked as one considers long-term outcomes. Wolke (1998) recommends that an ideal study should,

"be prospective, be based on large populations (geographical, epidemiological, or multi-centre studies), have few infants lost to follow up or good documentation of the dropouts, include full term control groups for cohort specific comparisons, be long term (that is, into school age to assess the full spectrum of abilities and behaviours), include differential reports of sub-populations (for example, according to social class, small for gestational age versus appropriate for gestational age, single v multiple birth, ELBW vs VLBW); and be conducted by independent (group blinded) psychology researchers not involved in the neonatal care of the infants under investigation." (page 567)

Increasing numbers of studies on the outcomes of VLBW children over the years have revealed areas of developmental deficits other than those of clear handicapping conditions. However, the nature and extent of such deficits have remained less clearly defined. Whilst some studies consistently showed areas of concern, for example, lower IQ scores and poorer school performance, inconsistent findings were reported in other areas such as emotional and behaviour difficulties. The picture given is often complex as it is
confusing. On a more positive note, there is consensus among the studies that VLBW children are at risk of difficulties at school age and it is important for research to direct its attention in helping these children. Increased emphasis on factors such as functional levels, non-respondents and non-cooperative respondents is warranted. Intricately associated with these issues would be the crucial areas of parental factors. Wolke et al. (1995) wrote: "It seems that parents who have not come to terms with their child's developmental deficits may tend to avoid situations where these difficulties are highlighted. Selective subject loss must be accounted for in follow-up reports to avoid under-reporting of developmental sequelae of very preterm births, a demand rarely met by follow-up studies." (Page 447). As for those who do respond, follow-up should extend to beyond the doors of the preschool and primary school.

Implicit in the above paragraph, especially in the quotation from Wolke, is the influence of parents on the development of VLBW children. Although this may seem a digression from the research questions to be answered in this study, the role of parents in the developmental outcomes of VLBW children is an issue that cannot be underestimated and needs to be re-appraised. Stengel (1982) carried out a selected review of literature pertaining to infant behaviour, maternal psychological reactions and mother-infant interaction. In some mothers, there were a sense of failure and feelings of guilt which in turn affected a mother's ability to care for and understand the VLBW child. Other negative emotions noted were anticipatory grief that the child might not survive or fear that the child might not be normal. These findings were in agreement with earlier studies such as Choi's (1973) who found that mothers with low birth weight infants had more anxiety and depression. Two decades on, Miles and
Holditch (1997) synthesised previous research findings and found similar responses,

"most commonly reported responses are anxiety, helplessness and loss of control, and fear, uncertainty, and worry about the outcome for their infant. Parents also commonly reported guilt and shame, depression and sadness, and a sense of failure and disappointment. While short-term longitudinal studies indicate that the intense anxiety of parents lowers over time, it is clear that parents continue to have many concerns and related anxiety when the infant is discharged to their care" (pages 256, 257).

With a broader purpose in mind, the authors presented a framework on the 'pathways of influence' in parenting and recommended intervention that will help these parents. While the needs of parents are not top priority within a neonatal intensive care unit, the effect of this experience on subsequent parenting cannot be undermined.

2.4 Summary of the literature review

The range of studies on the developmental outcomes of VLBW children has identified not only areas of concern but also the prevalence and profile of deficits. More specifically, literature on school performance, motor skills, cognitive ability, behavioural difficulties and VLBW follow-up was appraised. From the studies on areas of deficits, more consistent findings were found among those on school performance, motor skills and cognitive ability. The overall picture is that VLBW children do not do well. In studies where comparisons were made, the VLBW children fared less well than their NBW
peers in these areas despite the fact that like the NBWs, they do not have major or overt handicaps. Partly due to greater variation in definitions, more inconsistent findings existed when studies on behaviour were compared. For example, some included attentional problems whilst others encompassed emotional difficulties. Some looked at gender or differences in age group. Yet more studies investigated the impact of social, environmental and family factors on the behaviour of VLBW children. Due to the constraints of this study, the latter were not reviewed in depth. Studies on follow-up issues were also covered in terms of difficulties and directions. Methodological difficulties appeared to take the centre stage in the studies on the former whilst the latter found a more constructive move towards methodological improvements and coverage of issues such as lesser known groups like those who default or were more difficult to follow-up and parental factors.

The literature reviewed thus far suggests that investigators and researchers have come a long way in VLBW research. Escobar et al. (1991) sums up the situation well by stating, "Our ability to assess and report the outcome of surviving VLBW infants has lagged behind our willingness to resuscitate them" (page 211). This chapter is but a pale reflection of the depth and breadth of interest on the lives of these once tiny children. However, it serves as a foundation stone for this study which seeks to describe a sub-group of such children with similar beginnings in the Far East.
Chapter Three

METHODOLOGY

This chapter seeks to give a profile of the sample as well as to
describe the process and product of the investigation in both quantitative and
qualitative terms. The approaches and instruments used to capture the data are
elucidated followed by an explanation of the procedures used in data analyses.

3.1 The Research Design

The research design of a study is described as representing “the
major methodological thrust of the study, being the distinctive and specific
research approach which is best suited to answering the research question/s”
(Cormack, 1991, page 116). The design selected for this study is the Ex Post Facto
research design. Ex post facto, or ‘after the fact’, research is “conducted after the
variations in the independent variable have occurred” (Pannbacker & Middleton,
1994, page 268). Other authors have termed it a retrospective study, case control
study, case history study, correlational research, and trohoc study (e.g. Cormack,
1991, Rosenfeld, 1991). In this type of design, both the independent variables and
the projected effect or dependent variables have already taken place. The
researcher attempts to identify the factors which have resulted in the effect or
which brought about the difference. The data collected are then examined
retrospectively to establish causes, relationships or associations, and their
meanings. It has to be borne in mind that association here does not necessarily
mean causation, that is, it does not result in cause-and-effect conclusions. The
design has its strength in research situations where experimental enquiry is not
feasible. It is especially useful in evaluating existing clinical data where there are
practical as well as ethical considerations with regard to the subjects. Cohen and Manion (1994, page 150) illustrate this point by citing the well-known example of the alleged relationship between smoking and lung cancer. In this situation, it is unethical to subject human beings to experimental conditions that are detrimental to health. The other advantages of the ex post facto design include its efficacy as an exploratory tool. A researcher has the flexibility of working out relationships of interest and to obtain information on factors affecting them where associations do exist. The reason for choosing this design for the study is quite straightforward. It is deemed the most suitable framework to facilitate the answering of the research questions posed. In other words, one is seeking to retrospectively answer the research questions based on information gathered from events that have already taken place, for example, psychological assessment outcomes and school results of VLBW children previously obtained over a period of time are evaluated to provide an answer to research questions 1 and 2. The outcomes of these children are multifaceted and often complicated, requiring clarification. More importantly perhaps, a holistic picture of the situation is often found lacking in the literature generally and evidently absent in the local context.

In the quest for a more comprehensive picture, both quantitative and qualitative methods, an example of 'Methodological Triangulation', are utilised. This is defined as "the use of two or more methods of data collection in the study of some aspect of human behaviour...to map out, or explain more fully, the richness and complexity of human behaviour by studying from more than one standpoint." (Cohen and Manion, page 233). Advocating integration, Steckler et al. (1992) emphasised that "..each method is based on different yet complimentary assumptions and each method has certain strengths that can be used to compensate
for the limitations of the other." (page 4). A variant of triangulation, 'Investigator Triangulation' is where "more than one observer (or participant) in a research setting" (Cohen and Manion, 1994, page 238) is involved. 'Investigator Triangulation' has its aims in achieving greater validity in the data collected and credibility in the findings. There should also be a corresponding increase in the confidence of the researcher should the findings agree. If they do not, there is the opportunity for the researcher to seek to understand why and to determine which of the results are the more valid. To a certain extent, the use of Investigator Triangulation used in this study is not as 'formalised' as with Methodological Triangulation. For example, a case study may comprise different views noted verbatim and in an unstructured manner. These views may have been contributed by different members of the team on the possible reasons why a VLBW child was failing in school even though formal testing showed normal IQ. The integration of this means of data collection "has special relevance when a complex phenomenon requires elucidation" (Cohen and Manion, page 241).

3.2 The children

The population in this study comprises a special group of children commonly known as VLBWs within Paediatrics or more specifically, Neonatology settings. These children were born prematurely with Very Low Birth Weights, that is, below 1500 grams at a local women’s and children’s hospital during the period 1990 to 1991. Those born with a very low birth weight of 1000 grams were further classified as Extremely Low Birth Weight or ELBWs. They were inpatients at the Neonatal Intensive Care Unit (NICU). Following discharge from the wards, the parents were given details of the outpatient follow-up programme conducted by
a multi-disciplinary child development unit in the same hospital. Two of the aims of the unit are to provide early identification and intervention of the child's developmental problems and to support the family in coping with the child's difficulties. The primary members of the team comprise a paediatrician who manages the case, a psychologist and a nurse. This team is supported by professionals from the Departments of Medical Social Work and Rehabilitation. Their contribution has been particularly valuable where there are developmental difficulties. Moreover, when concerns are raised during the scheduled sessions at two, five and eight years of age, the parents would have been given another appointment in order to address those needs. Administratively, fees were charged for each visit to the paediatrician, psychologist and any of the therapists, that is, the physiotherapist, occupational therapist and speech and language therapist.

The main follow-up sessions typically involved a physical and neurological examination by the paediatrician and psychological assessment by a psychologist. A hearing assessment by an audiologist was conducted when the child was two years old. The presence and degree of functional handicap were then classified as 'Severe', 'Moderate', 'Mild' and 'No Functional Handicap' by the paediatricians. These medical and developmental outcomes continued to be monitored up to eight years of age. In addition, as the child approached formal schooling, attempts were made to establish his or her level of school performance.

3.2.1 The sample

Generally, the sampling method employed in this study is described as Convenience sampling. This is one of the most common non-probability sampling methods. The reason for this choice was because the information on the VLBW children was readily available to the researcher as she was part of the multi-
disciplinary team that followed the children up. To put it simply, the researcher
first drew “the sample that is easiest to come by” (Mertens & McLauglin, 1995,
page 78) to begin with, then sought to refine and define it in accordance with pre-
set criteria. The sample in this study was therefore retrospectively recruited from
the cohort of children described in the preceding section 3.2. As mentioned earlier,
the parents were informed of the VLBW follow-up programme. Consent to
participate was based on the understanding that this was primarily a service for the
children. Not all parents wanted the service and some subsequently defaulted.
Whilst the reasons for their refusal or default were not consistently documented,
there appears to be a consensus of perception such as “my child is not sick, there is
no need to see a doctor” or “it is too expensive, I cannot afford it”. There is also a
small number who have changed residence and could not be contacted. A total of
107 VLBW children satisfied the following pre-set criteria:

1. The children in the sample are those without neurologic abnormalities or
   clear handicapping conditions, that is, they would have been classified by
   their Paediatricians as ‘neurologically normal’.

2. These were children of Chinese descent with Mandarin as their ‘Mother
   Tongue’.

3. They would have undergone at least two psychological assessments, at five
   years of age and another at eight years.

4. At the time of assessment, they were studying at the primary two level in
   mainstream primary schools in Singapore.

5. All were assessed by the Researcher on the Wechsler Intelligence Scale for
   Children (3rd Edition) at eight years old and their Full Scale IQ scores were
   greater than 70 i.e. not ’Intellectually Deficient’.

45
6. They have been \textit{eventually} discharged from the hospital (not necessarily at the eight year old appointment).

7. Prior to the appointment at age eight, they would not have received any intervention programmes conducted by any of the child psychologists in the hospital.

This group is a subset of a wider group of children or study population (3.2.1) namely, VLBWs born between 1990 and 1991. Given the preset criteria that led to the constitution of the sample, for example, VLBWs of Chinese descent, some of the findings in this study may not be representative of the population which is made up of different races, that is, Malay, Indian and Chinese.

The following flow-chart (Figure 1) shows how the sample was obtained:

280 VLBWs born and warded between 1990-1991

- 254 survivors
  - 185 VLBWs, 69 ELBWs
  - 26 deaths

- 168 discharged
  - 118 VLBWs, 50 ELBWs
  - 86 other outcomes
    - 67 VLBWs, 19 ELBWs

- 146 in mainstream
  - 103 VLBWs, 43 ELBWs

- 22 in special schools or programmes
  - 15 VLBWs, 7 ELBWs

- 36 refusals or defaulters
  - 26 VLBWs, 9 ELBWs

- 50 lost
  - 41 VLBWs, 9 ELBWs

111 Chinese

35 non-Chinese

107 had

IQ \geq 70

4 had

IQ < 70
Out of these 107 children, the 37 children who did not have a "well/normal" diagnosis formed the pool of cases that could be used for the case studies. In other words, the "well/normal" diagnosis was used as an exclusion criterion which eventually identified the six children for the case studies. The primary aim of this exercise was to obtain a more in-depth and accurate picture of the difficulties some of these children have experienced in the course of the follow-up or after discharge and returned to the unit for further investigations and monitoring. Furthermore, the SPSS 10.0 (2000) (Statistical Products and Service Solutions Version 10.0), a statistical system for data analyses, enabled a random sampling of a child from the 70 who had a "well/normal" diagnosis. This led to a seventh case study for the purpose of providing the reader a means of comparison with those who 'have been in the same boat' albeit with difficulties.

3.2.2 The variables

The 41 variables in this study comprise nominal, ordinal and scaled data. According to their purposes based on the research questions, these are categorised into five sections, summarised in Table 3.2.1:

<table>
<thead>
<tr>
<th>Variables</th>
<th>Description</th>
<th>Aims</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>birthwt</td>
<td>Birth weight</td>
<td></td>
</tr>
<tr>
<td>gestatn</td>
<td>Gestation period</td>
<td></td>
</tr>
<tr>
<td>gbwclass</td>
<td>Gestational birth weight classification</td>
<td></td>
</tr>
<tr>
<td>bwgroup</td>
<td>Birth weight grouping</td>
<td></td>
</tr>
<tr>
<td>ivh</td>
<td>Neonatal problems: intraventricular haemorrhage</td>
<td></td>
</tr>
<tr>
<td>rop</td>
<td>Neonatal problems: Retinopathy</td>
<td></td>
</tr>
<tr>
<td>bpd</td>
<td>Neonatal problems: Bronchopulmonary dysplasia</td>
<td></td>
</tr>
<tr>
<td>neoprbm</td>
<td>Sum of neonatal problems listed above</td>
<td></td>
</tr>
<tr>
<td>wt@8yrs</td>
<td>Measured weight at 8 year old assessment</td>
<td></td>
</tr>
<tr>
<td>ht@8yrs</td>
<td>Measured height at 8 year old assessment</td>
<td></td>
</tr>
</tbody>
</table>

Table 3.2.1 A description of the variables and the aims of various categories

47
<table>
<thead>
<tr>
<th>Variables</th>
<th>Description</th>
<th>Aims</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Educational outcomes</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mandarin</td>
<td>Performance on school subject: Mandarin</td>
<td>To give an overview of the performance of Singaporean Chinese VLBW children at mainstream schools</td>
</tr>
<tr>
<td>english</td>
<td>Performance on school subject: English</td>
<td></td>
</tr>
<tr>
<td>maths</td>
<td>Performance on school subject: Mathematics</td>
<td></td>
</tr>
<tr>
<td>pteprog</td>
<td>Child has been receiving private tuition or attending an enrichment programme privately</td>
<td></td>
</tr>
<tr>
<td>tchcompl</td>
<td>Reports of complaints by teachers</td>
<td></td>
</tr>
<tr>
<td><strong>Cognitive outcomes</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>bsid mdi</td>
<td>Mental development index (MDI) score of Bayley Scales of Infant Development</td>
<td>To give an indication via formal testing of the cognitive functioning of VLBW from two until eight years old</td>
</tr>
<tr>
<td>bsid clas</td>
<td>Classification of Bayley’s MDI</td>
<td></td>
</tr>
<tr>
<td>s bis</td>
<td>Test composite of the Stanford Binet Intelligence Scale</td>
<td></td>
</tr>
<tr>
<td>s bis cl as</td>
<td>Classification of S-BIS’ test composites</td>
<td></td>
</tr>
<tr>
<td>wisc3 iq</td>
<td>Full Scale IQ of WISC-III</td>
<td></td>
</tr>
<tr>
<td>wisc3 cla</td>
<td>Classification of the full scale IQ of WISC-III</td>
<td></td>
</tr>
<tr>
<td>w verb iq</td>
<td>Verbal IQ score of WISC-III</td>
<td></td>
</tr>
<tr>
<td>v iq clas</td>
<td>Classification of verbal IQ of WISC-III</td>
<td></td>
</tr>
<tr>
<td>w perf iq</td>
<td>Performance IQ score of WISC-III</td>
<td></td>
</tr>
<tr>
<td>p iq clas</td>
<td>Classification of performance IQ of WISC-III</td>
<td></td>
</tr>
<tr>
<td><strong>Needs and impairments</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>learn pbm</td>
<td>Presence of problems in the area of learning</td>
<td>To illustrate the presence and types of needs &amp; difficulties VLBW children experience</td>
</tr>
<tr>
<td>spch lang</td>
<td>Speech and language impairments</td>
<td></td>
</tr>
<tr>
<td>motor pbm</td>
<td>Motor problems e.g. fine motor coordination</td>
<td></td>
</tr>
<tr>
<td>famsoc pb</td>
<td>Family and social problems</td>
<td></td>
</tr>
<tr>
<td>beh pr blm</td>
<td>Behavioural problems</td>
<td></td>
</tr>
<tr>
<td><strong>Issues of follow-up and recommendations</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>liai sch</td>
<td>Liaison with school principal or teachers</td>
<td>To present the recommendations and infer from them the issues of following up Singaporean Chinese Very Low Birth Weight children</td>
</tr>
<tr>
<td>learn sup</td>
<td>Learning support or underachievers’ programmes</td>
<td></td>
</tr>
<tr>
<td>speclist</td>
<td>Referrals to specialists or specialised organisations</td>
<td></td>
</tr>
<tr>
<td>s l ther</td>
<td>Referral for speech &amp; language therapy</td>
<td></td>
</tr>
<tr>
<td>phyocoth</td>
<td>Referral for physiotherapy and/or occupational therapy</td>
<td></td>
</tr>
<tr>
<td>psy sessn</td>
<td>Psychologist’s session with child and/or parents</td>
<td></td>
</tr>
<tr>
<td>paedmoni</td>
<td>Need for paediatrician to further monitor</td>
<td></td>
</tr>
<tr>
<td>diagnose</td>
<td>Paediatrician’s diagnosis at eight year old assessment</td>
<td></td>
</tr>
<tr>
<td>dischrg</td>
<td>Paediatrician’s decision to discharge at eight year old visit</td>
<td></td>
</tr>
</tbody>
</table>
3.3 Methods

The methods of data collection are the survey and formal psychological tests as well as paediatricians' and psychologists' notes recorded during discussions with parents and teachers in the case studies. Prior to looking at the methods used in data collection, there are ethical issues to be considered.

3.3.1 Ethical considerations

Based on the fact that a retrospective research design was adopted, the author was able to gain access to the data of children who fulfilled the pre-set criteria in 3.2.1. as well as whose parents had already given their consent for the follow-up and its ensuing investigations. Nevertheless, it was needful for the researcher to exercise caution in revealing information that would identify any child. Anonymity and confidentiality were the key issues. These are especially important as the study is carried out within a hospital setting and all staff is bound to ‘keep patient confidentiality’. In addition, there was the tension of being a ‘detached’ researcher and a practitioner actively involved in the assessment of VLBW children. This was, in a way, resolved by the fact that the sample was retrospectively recruited and therefore consisted of children who had been discharged from the hospital. In analysing the data, on the other hand, the author had to evaluate her work as a psychologist with the sample from a researcher’s perspective instead. Moreover, upon requesting permission to carry out this investigation, it was made clear to the Head and the members of the team that the author was a researcher only after office hours which also included Saturday afternoons. This in turn meant less conflict of interest as one’s roles and boundaries were defined. The ethics of practitioner research in one’s professional field could be likened to walking on a tightrope. Edwards and Talbot (1994)
provides 'hard-pressed researchers' in the caring professions with a list of pointers when considering research ethics:

* "Will the data collection method cause pain or distress to participants?"
* Am I satisfied that any conclusions reached are appropriately supported by enough evidence?
* Can I keep promises of confidentiality?
* Am I taking undue advantage of my position to gain information (e.g. from teachers in the school in which you are head teacher?)
* Does the research raise false hopes amongst the participants?
* Can I reproduce my findings in ways that authentically represent the concern of participants?" (page 13)

Research with children, in particular, is an area that raises ethical issues as they are more vulnerable and require protection. This is especially true if they are young or do not have the required level of competence to give informed consent. From their experience, Edwards and Talbot (1994) found that accessibility problems in research on children are rare although parental permission is normally required.

3.3.2 The survey

Certain portions of Cohen and Manion's (1994) definition of the survey best describe its use in this study: "...surveys gather data at a particular point in time with the intention of describing the nature of existing conditions...or determining the relationships that exist between specific events" (page 83). Definitions on the survey method in the literature tend to agree that a major feature of it is that numerical data is first obtained from a group of subjects drawn from a
defined population; a description of the whole population and an analysis of the relationships within is then carried out. This study is an example of a survey in which, based on pre-set criteria, a sample is drawn from a hospital population of VLBWs. The survey method was first chosen by the paediatricians and nurse co-ordinator in charge of the follow-up programme of the VLBWs. The main reason was the need to obtain as much 'up-to-date' information as possible within the shortest period of clinic time when a VLBW child came for the scheduled assessments at two, five and eight years old. A structured form (Appendix 1) was thus constructed by the team and the nurses were trained to conduct the interview. The form also served as a recording sheet for the paediatricians and psychologists.

3.3.2.1 Interviews

When the children arrived for their scheduled assessment at two, five and eight years old, the nurses conducted the interview using the form. The paediatricians and psychologists continued the process by recording their investigations on the form. This served to standardise the process. After the child had been discharged after or on the eight-year-old scheduled assessment, relevant data were then collated, numerically coded and analysed.

3.3.2.2 School reports

At the interview when the child had turned eight years old, the nurses obtained a copy of the latest school report from the parents. Should this be unavailable, school achievement was verbally reported by the parents. School achievement comes in the form of Bands:
A child's 'Bands' were thus noted in the interview schedule. In addition, any comments from parents and teachers concerning the child were recorded. Specifically, negative comments on reports cards or active approaches made by teachers to discuss with parents their child’s problems were interpreted to constitute a ‘complaint’. The frequency of its occurrence in the medical records is represented by the variable ‘tchcompl’ (teacher complaints) in Chapter Four and examples of these ‘complaints’ are given in the selected case study reports in Chapter Five.

The goal of the interview throughout was to gather as much information as possible in order to obtain a fair description of the child and his or her current situation. Following the interview, the child was assessed by the psychologist.

3.3.3 Formal testing

The allocation or 'match' of child to psychologist in a psychological assessment depended on the race of the child and his or her preferred language of communication as well as the demands of the appointment listings at the Unit. Generally, the researcher assessed the Chinese VLBWs whilst her colleague saw children of other races, mainly Malay. Unless English was spoken at home, it would have been acquired as a second language as the child attended kindergarten and primary school. No match, therefore, of child to psychologist was necessary.
for children who were brought up in an English speaking environment as the two psychologists involved spoke English. The need of a child-to-psychologist match was found to be necessary for children who were more comfortable with their Mother Tongue.

The following sections give brief descriptions of the formal developmental or IQ tests used. These assessed not only the level of development or intellectual functioning but provide a profile of a child's strengths and weaknesses. The psychologists involved in the follow-up were trained to administer these tests.

3.3.3.1 Bayley Scales of Infant Development (Second Edition) (BSID-II)

Except for those who refused, defaulted follow-up or who, for reasons such as migration, were 'lost' in the course of it, the two year old VLBW survivors in the cohort were assessed on the Bayley Scales of Infant Development, an instrument that assesses infant development. Those who performed poorly on this test were referred to the appropriate special schools or programmes that provided early intervention.

The BSID-II consists of three parts: the Mental Development Index (MDI), the Psychomotor Index (PDI) and the Infant Behavior record (IBR). Their functions are summarised as follows: "Functions assessed with the MDI include perceptual abilities, object permanence, memory, problem-solving skills, imitative abilities, and early symbolic thinking. The PDI provides evaluation of gross and fine motor development. Whereas the IBR includes assessment of social, behavioral and emotional functioning. Therefore, the BSID-II is helpful in allowing the clinician to evaluate the child's gross motor, fine motor, personal/social, language, and cognitive/adaptive abilities." (Aylward, 1994, pages 23-24).
104 of the children in the sample were assessed on the BSID with outcomes of a Mental Development Index (MDI). Three of the children did not attend the scheduled two year old assessment. Moreover, not all had a Psychomotor Index (PDI) due to constraints of time and facilities. This inconsistency meant that only MDIs were studied. The MDI outcomes are classified as follows:

Table 3.3.2 Classification of the Bayley Scale of Infant Development (Second Edition) Mental Development Index

<table>
<thead>
<tr>
<th>Mental Development Index (MDI)</th>
<th>Classification</th>
</tr>
</thead>
<tbody>
<tr>
<td>115+</td>
<td>Accelerated Performance</td>
</tr>
<tr>
<td>85-114</td>
<td>Within Normal Limits</td>
</tr>
<tr>
<td>70-84</td>
<td>Mildly Delayed performance</td>
</tr>
<tr>
<td>69 &amp; below</td>
<td>Significantly Delayed Performance</td>
</tr>
</tbody>
</table>

3.3.3.2 Stanford-Binet Intelligence Scale (4th Edition) (SBIS-IV)

At five years old, the children underwent an assessment carried out by a psychologist using the Stanford-Binet Intelligence Scale (4th Edition). This test measures the neuropsychological abilities of the children and comprises four sub-scales: verbal, abstract, memory and quantitative skills. The composite score computed from the four sub-scales gives an indication of the cognitive and language abilities of the children assessed. The scores of the SBIS-IV are classified as:

Table 3.3.3 Classification of the Stanford-Binet Intelligence Scale (Fourth Edition) Test Composites

<table>
<thead>
<tr>
<th>Test Composite</th>
<th>Classification</th>
</tr>
</thead>
<tbody>
<tr>
<td>132+</td>
<td>Very Superior</td>
</tr>
<tr>
<td>121-131</td>
<td>Superior</td>
</tr>
<tr>
<td>111-120</td>
<td>High Average</td>
</tr>
<tr>
<td>89-110</td>
<td>Average</td>
</tr>
<tr>
<td>79-88</td>
<td>Low Average</td>
</tr>
<tr>
<td>68-78</td>
<td>Slow Learner</td>
</tr>
<tr>
<td>67 &amp; below</td>
<td>Mentally Retarded</td>
</tr>
</tbody>
</table>
Children who showed significant discrepancies in any of the areas, that is, in their verbal, abstract, memory or quantitative skills were monitored by the Paediatrician as they went through their kindergarten education. Where necessary, some of these children were given further appointments with the psychologist for further investigations.

3.3.3.3 Wechsler Intelligence Scale for Children (3rd Edition) (WISC-III)

At eight years of age, an assessment was carried out by the psychologist using the Wechsler Intelligence Scale for Children (Third Edition) (WISC-III). This was to be the final assessment of the VLBW child. The WISC-III measures the verbal and performance (non-verbal) abilities of school age children. Three scores are obtained: the Full Scale IQ score, the Verbal IQ score and the Performance (or non-verbal IQ scores). Using test interpretation, these scores and the specific patterns of strengths and weaknesses give an indication of where the child is at intellectually. The outcomes of the WISC-III are classified as:

<table>
<thead>
<tr>
<th>Intelligence Quotients (IQ)</th>
<th>Classification</th>
</tr>
</thead>
<tbody>
<tr>
<td>130+</td>
<td>Very Superior</td>
</tr>
<tr>
<td>120-129</td>
<td>Superior</td>
</tr>
<tr>
<td>110-119</td>
<td>High Average</td>
</tr>
<tr>
<td>90-109</td>
<td>Average</td>
</tr>
<tr>
<td>80-89</td>
<td>Low Average</td>
</tr>
<tr>
<td>70-79</td>
<td>Borderline</td>
</tr>
<tr>
<td>69 &amp; below</td>
<td>Intellectually Deficient</td>
</tr>
</tbody>
</table>
Some of the mainstream school difficulties that VLBW children experienced surfaced by the time of their psychological assessment at eight years' old. In such situations, further discussion with the parents and liaison with the teachers had to be arranged. Additionally, it was 'diversions' like these that led the Researcher to see the necessity of adopting an approach that would capture the complexities of being a VLBW child in a mainstream school.

3.3.4 The case study

As seen from the literature review, much of the work done in the past has focused on outcomes as a group as opposed to individuals. However, as each infant develops into a unique child with his or her own needs and is followed up from infancy until the point of discharge, one can appreciate that quantitative information alone is insufficient to give a comprehensive picture of the often intricate lives of VLBW children. The assessment, description and subsequent prediction of individual outcomes using different approaches are therefore crucial. This is where the value of the Case Study method lies. What then, is the definition of the case study?

Despite the fact that "the literature is replete with references to case studies and with examples of case study reports, there seems to be little agreement about what a case study is", wrote Lincoln and Guba in 1985 (page 360). Some authors (e.g. Stake, 1995) viewed the case study in interpretive terms: "the study of the particularity and complexity of a single case, coming to understand its activity within important circumstances" (page 11). Cohen and Manion (1994) describe it in terms of how it is applied in an educational setting, "the case study researcher typically observes the characteristics of an individual unit – a child...a class..." (page 106).
One of the advantages these authors adopted from Adelman et al. (1980) speaks of the paradox of case study data: “case study data paradoxically, is strong in reality but difficult to organise. In contrast, other research data is often ‘weak in reality’ but susceptible to ready organisation. This strength in reality is because case studies are down-to-earth and attention holding, in harmony with the reader’s own experience, and thus provide a ‘natural’ basis for generalisation.” (in Cohen & Manion, 1994, page 123). On the contrary, a key point of criticism has been the limitation in its generalisability (e.g. Isaac & Michael, 1987). How one man’s meat is another man’s poison! Convincingly written, Simmons (1996) sought to reconcile the case study’s strength in reality, hence uniqueness versus its weakness in generalisability by declaring: “What we have is a paradox, which if acknowledged and explored in depth, yields both unique and universal understanding” (page 225). Leaving the controversial and perhaps more philosophical issues aside, let us move on look at actual definitions of a case study. Yin (1994) took a more scientific position and offered a two-part technical definition of a case study:

"I. A case study is an empirical inquiry that
   - investigates a contemporary phenomenon within
     its real life context, especially when
     - the boundaries between phenomenon and context
       are not clearly evident.
   II. The case study inquiry
     - copes with the technically distinctive situation in
       which there will be many more variables of interest than
       data points, and as one result
relies on multiple sources of evidence, with data needing to converge in a triangulating fashion, and as another result
- benefits from the prior development of theoretical propositions to guide data collection and analysis." (Yin, 1994, page 13)

In addition to varying definitions, different types of case study have also been identified. Stake (1995) drew a dichotomy between intrinsic case study, in which one seeks to learn about a particular case or takes an intrinsic interest in the case and instrumental case study whose use is "...get insight into the [research] question by studying a particular case...to understand something else" (page 3). Yin (1993) identified three categories which he succinctly described as: "an exploratory case study...is aimed at defining the questions and hypotheses of a subsequent (not necessary case) study...A descriptive case study presents a complete description of a phenomenon within its context. An explanatory case study presents data bearing on cause-effect relationships—explaining which causes produced which effects" (page 5). For the purpose of this study, the case study adopted here could be best described as both instrumental and descriptive. This is deemed as being particularly useful when one needs to understand the situation in greater depth.

3.3.4.1 The use of case study in VLBW investigations

An example of a case study from the published literature would be the work of Leonard & Piecuch (1997) who investigated school age outcomes in low birth weight preterm infants. Their reason for doing so was that they "...hope to add [their] clinical experience to research findings to illustrate the complexity of follow-up of the school age VLBW infant" (page 241). In addition, this study was
"concerned with understanding real-life events or situations" (Pannbacker & Middleton, 1991, page 147) of this special group of children holistically and in greater depth. Gomm et al. (2000, page 121) established the use of this approach in a clinical setting and stated, "reports of the findings of clinical study are generally characterised as narrative and descriptive: they provide case histories and detailed portraiture". In our case, the primary source of the data for the case studies was the medical records of each child. Information in the records was obtained via the nurses' interviews, descriptive observation notes via psychological assessments and paediatricians' consultations. Where concerns arose, an appointment was given for the child and/or parent to see either the paediatrician or psychologist or both. Comments from parents and teachers were usually recorded verbatim with the latter via telephone interviews. Such opportunities allowed the researcher to document further details through conversation and observations. Case reports are then constructed from the information in the medical records.

3.3.5 Data analyses

The SPSS (Statistical Products and Service Solutions) Student Version 10.0 for Windows, a statistical system for data analyses was used. The following table taken from Morgan, Griego & Gloeckner (2001, page 17) is adopted here in order to relate the research questions to the type of statistics used in the analyses of the VLBW data:
In terms of the quantitative data, descriptive statistics were used to portray the outcomes of the survey and formal tests. Where appropriate, inferential statistics were used in order to provide answers to several kinds of questions about the data collected. More specifically, where relationships between variables were explored, a technique of correlation, Pearson's Product Moment Correlation Coefficient for example, was used. The outcome of this technique is a statistic or coefficient that depicts the strength and direction of the relationship between two variables.

The analysis of qualitative data follows the theme of 'portraiture'. The vast amount of recorded information is analysed with the aim of producing a meaningful and representative picture or case report of the VLBW child. Bassey (1999) took pains to clarify that the case report is "often called the 'case study', although in reality it is just the end point and the complete enquiry is the case
study. The case report is constructed from the case record to serve the end of theory seeking, theory testing, evaluation, an educational story or an educational portrayal.” (Page 80). It is hoped that the case reports in the next chapter would provide a useful portrayal of the VLBW situation in Singapore.

3.4 Summary of methodology

The design selected for this study was the *ex post facto* research design where attempts were made to identify the factors that resulted in the effect or brought about the difference. In this situation, the data collected were examined *retrospectively* to establish relationships or associations and their meanings. The design has been known to be especially useful in evaluating existing clinical data where there are practical and ethical considerations. Moreover, it has been effective as an exploratory tool in complex phenomena such as being a VLBW child in a mainstream school setting.

The sample in this study consisted of 107 Chinese Singaporean VLBW children in mainstream schools. These were retrospectively recruited from a cohort of children born in a tertiary care hospital between 1990 and 1991 with birth weights less than 1500 grams. The situation these survivors were in is a complex one that could not have been adequately explained by a single method of investigation. Methodological and investigator triangulation were adopted in order to provide a more holistic picture of being born with a very low birth weight and attending local mainstream schools. Both quantitative and qualitative methods were used. The instruments included structured interviews, formal tests as well as notes recorded verbatim by members of the multi-disciplinary team who followed
the children until they turned eight. Case studies of those who had difficulties were conducted in order to illustrate as well as to evaluate the process of follow-up.

In summary, the nature of the VLBW data in this study is such that they could not only be examined retrospectively but also by the use of different methods via different people. The methodology adopted here aims firstly, to obtain an overall picture of psychological and educational outcomes; secondly, to capture some of the difficulties individual VLBWs have and thirdly, evaluate the process of following up this special group of children. It is to the Quantitative (Chapter Four) and Qualitative (Chapter Five) findings that we now turn.
Chapter Four

QUANTITATIVE FINDINGS

This chapter seeks to portray the character of this sub-group of VLBW children and the relationships among certain variables. Its focus lies primarily on the quantitative aspect of the data.

4.1 Quantitative results and analyses

The following table gives a composite picture of the 107 VLBW children in this study:

Table 4.1.1 Sample characteristics of Singaporean Chinese VLBW children (N=107)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequencies / Descriptives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>61 boys (57%) 46 girls (43%)</td>
</tr>
<tr>
<td>Birth weight</td>
<td>Min 520 g Max 1480 g Mean = 1117.66g SD = 237.85</td>
</tr>
<tr>
<td>Birth weight classification</td>
<td>76 VLBW (71%) 31 ELBW (29%)</td>
</tr>
<tr>
<td>Gestation</td>
<td>Min 24 weeks Max 36 weeks Mean = 30.04 weeks SD = 2.6</td>
</tr>
<tr>
<td>Gestational Age/Birth weight classification</td>
<td>40 AGA (37.4%) 67 SGA (62.6%)</td>
</tr>
<tr>
<td>IVH</td>
<td>‘Yes’ or present 45 (42.1%) 62 (57.9%)</td>
</tr>
<tr>
<td>ROP</td>
<td>45 (42.1 %) 62 (57.9%)</td>
</tr>
<tr>
<td>BPD</td>
<td>49 (45.8%) 58 (54.2%)</td>
</tr>
<tr>
<td>Common neonatal problems</td>
<td>None 30 (28%) 1 out of 3 32 (29.9%) 2 out of 3 28 (26.2%) All 3 17 (15.9%)</td>
</tr>
<tr>
<td>Weight at 8 years old</td>
<td>&lt;3rd %ile 3rd-49th %ile 50th-96th %ile &gt;97th %ile</td>
</tr>
<tr>
<td></td>
<td>13 (12.1%) 67 (62.6%) 26 (24.3%) 1 (0.9%)</td>
</tr>
<tr>
<td>Height at 8 years old</td>
<td>&lt;3rd %ile 3rd-49th %ile 50th-96th %ile &gt;97th %ile</td>
</tr>
<tr>
<td></td>
<td>18 (16.8%) 64 (59.8%) 23 (21.5%) 2 (1.9%)</td>
</tr>
</tbody>
</table>
The 61 boys and 46 girls studied had a mean gestation age of 30.04 weeks and a mean birth weight of 1117.66 kg. By definition, these figures satisfy the WHO criteria of prematurity (≤37 weeks gestation) and ‘Very Low Birth Weight’ or VLBW (1000g ≤ birth weight ≤ 1500g). It has to be borne in mind that the sample does not consist solely of VLBWs but ELBWs as well. There were more VLBWs (71%) than ELBWs (29%). A larger proportion (62.6%) of the sample would have been classified as being born ‘small for gestational age’ or SGA. This contrasted with the close to 40% who were premature with birth weights expected for the gestational age they were at, hence the term ‘appropriate for gestational age’ or AGA.

The common neonatal problems listed in Table 4.1.1 are by no means an exhaustive list of the children’s experiences during their turbulent early months. The figures simply indicate that almost three quarters of the children would have at least one of the three problems commonly found amongst VLBW neonates. Findings pertaining to the height and weight when the children were assessed at eight years old revealed that a large proportion was relatively short as well as underweight. Most, 62.6% and 59.8% lay within the 3rd to 49th percentile for weight and height respectively. Two interesting outliers were also found. One child was obese and was attending a ‘Tough Club’ (a physical programme held in mainstream schools for overweight children), another was ‘too’ tall and thin possibly due to the fact that both parents were of similar stature.

The school performance of these children is represented by Figures 3A, 3B and 3C.
Figure 3A School performance in Mandarin

Figure 3B School performance in English

Figure 3C School performance in Mathematics
A quick recapitulation of Band descriptions in the context of local school achievement should help clarify the above findings.

Table 4.1.2  A summary of Singapore guidelines on school achievement

<table>
<thead>
<tr>
<th>Achievement Band</th>
<th>Marks Range</th>
<th>Brief Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Band 1</td>
<td>&gt;85</td>
<td>Very good in the subject</td>
</tr>
<tr>
<td>Band 2</td>
<td>70-84</td>
<td>Good in the subject</td>
</tr>
<tr>
<td>Band 3</td>
<td>50-69</td>
<td>Adequate grasp of the subject</td>
</tr>
<tr>
<td>Band 4</td>
<td>&lt;50</td>
<td>Elementary grasp of the subject</td>
</tr>
</tbody>
</table>

The findings on educational outcomes show that more children performed better in Mandarin than in English. More (69.2%) of the sample obtained Band 1 or 2 that is a ‘Very good’ or ‘Good’ performance in Mandarin compared with 51.4% in English. In addition to the contextual factors given in 1.3, this can also be explained by the fact that the researcher/psychologist was usually ‘assigned’ VLBWs from predominantly Mandarin speaking homes. (Please see 3.3.2 on formal testing for details of this arrangement). Within individual Bands, most (34.6%) obtained Band 3 in English that is, an ‘Adequate grasp of the subject’. Although more (31.8%) displayed a Band 2 or ‘Good’ performance in their Mathematics, there were also proportionately more (20.6%) who fared poorly (Band 4) in this as compared with Mandarin (14%) and English (14%).

Table 4.1.3 School related issues of Singaporean Chinese VLBW children (N=107)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Presence of variables</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Private tuition or programme</td>
<td>Yes (in receipt of tuition) 48 (44.9%)</td>
<td>No (not in receipt of tuition) 42 (39.3%)</td>
</tr>
<tr>
<td>Teacher complaints</td>
<td>Yes (present) 33 (30.8%)</td>
<td>No (absent) 65 (60.7%)</td>
</tr>
</tbody>
</table>
Figure 4A shows the proportion of children in receipt of privately arranged support such as tuition and Figure 4B gives the amount of teachers' complaints as reported by parents who had received these verbally from the teachers or via the children’s school report cards. The missing values represent cases where there has been no mention of privately arranged tuition or teacher complaints in the medical records. From the information given, most of the children in the sample were in receipt of private tuition, a common phenomenon in Singapore. However, a high proportion of complaints from the teachers was reported by the parents.

Figure 4A  Pie chart showing percentages of VLBW children in receipt of privately arranged support such as tuition.

- In receipt: 44.9%
- Not in receipt: 38.3%
- Missing data: 15.8%

Figure 4B  Pie chart showing percentages of teacher complaints

- Present: 30.4%
- Absent: 69.6%
- Missing data: 8.8%
Table 4.1.4 Performance (Mental Development Index) of Singaporean Chinese VLBW children at two years old using the Bayley Scales for Infant Development (BSID)

<table>
<thead>
<tr>
<th>BSID</th>
<th>N</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Development Index</td>
<td>104</td>
<td>61</td>
<td>137</td>
<td>95.9 (17.22)</td>
</tr>
</tbody>
</table>

Figure 5 Histogram showing BSID (Mental Development Index) classifications of Singaporean Chinese VLBW children at two years old

The findings from the BSID assessment gave a mean Mental Development Index or MDI of 95.9. This classifies the group of children as functioning ‘Within Normal Limits’ when they were assessed at two years old.

Table 4.1.5 Performance (Test Composite) of Singaporean Chinese VLBW children at five years old using the Stanford Binet Intelligence Scale for Children (4th Ed) (SBIS-IV)

<table>
<thead>
<tr>
<th>S-BIS</th>
<th>N</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Test Composite</td>
<td>107</td>
<td>73</td>
<td>117</td>
<td>101.49 (8.87)</td>
</tr>
</tbody>
</table>
The average Test Composite or IQ from the five-year-old assessment was 101.5. This places the children within the 'Average' range of intellectual functioning as assessed on the Stanford-Binet Intelligence Scale (S-BIS).

Table 4.1.6 Full Scale Intelligence Quotients (FSIQ), Verbal IQs (VIQ) and Performance IQs (PIQ) of Singaporean Chinese VLBW children at eight years old using the Wechsler Intelligence Scale for Children (3rd Edition) (WISC-III)

<table>
<thead>
<tr>
<th>WISC-III</th>
<th>N</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full Scale IQ</td>
<td>107</td>
<td>72</td>
<td>135</td>
<td>104.04 (11.60)</td>
</tr>
<tr>
<td>Verbal IQ</td>
<td>107</td>
<td>67</td>
<td>135</td>
<td>100.59 (11.51)</td>
</tr>
<tr>
<td>Performance IQ</td>
<td>107</td>
<td>70</td>
<td>144</td>
<td>107.34 (12.94)</td>
</tr>
</tbody>
</table>
Figure 7A Histogram showing WISC-III Full Scale Intelligence Quotients (FSIQ)

Wechsler Scale (WISC-III) Full Scale IQ

Figure 7B Histogram showing WISC-III Verbal Scale Intelligence Quotients (VIQ)

Wechsler Verbal Scale IQ
The WISC-III findings appear more complicated when they are compared to the earlier tests as there are separate IQs representing different areas or skills namely, Verbal and Performance (non-verbal). The overall results place the children within the 'Average' classification of intelligence. A curve superimposed over the histograms appears 'normal'. However, such visual inspection can be deceptive.

"SPSS recommends that one divides the skewness by its standard error. If the result is less than 2.5 (which is approximately the $p = 0.01$ level) then skewness is not significantly different from normal...a simpler rule of thumb is that if the skewness is less than plus or minus one (< ±1.0), the variable is at least approximately normal." (Morgan et al., 2001, page 67). Further details of the tests’ results found in Table 4.1.7 indicate that the variables considered are approximately normal.
Table 4.1.7 Further details of BSID, S-BIS and WISC-III outcomes

<table>
<thead>
<tr>
<th>Variables considered for normality</th>
<th>BSID (MDI)</th>
<th>S-BIS (Test Composite)</th>
<th>WISC-III (Full Scale IQ)</th>
<th>WISC-III (Verbal Scale IQ)</th>
<th>WISC-III (Performance Scale IQ)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>95.9</td>
<td>101.49</td>
<td>104.04</td>
<td>100.59</td>
<td>107.34</td>
</tr>
<tr>
<td>Median</td>
<td>94.5</td>
<td>102</td>
<td>104</td>
<td>101</td>
<td>107</td>
</tr>
<tr>
<td>Mode</td>
<td>85</td>
<td>101</td>
<td>104</td>
<td>93</td>
<td>104</td>
</tr>
<tr>
<td>Std. Deviation</td>
<td>17.22</td>
<td>8.87</td>
<td>11.60</td>
<td>11.51</td>
<td>12.94</td>
</tr>
<tr>
<td>Variance</td>
<td>296.38</td>
<td>78.70</td>
<td>134.49</td>
<td>132.53</td>
<td>167.45</td>
</tr>
<tr>
<td>Skewness*</td>
<td>0.101</td>
<td>-0.589</td>
<td>-0.117</td>
<td>-0.069</td>
<td>-0.021</td>
</tr>
<tr>
<td>Std. Error of Skewness</td>
<td>0.237</td>
<td>0.234</td>
<td>0.234</td>
<td>0.234</td>
<td>0.234</td>
</tr>
<tr>
<td>Range</td>
<td>76</td>
<td>44</td>
<td>63</td>
<td>68</td>
<td>74</td>
</tr>
</tbody>
</table>

* Skewness is less than ± 1.0 suggesting approximate normality.

4.1.1 Further investigations into outcomes

Further analyses were carried out in order to explore the relationships between pairs of variables. Specifically, the researcher was interested to see if a correlation between ten sets of paired variables, that is, birth weight (4.1.1.1) or gestational age (4.1.1.2) with: i) BSID Mental Development Index, ii) S-BIS Test Composite, iii) WISC III Full Scale IQ, iv) WISC III Verbal IQ and v) WISC III Performance IQ existed and if so, what the direction of correlation was. The relationships among cognitive outcomes (4.1.1.3) as well as differences of ELBW and VLBWs on these (4.1.1.4) and educational outcomes (4.1.1.5) were also investigated.

4.1.1.1 Relationships between birth weight and cognitive test scores

A technique of correlation, Pearson’s Product Moment Correlation Coefficient, was employed to investigate the relationships between birth weight and the Bayley’s Mental Development Index, Stanford Binet’s Test Composite and Wechsler’s IQs. Pearson’s, as it is simply known, is a measure of linear association. It gives a statistic or coefficient $r$ that summarises the strength and
direction of the relationship between two variables (Polit & Hungler, 1991; Silverman, 1993). Values of the coefficients vary between plus and minus 1.00. The closer the correlation coefficient is to plus or minus 1.00, the stronger the relationship will be. A positive correlation coefficient means that the two variables increase or decrease together whilst a negative one implies that they differ inversely.

Table 4.1.8 Summary of Pearson's correlation coefficients with regard to birth weight and cognitive test scores

<table>
<thead>
<tr>
<th>Paired variables</th>
<th>Pearson's Correlation coefficient (r)</th>
<th>Level of Significance (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth weight vs Bayley Scale’s MDI</td>
<td>0.098</td>
<td>Not significant</td>
</tr>
<tr>
<td>Birth weight vs SBIS Test Composite</td>
<td>0.19*</td>
<td>Sig. at 0.05 level</td>
</tr>
<tr>
<td>Birth weight vs WISC-III Full Scale IQ</td>
<td>0.26**</td>
<td>Sig. at 0.01 level</td>
</tr>
<tr>
<td>Birth weight vs WISC-III Verbal IQ</td>
<td>0.22*</td>
<td>Sig. at 0.05 level</td>
</tr>
<tr>
<td>Birth weight vs WISC-III Performance IQ</td>
<td>0.208*</td>
<td>Sig. at 0.05 level</td>
</tr>
</tbody>
</table>

* significant at 0.05 level (2-tailed)    ** significant at 0.01 level (2-tailed)

Further analyses yielded results which showed significant relationships between birth weight and the SBIS Test Composite, WISC-III Verbal and Performance IQ scores at the 95% confidence level. The value of the Pearson correlation coefficient (r) for birth weight and WISC-III Full Scale IQ was highly significant at 0.01 level (99% confidence level). These suggest the existence of a positive association between birth weight and the SBIS Test Composite, WISC-III Full Scale, Verbal and Performance IQs. Furthermore, a strong relationship existed between birth weight and the Full Scale IQ score. This is commensurate with the findings of Richards et al. (2001) on the upward trend of the relationship between birth weight and cognitive function.
4.1.1.2 Relationships between gestational age and cognitive test scores

Table 4.1.9 Summary of Pearson’s correlation coefficients with regard to gestational age and cognitive test scores

<table>
<thead>
<tr>
<th>Paired variables</th>
<th>Pearson’s correlation coefficient (r)</th>
<th>Level of Significance (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gestational age vs Bayley Scale’s MDI</td>
<td>0.018</td>
<td>Not significant</td>
</tr>
<tr>
<td>Gestational age vs SBIS Test Composite</td>
<td>0.069</td>
<td>Not significant</td>
</tr>
<tr>
<td>Gestational age vs WISC-III Full Scale IQ</td>
<td>0.211*</td>
<td>Sig. at 0.05 level</td>
</tr>
<tr>
<td>Gestational age vs WISC-III Verbal IQ</td>
<td>0.162</td>
<td>Not significant</td>
</tr>
<tr>
<td>Gestational age vs WISC-III Performance IQ</td>
<td>0.185</td>
<td>Not significant</td>
</tr>
</tbody>
</table>

* significant at 0.05 level (2-tailed)  ** significant at 0.01 level (2-tailed)

Among the cognitive tests scores examined, only the Full Scale IQ score on the WISC-III bore a positive relationship with gestational age. This shows general agreement with studies carried out both overseas (e.g. Sommerfelt et al., 2000, Larroque et al., 2001) and locally (Yeo et al., 2001, Ho, 2001 (for the Malaysian Very Low Birth Weight Study Group)).

4.1.1.3 Relationships among cognitive outcomes

Table 4.1.10 Relationships among cognitive test scores indicated by Pearson’s r

<table>
<thead>
<tr>
<th>Variables</th>
<th>SBIS Test Composite</th>
<th>WISC-III Full Scale IQ</th>
<th>WISC-III Verbal IQ</th>
<th>WISC-III Performance IQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>BSID’s MDI</td>
<td>0.297**</td>
<td>0.359**</td>
<td>0.337**</td>
<td>0.302**</td>
</tr>
<tr>
<td>SBIS Test Composite</td>
<td></td>
<td>0.541**</td>
<td>0.483**</td>
<td>0.454**</td>
</tr>
</tbody>
</table>

* significant at 0.05 level (2-tailed)  ** significant at 0.01 level (2-tailed)

These results indicate positive relationships among the Bayley’s MDI, SBIS test composite and WISC-III IQs. In other words, a higher MDI obtained on the Bayley Scale when a child is two years old tends to correspond with a higher test composite on the Stanford Binet Scale at five as well as WISC-III IQs at eight years old.
4.1.1.4 Comparison of ELBWs and VLBWs on cognitive outcomes

Taking a step further to investigate whether being of an even lower birth weight, i.e. Extremely Low Birth Weight or ELBW, implies a difference in cognitive performance, the means of the test scores were compared using the two birth weight classifications, VLBW and ELBW. The literature has pointed to greater disadvantages in the latter group. The contents of Table 4.1.7 have indicated that the variables pertaining to cognitive outcomes are approximately normal. In addition, the use of Levene's Test for Equality of Variances permitted the assumption that the variances of the MDI, Test Composite and IQs were equal within each group. An Independent Samples t-test for Equality of Means was run and Table 4.1.11 gives the outcome:

<table>
<thead>
<tr>
<th>Test scores (Equal variances assumed)</th>
<th>T</th>
<th>df</th>
<th>Sig. (2-tailed)</th>
<th>Level of Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bayley Scale MDI</td>
<td>0.827</td>
<td>102</td>
<td>0.41</td>
<td>Not significant</td>
</tr>
<tr>
<td>SBIS test composite</td>
<td>2.143*</td>
<td>105</td>
<td>0.034</td>
<td>Significant at the 0.05 level</td>
</tr>
<tr>
<td>WISC-III Full Scale IQ</td>
<td>3.13**</td>
<td>105</td>
<td>0.002</td>
<td>Significant at the 0.01 level</td>
</tr>
<tr>
<td>WISC-III Verbal IQ</td>
<td>3.23**</td>
<td>105</td>
<td>0.002</td>
<td>Significant at the 0.01 level</td>
</tr>
<tr>
<td>WISC-III Performance IQ</td>
<td>2.084*</td>
<td>105</td>
<td>0.04</td>
<td>Significant at the 0.05 level</td>
</tr>
</tbody>
</table>

Apart from the MDI on the Bayley Scales, there are significant differences between the ELBWs and VLBWs in their cognitive performance on the Stanford-Binet at five years old and the Wechsler Scales at eight years old.

The differences between the two groups on the WISC-III Full Scale IQ score and the WISC-III Verbal Scale IQ score are more pronounced (P<0.01 or 99 % confidence level). These findings confirm those of the literature that ELBW
children do not perform as well as their heavier VLBW counterparts in terms of cognitive outcomes. It is interesting to note that in this sample, birth weight do not have much association with or effect on the MDI of the Bayley Scales when the children were assessed at two years old.

4.1.1.5 Comparison of ELBWs and VLBWs on educational outcomes

Due to the non-parametric, ordinal nature of the educational data, the Mann-Whitney Test was used to evaluate whether there is a difference in school performance between ELBWs and VLBWs.

Table 4.1.12 Differences between VLBWs and ELBWs in their educational outcomes

<table>
<thead>
<tr>
<th>Educational Outcomes</th>
<th>Mandarin</th>
<th>English</th>
<th>Mathematics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mann-Whitney U</td>
<td>1177</td>
<td>1131</td>
<td>1091.5</td>
</tr>
<tr>
<td>Z</td>
<td>-0.165</td>
<td>-0.489</td>
<td>-0.765</td>
</tr>
<tr>
<td>Asym.Sig. (2 tailed)</td>
<td>0.869</td>
<td>0.625</td>
<td>0.444</td>
</tr>
</tbody>
</table>

* significant at 0.05 level (2-tailed) ** significant at 0.01 level (2-tailed)

Contrary to findings from the literature (e.g. Hack et al., 1994), no significant differences were detected between the two birth weight classifications in their school performance within this sample. A possible explanation for this discrepancy is that the Band descriptions in the context of local school achievement are fairly broad. More importantly, the educational data obtained is skewed due to methodological constraints such as these children being primarily from Mandarin speaking homes and any negative effect could have been counteracted by better performance in Mandarin. Perhaps a more accurate picture regarding school performance could be obtained via its relationship to actual birth weights instead of classifications. It would be interesting to note later in Table 4.1.13 that whilst the correlation between birth weight and school performance
remains small, the relationship between birth weight and Mathematics is larger than the others and is close to the 0.05 level of significance.

Table 4.1.13 Relationship between birth weight and school performance

<table>
<thead>
<tr>
<th>Birth weight</th>
<th>Mandarin</th>
<th>English</th>
<th>Maths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Correlation</td>
<td>-0.047</td>
<td>-0.063</td>
<td>-0.185</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>0.634</td>
<td>0.522</td>
<td>0.056</td>
</tr>
</tbody>
</table>

Despite the lack of any significant correlation between the two groups, the above results seem to support the general view that heavier birth weights are linked to better academic performance. In other words, whilst the Pearson’s correlation coefficients describing the relationships between birth weight and school performance (Bands) are weak, the negative trend suggests that the lower the birth weight the higher (or poorer) the Band. On the other hand, a quick comparison of AGAs and SGAs on educational outcomes, provided in table 4.1.14, yielded results that were not significant.

Table 4.1.14 Differences between AGAs and SGAs in their educational outcomes

<table>
<thead>
<tr>
<th>Educational Outcomes</th>
<th>Mandarin</th>
<th>English</th>
<th>Mathematics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mann-Whitney U</td>
<td>1309</td>
<td>1116</td>
<td>1172.5</td>
</tr>
<tr>
<td>Z</td>
<td>-0.211</td>
<td>-1.503</td>
<td>-1.117</td>
</tr>
<tr>
<td>Asym.Sig. (2 tailed)</td>
<td>0.833</td>
<td>0.133</td>
<td>0.264</td>
</tr>
</tbody>
</table>

* significant at 0.05 level (2-tailed)  ** significant at 0.01 level (2-tailed)

4.1.2 Profile of difficulties and needs

Of the problems that have been identified in the course of follow-up (Table 4.1.15), a myriad of behaviour problems were more commonly noted. Other areas of concern, for example, learning problems could possibly surface later
on as the children are subjected to formal schooling. These may have been deemed more manageable or negligible in the early stages of development and hence under reported by the parents or not detected by the team. Table 4.1.16 gives a fuller picture of the children’s needs and difficulties in terms of the types of intervention they were to receive.

Table 4.1.15 Percentages of types of problems noted by the follow-up team

<table>
<thead>
<tr>
<th>Types of problems and impairments</th>
<th>Learning &amp; language</th>
<th>Motor &amp; family &amp; social</th>
<th>Behaviour/emotional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recorded (%)</td>
<td>14%</td>
<td>21%</td>
<td>23%</td>
</tr>
</tbody>
</table>

By the time of follow-up at age eight, the nature of problems would be more clearly defined, for example, ‘learning problems’ are further categorised into *Dyslexia*, and therefore a referral to a specialist organisation such as the Dyslexia Association of Singapore, or *Dysgraphia* which warrants a referral to the Occupational Therapist. More than a quarter received the recommendations of “Paediatrician to monitor” at the eight-year-old visit.

Table 4.1.16 Percentages of needs in terms of intervention services and recommendations noted by the follow-up team

<table>
<thead>
<tr>
<th>Types of intervention/recommendations</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Liaison with school</td>
<td>14 %</td>
</tr>
<tr>
<td>Learning support</td>
<td>23.4 %</td>
</tr>
<tr>
<td>Specialists/ specialist organisations</td>
<td>33.6 %</td>
</tr>
<tr>
<td>Speech &amp; language therapy</td>
<td>15 %</td>
</tr>
<tr>
<td>Physio- and/or Occupational therapy</td>
<td>15.9 %</td>
</tr>
<tr>
<td>Session with the Psychologist</td>
<td>20.6 %</td>
</tr>
<tr>
<td>Paediatrician to monitor</td>
<td>27.1 %</td>
</tr>
</tbody>
</table>
Despite a good proportion of "Well/normal" diagnoses at eight years old, the figures show that more than a quarter of the children in the sample have specific difficulties (Figure 8). Fourteen of these children were discharged in spite of being thus diagnosed at the eight year old appointment. Selected examples of these will be given in the next chapter.

**Figure 8**  Pie chart showing proportion (percentages) of types of diagnoses at the eight year old assessment

*Abbreviations used:*
- 'Lang pbms' = language problems
- 'Beh/emo. pbms' = behaviour emotional problems
- 'pbms' = problems

<table>
<thead>
<tr>
<th>Diagnosis Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motor problems</td>
<td>3.7%</td>
</tr>
<tr>
<td>Speech/lang pbms</td>
<td>3.7%</td>
</tr>
<tr>
<td>Beh/emo. pbms</td>
<td>6.5%</td>
</tr>
<tr>
<td>Learning pbms</td>
<td>17.8%</td>
</tr>
<tr>
<td>Attention pbms</td>
<td>.9%</td>
</tr>
<tr>
<td>Autism</td>
<td>1.9%</td>
</tr>
<tr>
<td>Well/normal</td>
<td>64.5%</td>
</tr>
</tbody>
</table>
4.2 Summary of quantitative findings

The overall findings from the sample suggest that this group of VLBW children are faring well in their educational achievements especially in Mandarin and Mathematics. An in-depth investigation shows that there is bias in the sample with most of the children being stronger in Mandarin to begin with. The proportion of teacher complaints turned out to be more informative on how these children may not be performing as well as they appeared to be. Intellectually, the sample showed overall average performance on cognitive tests. However, as a control group as well as standardised local norms were absent, one could not be certain that the scores, although average, were not lower than those of a normal birth weight group. Further investigations into outcomes revealed significantly positive relationships of varying degrees between birth weight and the test measures at ages five and eight years. Similarly, there were positive relationships among the Bayley, Stanford-Binet and Wechsler Scales. Differentiating the ELBW group from the larger VLBW group revealed greater disadvantages in the former group cognitively but not educationally. Whilst not significant, the trend of the results suggests school performance in terms of Bands is inversely proportional to birth weight in the context of this study.

It would be of interest for the reader to note that a scrutiny of the children discharged at eight years old showed fourteen of them to be diagnosed as having some difficulties, that is, not “well/normal”. Again, the proportions of problems, recommendations of intervention and types of diagnoses bear stronger testimonies to the fact that there is more than meets the eye in the quantitative findings. Perhaps this is where the value of qualitative results can be seen.
Chapter Five
QUALITATIVE FINDINGS

5.1 The case study reports

As seen from the preceding chapter, a variety of specific difficulties beset VLBW children in mainstream schools. Bearing in mind that these categories are not necessary mutually exclusive, the case study reports of six selected VLBWs with different difficulties presented in this chapter focus on the primary problem. The seventh case serves as a means of comparison and perhaps, provides some encouragement that the picture may not always be as bleak! The case study reports therefore aim to firstly, put flesh on the preceding survey; secondly, to identify salient factors in the process of VLBW follow up and thirdly, to highlight the plight of some of the children in their difficulties. It is important to have these in mind as one goes through the portraiture of each child via the following case study reports.

Each case study report commences with a description of the child’s neonatal history and family background. Details of each assessment by the Psychologist, either carried out on ‘scheduled’ appointments i.e. at two years, five years and eight years old or ‘unscheduled’ ones, for example at three years old or after the eight-year-old supposedly ‘final’ assessment are then given. The common thread that runs through the case study reports is the process of follow-up and this ends with a summary of the outcomes.

5.1.1 A VLBW child with Dyslexia/Specific Learning Difficulties

Eddie (not his real name) was born via normal vaginal delivery with a very low birth weight of 1250g at 32 weeks gestation and hence his being
classified as 'small for gestational age' (SGA). He had intraventricular haemorrhage (IVH) or bleeding into the ventricles of his brain and bronchopulmonary dysplasia (BPD), a form of chronic lung disease. He had difficulty breathing independently and was intubated for a fortnight. Following discharge as an inpatient, he was on oxygen therapy for a week. Eddie's parents were educated up to 'O' level and ran a small family business. He has a brother who is a year older and said to be doing fine at school. Throughout the course of follow-up, his parents did not think that they treated him any differently from their older son who was born full term. However, they admitted that they often saw him as the weaker child as he has asthma and occasional bronchitis. He was also physically much smaller when compared with his brother at the same age. Moreover, his grandmother who was the main caregiver tended to dote on him which meant that he lacked the opportunities to acquire some of the developmental skills appropriate for his age. Eddie's parents were willing to attend all appointments on the programme as they saw it as a precautionary measure instead of a process of follow-up where further investigations could be necessary.

The Bayley Scales of Infant Development (BSID-II) (Bayley, 1993), an instrument that assesses the development of infants was administered when two-year-old Eddie came for his first assessment. He was noted to be shy of strangers and took a while to warm up to the test situation. His development, especially in the area of expressive language was found to be mildly delayed. He was relatively quiet during the session and was heard to use a few single words accompanied by simple gestures to communicate his needs. His articulation was noted to be immature. The paediatrician who saw him after the psychological assessment diagnosed him as having speech delay. She felt that this was due to the
lack of stimulation at home. For example, Eddie's needs were often being met without his having to indicate them. He was referred to the Rehabilitation Department for Speech & Language Therapy. His mother was given advice on managing him at home especially in giving him more opportunities to acquire and use language. She was also advised to wean him off the pacifier he was using as soon as possible. Another psychological assessment in a year's time was not deemed necessary and an appointment was made for his fifth birthday.

The test used for all five-year-old VLBWs was the Stanford Binet Intelligence Scale (Fourth Edition) (SBIS) (Thorndike et al., 1986). The four areas of verbal reasoning, quantitative reasoning, abstract/visual reasoning and short-term memory were assessed. Eddie's test behaviour was described by the psychologist as "fairly quiet...took some time before he was sufficiently at ease to spontaneously respond verbally." He obtained an IQ of 101 that placed him in the Average range. Despite this, his verbal reasoning ability and verbal expression was found to be below expectations for his age. The Vineland Adaptive Behaviour Scales (VABS) by Sparrow et al. (1984), a measure of adaptive functioning was also administered in this case. This is composed of four 'domains': communication, daily living, socialisation and motor function, all evaluated via an interview form. On this, Eddie's communicative skills were reported to be marginally 'Adequate' and his motor skills, particularly the fine motor ones, 'Moderately Low'. His mother reported that he was unable to draw recognisable figures or use a pair of scissors to cut complex shapes. Based on these findings, the Paediatrician referred him for Occupational Therapy at the Department of Rehabilitation. His verbal needs were however, not addressed as these fell within the Average (on SBIS) or Adequate (on VABS) classifications. He was also said to
be coping with the first year (K1) of normal kindergarten curriculum and there were no complaints from his teachers at that point.

Eddie came for his eight year old assessment accompanied by his mother who was tired and depressed. Eddie has been failing all subjects at primary school despite her efforts and those of a private tutor to coach him in his school work. He looked subdued as his mother complained about him. She said he was being "lazy" and "stubborn" and he would "day dream" whenever he was told to do his homework. He preferred to play with his neighbours' children anytime. She added that his mainstream school teachers have been complaining about him and recently labelled him as "a passive and slow learner". During the assessment which was conducted in Mandarin, a language Eddie was more comfortable with, he was observed to be nervous but compliant. His mother had to leave the room during testing as she was highly stressed. Eddie, on the other hand, showed an eagerness to continue with the tasks after he had warmed up. At a chronological age of eight years old, Eddie achieved an overall Average IQ score of 102 on the Wechsler Intelligence Scale for Children - Third Edition. (WISC-III) (Wechsler, 1991). Classified as ‘High Average’ (Performance IQ = 113), his performance or non-verbal ability was stronger than his verbal skills which was Average (Verbal IQ = 92). Overall, his profile was fairly even between and within each scale. During the session, he was observed to be relatively weak on tasks that required him to describe a word or relate an event in a sequence, for example, on the WISC-III's vocabulary sub-test that required word definition. A quick informal assessment on basic spelling and reading in English found him to have some difficulty in deciphering sounds as he attempted to read and spell. As the results were discussed with Eddie's mother, she repeatedly questioned, "Why is he failing
in all his subjects if he isn't stupid (meaning that he has an overall average IQ)? He must be lazy!" With the agreement of the paediatrician who counselled the mother in her understanding and management of Eddie's problems, an additional session was organised to investigate his learning needs further. Based on the discrepancy between his cognitive ability, achievement and school performance, the hypothesis was that Eddie had dyslexia or specific learning difficulties.

In addition to the observation of Eddie's handwriting skills, two scales of the British Ability Scales (BAS) (Elliot, C.D, 1992) namely, Spelling and Word Reading, were administered in English. Both areas were found to be below the level expected of his age. His spelling age was 6 years 9 months and his reading age 6 years 4 months. He struggled with phonological strategies and made little attempt in applying phonics. His knowledge of initial consonants and rhymes were weak. Notwithstanding his poor spelling, his letter formation as he wrote out the letters of the alphabet was haphazard and disorganised. He failed to leave a space between words when he was asked to copy a sentence. Given this situation, Eddie's attention to the tasks was observed to deteriorate rapidly and he became stressed and fidgety. Correspondingly, his eye contact with the Examiner decreased.

Despite a normal Full Scale IQ, not all was well. Eddie was eventually diagnosed as having dyslexia. However, this was not the only concern as he was also suspected to have dysgraphia, defined as "retarded development or an acquired loss in the skill of writing" (O'Hare & Brown, 1989a, page 80). The plan of management thus included further liaison with and investigations by the occupational therapist (OT). It was deemed necessary that Eddie's school be informed of the findings with the consent of his mother. A referral to the Dyslexia...
Association of Singapore (DAS) was made. Six months later, the case manager received word that Eddie was in receipt of remedial help in his primary school and was placed on the waiting list of the DAS programme. This was subject to a review to see if he had a sufficient command of English in order to benefit from the Association's programme.

5.1.2 A VLBW child with an Autistic Spectrum Disorder

Jennifer (not her real name) was born at 30 weeks gestation with a very low birth weight of 1050g following an emergency caesarean section. She was classified as 'small for gestational age'. She was hospitalised for more than two months and spent most of her stay in special care. Her neonatal history included retinopathy of prematurity (ROP) and neonatal jaundice. Her parents are 'A' level holders who both work. She has an older brother who is doing his 'O' levels. The family could be described as middle class and closely knit with Jennifer as the 'baby' of the family. Jennifer has been followed up as an outpatient at the hospital since she was two years old. Her parents have been faithful in their attendance with the appointments. The initial cause of concern was poor feeding and delayed gross motor skills in her toddler years.

On the Bayley Scales of Infant Development (Bayley, 1993), tiny two year old Jennifer showed a normal but "marginally adequate" mental development index (MDI). Whilst weakness in her motor skills were observed, this was attributed largely to her having been born with an almost extremely low birth weight (< 1000 grams) hence as it were, more physical growth to 'catch up' with. The psychologist who assessed her at that time also reported some echolalia of words and poor articulation. This was in spite of her ability to speak two to three
word sentences. She was able to name objects but did not like naming pictures. Her behaviour was described by the psychologist as "active and restless with poor attention". After the psychological assessment, the paediatrician who examined her felt that the main concern remained her motor skills and referred her on for physiotherapy with the hospital's Rehabilitation Department. Her parents defaulted the appointment as they wanted to give their daughter more time. However, sensing that not all was well with her development, they contacted the hospital for a 'non-scheduled' appointment with the psychologist the following year.

On this second occasion, the Stanford Binet Intelligence Scale (Fourth Edition) (SBIS) was administered. At age three, Jennifer scored in the Average range for skills. Scrutiny of her results however, showed that her IQ score was a partial test composite or IQ based on three domains instead of four. The domain of verbal reasoning had been omitted. The reason was that "she refused to participate in all tasks that required verbal responses." Jennifer's behaviour at that time was also described as "shy, uncooperative and clingy". With the hypothesis that Jennifer's parents were being overprotective, they were advised by the paediatrician to provide more exposure and opportunities for greater independence. Based on her overall normal IQ, she was described as "developing normally" by the paediatrician. The next review was to be when Jennifer had turned five years old.

Jennifer presented as a pale thin girl when she came for her five-year-old assessment. Her mother described her as an impatient and active girl who regularly spoilt the toys she played with. She took some time before rapport could be established and worked quietly on the tasks. Although her IQ as assessed on SBIS-IV was Average, some concern was raised over her difficulty in using factual knowledge and relating this to general life experiences. Her adaptive behaviour as
assessed on the Vineland Adaptive Behaviour Scales (VABS) found her to be approximately a year delayed in socialisation skills albeit with overall Adequate adaptive behaviour. Jennifer's mother was concerned about her behaviour especially in relation to her interaction with peers in kindergarten. Advice was given to increase opportunity for social interaction as well as independence. The paediatrician found her to be "well" upon examination and requested that the next appointment be arranged for Jennifer's eighth birthday. The supposedly final session turned out to be a session beyond one's expectations.

Eight-year-old Jennifer came in her leotard. When commented on how pretty she looked, she looked away and moved closer to her mother. She appeared unsure of herself when she was interacting with the psychologist on an informal basis. She tended to avoid eye contact even though she answered politely with single words and short phrases. The conversation was unidirectional. Jennifer became more comfortable when it came to doing tasks. She was compliant with the instructions. On the WISC-III which was administered in Mandarin, she achieved a verbal IQ of 93 that placed her verbal skills within the Average classification. Her Performance or non-verbal IQ score was classified as High Average (Performance IQ= 115). Her Full Scale IQ fell within the Average classification (FSIQ = 104). Notwithstanding her normal scaled scores, her profile was uneven with weakness in areas that measured social knowledge and judgement. Throughout the testing, she was observed to avoid eye contact especially when she was looked at. She was also literal in her understanding of instructions and questions, for example, she stopped exactly where the psychologist's finger pointed when she was giving the instructions for Coding tasks. Interestingly, she gave a typical literal answer "bleed" to the question, "What
is the thing to do when you cut your finger?" on Comprehension. She was meticulous and took her time in ensuring that the picture cards on Picture Arrangement were neatly aligned at their corners. Her low score on this sub-test could in part be explained by the loss of time and hence credit. However, it is important to note that like her low score on Comprehension, this may have been suggestive of some impairment in her social judgment and anticipation of consequences.

During the session, there was something about Jennifer that could not be neatly explained based on her WISC-III test performance alone. It could be said of her that she was "too compliant to be true". She was observed to follow instructions in a literal manner on a number of occasions. Her non-verbal behaviour was observed to be unusual for her age and family background. It was her mother's parting sentence, "I wish she wasn't so hard to please" that caught the researcher's attention after her feedback of Jennifer's performance on her supposedly final eight year old psychological assessment. Her mother was asked to elaborate on what she said. She reported behaviour that was atypical of a child her age. For instance, she would insist on taking the same route to school. Entry to school had to be by the same gate. She was often literal in her understanding of her teachers' instructions such as "take four pencils to school" meant exactly four, five would not do. She also had the unusual habit of lining stationery up in a long row and would get upset when these were out of line.

Socially, Jennifer was reported to be very quiet at school and lacked the initiative to start a conversation or to make friends. She was unable to participate in project work that involved group discussion. She was a loner during recess time. Her classmates at dance classes noticed that she was different and
have refused to be her partner when this was required for the dance. Whilst her teachers did not have complaints about her academic performance as she was coping with the help of a private tutor, they commented that she was a loner who did not have any friends at school. Although Jennifer was discharged from follow-up by the paediatrician at this appointment, a separate session was arranged in order to investigate her social difficulties using a new diagnostic tool for autism, the Diagnostic Interview for Social and Communication Disorders (DISCO) (Wing, 1999). Her parents consented and were requested to come without Jennifer. The objectives of the DISCO include:

"1. Systematic collection of information needed to compile a clinical history and a description of the present clinical picture, including level of development in everyday skills and the pattern of behaviour. The findings can be used as the basis of a narrative clinical report. 2. Clinical diagnosis of autistic spectrum disorders and other disorders of development affecting social interaction and communication." (page 2).

The schedule consists of eight parts with the first part being a record of factual information for example, family and medical. This is followed by six parts concerning the personal history and present behaviour of the individual in the areas of infancy, developmental skills, repetitive, stereotyped activities, emotions, maladaptive behaviour and quality of social interaction. The eighth and last part investigates psychiatric conditions and forensic problems.

The semi-structured interview and discussion with Jennifer's parents took more than four hours. It was as if one was catching up with lost time and information over the last six years of follow-up. Jennifer was reported to have an
unusual infancy with the absence of behaviours typical of babies in that there was no reciprocation in baby games or pre-speech conversation. She missed the crawling stage when she was learning to walk and was delayed in acquiring age-appropriate self-help skills. Basic activities such as eating and toileting when she was outside her home were a big problem for her mother. Jennifer was insistent on eating the same type of food, usually crispy fried chicken wings and refused to go to the toilet other than the one at home. During a recent holiday overseas, the family had to take with them an "agreed potty" from the toilet at home to minimise the tension. Her communication skills were described as both delayed and disordered. When she was a younger child, she used her mother's hand as a tool to do or take something. She would hardly initiate a conversation and was very passive especially in the company of people other than members of her family. She does not have any friends at school and actively avoids interacting with her peers. Jennifer was eventually found to exhibit the triad of impairments, that is, impaired in social communication, interaction and imagination that placed her on the autistic spectrum. Whilst her mother felt relieved that there was an explanation for her behaviour, her father expressed doubt that there was something amiss apart from her being of a quiet and passive disposition. He turned down a further referral to the Autism Resource Centre for services which would have involved a specialist teacher helping children like Jennifer cope with mainstream primary school life. Her parents also requested that this new found information be kept from her teachers but accepted information on where to seek help should they require it.

Jennifer's normal IQs over the period of follow-up did little to highlight her hidden difficulties. No further plans were made for follow-up.
concerning these difficulties as she had been discharged from the VLBW follow-up programme.

5.1.3 A VLBW child with Attention Deficit Hyperactivity Disorder

Terence (not his real name) was born with a very low birth weight of 1095 grams at 28 weeks gestation. He was considered appropriate in weight for his gestational age (AGA). Despite his prematurity, his neonatal history was fairly uneventful. He was kept under observation in the Special Baby Care unit and was discharged within a week. He had bronchitis in the first year of life and was hospitalised for a week. His parents were educated up to Primary School level. His father works as a clerk and his mother is a housewife. She is the main caregiver to him and his younger sister. She also coaches them in their school work as they could not afford to engage a private tutor. During the period of follow-up, his parents have always accepted Terence's overactivity as the liveliness of a young boy. They became worried only when he was underachieving at school. They were also finding it increasingly difficult to cope with the complaints of his teachers. Their report of him was constantly along the lines of "Distractible child", "Needs to pay more attention", "Can do better".

At two years old, Terence presented as a friendly and happy child who separated easily from his parents during the assessment. Whilst he was cooperative, persistent and responsive, he was described by the psychologist as "very active physically but could be coaxed to sit for tasks". He spoke single words with emerging two-word phrases. His performance on the Bayley was within the normal limits. This finding and normal outcome from the medical examination led the paediatrician to report that he was "well" at that age. The next assessment was to be carried out at five years old.
On the Stanford Binet Intelligence Scale, Terence achieved an IQ of 117 which placed him within the High Average classification. His performance on all four areas of verbal reasoning, abstract/visual reasoning, quantitative reasoning and short-term memory was fairly even. His adaptive functioning as assessed on the Vineland Adaptive Behaviour Scales was reportedly adequate. The psychologist who assessed him on that occasion did not find him unusually active or distractible. There were however, complaints from his kindergarten teachers that he was 'on the active side'. He was nevertheless able to sit still in class upon demand. The paediatrician noted the findings of the psychologist and gave his parents the option of contacting the Unit for an appointment before his eight-year-old assessment should his attention problems at school persist. This offer was not taken up. When Terence next came to the Unit, he was already eight years old.

Terence's session at eight years old found him to be a different boy from previous sessions. He was very restless and was, for example, rocking in the chair and falling off it at one point. He was also impulsive and in need of firmness from the psychologist to obtain his co-operation on the WISC-III tasks that was administered in English at Terence's request. He achieved an overall IQ of 93 that placed him within the Average classification. Despite average Verbal (VIQ = 95) and Performance IQ (PIQ = 90) scores, his scaled scores among the sub-tests varied considerably. He was stronger in the areas that required verbal reasoning and expression. His weakness was in areas that required organisation in one's approach to tasks. He was impulsive in his approach and showed poor planning with few strategies.
The paediatrician suspected that Terence had Attention Deficit Hyperactivity Disorder (ADHD). She requested further investigations in order to embark on a plan of management. In addition to another appointment with the psychologist, the nurse ensured that his parents were given the Conners Parent Rating Scale - Revised (Long Version) and sent a copy of the Conners Teacher Rating Scale - Revised (Long Version) to his class teacher. The next session with the psychologist comprised an in-depth interview with Terence's parents. The Conners Parent and Teacher Rating Scales had been completed and returned. The psychologist was also able to contact Terence's teacher via phone before the session. Terence's parents provided scanty information on their son's developmental progress from birth to present. Interestingly, his father disclosed that he himself was a hyperactive child who could not sit still at school. His mother was passive during the interview. She was quick to say, however, that there were no family problems and that she was satisfied with her style of parenting when these areas were explored. Terence's attention problems appeared to be worse at school. The information provided by his teachers was found to be more helpful in the process of diagnosis. Terence's teacher, for example, reported that he had difficulty concentrating in class for more than a quarter of an hour and that he would go around the class disturbing the other children. He was impulsive and had little self-restraint. Whenever 'on-seat' behaviour was enforced, he would be fidgety and restless on his chair. He was also disorganised in his work and would hand in his homework without completing it. He had the tendency to put his hand up in class even when he did not know the answer to the question. He fared poorly at school having obtained a Band 4 for Mandarin, a Band 3 for English and a Band 4 for Mathematics.
The profiles of the Conners Parent and Teacher Rating Scales showed some pattern consistency between them. However, his teacher's report showed greater peaks which indicated that Terence had a clinically significant condition of Attention Deficit Hyperactivity Disorder (ADHD). The paediatrician agreed that ADHD best described his problems. However, she was undecided whether he should be given medication as his parents refused, fearing that he would be reduced to a "zombie" despite an explanation of the purpose of the medication. She decided to refer him to the occupational therapist for attention training before considering medication. As medication was an option, Terence was not discharged from follow-up at his eight-year-old assessment. The psychologist was asked to liaise with his class teacher on his progress at school and to explain that despite a normal IQ, not all was well with Terence.

5.1.4 An ELBW child with Dyspraxia

Born with a birth weight of only 673 grams, Alan (not his real name) was born small for his gestational age eleven weeks premature. His neonatal history was eventful. This included all three common neonatal problems surveyed in this study namely, retinopathy of prematurity (ROP), bronchopulmonary dysplasia (BPD) and intraventricular haemorrhage (IVH). He and his younger brother have as their main caregiver at home their maternal grandmother and a domestic help. His parents both work but his mother has been prioritising her work around his needs since his birth. Alan has been on regular follow-up with his mother consistently attending all the appointments in seeking to ensure that all was well with Alan given such a stormy start to his life.
Notwithstanding his initially cute presentation of a tiny, bespectacled toddler, Alan was fretful at the two-year-old psychological assessment on the Bayley Scales of Infant Development (BSID). His behaviour was likened to that of a baby with his mouthing and banging of objects in addition to gross and fine motor delay. He had just begun 'cruising’ along, that is, walking with support from, the furniture and displayed poor pincer prehension with his fingers. He was reported to be developmentally delayed but a score was not given as testing was abandoned after Alan refused to cooperate on most of the items. His speech and language skills were reportedly age appropriate and adequate. Physiotherapy and occupational therapy were recommended as well as a re-assessment by the psychologist in a year's time. The paediatrician agreed and added a request for a review of his motor skills by her within the year.

Alan returned for the non-scheduled appointment at three years old. This time, he was comfortable in adult company but depended on adult supervision to complete the tasks. His problem solving behaviour as noted by the psychologist was that he “gives up easily” and “prefers only easy ones”. His attention span was rated as a year delayed and this was most evident on tasks involving visual-motor and perceptual skills. His gross motor skills were not of concern at this point. He had also been discharged by the therapists as he was then deemed to be ‘functional’. The findings on this occasion suggested that whilst he was categorised as a ‘Slow Learner’, it was possible that his performance was depressed due to his test behaviour and his being “over-protected” by his mother. Meanwhile, enrolment in a playgroup was recommended by the paediatrician for more opportunities to develop his skills.
The five-year-old assessment found improvement in Alan’s behaviour especially his attention on tasks. There was the remnant of “giving up easily” with increasing complexity of tasks. Poor self-confidence was noted this time and this was especially evident on paper pencil tasks that required him to draw basic shapes. His pencil grasp was immature and his drawings poor. Again, little was said about his gross motor skills except that he could not hop on one foot even with support. On the Stanford-Binet Intelligence Scale, Alan was found to have a test composite of 80 that placed him within the Low Average classification of ability. An analysis of his profile found him to have, among other deficits in terms of output “a general lack of ability to generalise knowledge that he has acquired” and “a weakness in general problem solving”. Possibly due to his having just started kindergarten (K1), it seemed difficult to arrive at a diagnosis or specify what exactly the problem was. Alan’s mother was noted to comment that he was a slow child. The engagement of a private tutor was part of her plans to help him make progress as academic demands increased but this did not materialise. An option was given to his mother to ring for an appointment with the paediatrician should Alan’s difficulties persist. For some unknown reason however, the next assessment was held only three years later.

Alan’s final eight-year-old session with the psychologist was one that was filled with disappointments for his mother. On the Wechsler Intelligence Scale for Children (Third Edition) (WISC-III) that was administered in English, he obtained an overall Full Scale IQ of 78, which placed him within the Borderline classification. His Verbal IQ was 90, an Average score and his Performance IQ was 70 which fell within the Borderline group. The significant discrepancy between his Verbal and Performance scores meant that his Full Scale IQ was not
representative of his overall intellectual functioning. However, a composite score was required for medical documentation. The psychologist contend that to take his normal verbal IQ alone and discharge him on that basis was insufficient. Moreover, the difficulties he presented with were likely to have impacted upon his school performance since he had difficulty with paper and pencil tasks. Another scrutiny of his scores was deemed urgent and the details forwarded to the paediatrician for her consultation session.

The unevenness of Alan's profile implied that certain areas of functioning were fairly intact, for example in social knowledge, understanding and judgement as assessed on the Comprehension sub-test of the WISC-III. His strengths reflected by his verbal IQ also meant that he could cope with certain academic tasks such as those which required oral expression. Areas of verbal skills which involved written language posed a problem. Translated into academic terms, Alan managed a Band 3 on English and failed Mandarin and Mathematics (Band 4), subjects which required a greater proportion of paper and pencil skills. During this session, his handwriting was found scarcely legible and his mother reported that this drew the most complaints from his teachers. He was also said to be very clumsy and had difficulties with Physical Education (PE). At eight years of age, he was still unable to catch a ball thrown towards him or negotiate corners when he ran. The agility seen in his peers was markedly absent in him and he was sometimes laughed at as a result of his poor motor coordination.

Fortunately, Alan was not discharged at the eight-year old assessment. In spite of his normal verbal IQ, the paediatrician agreed for further investigations to be carried out. The investigations involved the services of the occupational therapist in the Department of Rehabilitation, and an additional
session with the paediatrician to be set at a later date. The occupational therapist found him to have poor visual motor integration. Alan had a lot of difficulty with tasks involving motor planning and co-ordination, a condition now better known as dyspraxia. Portwood (1996, page 15) defined dyspraxia as “motor difficulties caused by perceptual problems, especially visual-motor and kinaesthetic-motor difficulties”. Mckinlay (1998) stated that, “Dyspraxia is a delay or disorder of the planning and/or execution of complex movements. It may be developmental – part of the child’s make-up – or it can be acquired at any stage of life as a result or brain illness or injury” (page 9). Boon (2001) ingeniously asked her colleagues working with dyspraxic children for their definitions and found differing perspectives among physiotherapists, occupational therapists, speech and language therapists and teachers! Assimilating their definitions, Boon provides a list of terms that have been used over the years to describe the condition now termed as ‘developmental dyspraxia’ (page 10):

**Table 5.1 A list of terms used over the years to describe Dyspraxia**

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clumsy child syndrome</td>
<td>Minimal motor dysfunction</td>
</tr>
<tr>
<td>Developmental agnosia and apraxia</td>
<td>Motor learning difficulties</td>
</tr>
<tr>
<td>Developmental co-ordination disorder (DCD)</td>
<td>Perceptual/perceptuo-motor dysfunction</td>
</tr>
<tr>
<td>Learning difficulties/disabilities/disorders</td>
<td>Neurodevelopmental dysfunction</td>
</tr>
<tr>
<td>Minimal cerebral palsy</td>
<td>Physical awkwardness</td>
</tr>
<tr>
<td>Minimal cerebral dysfunction</td>
<td>Specific learning difficulties</td>
</tr>
<tr>
<td>Minimal brain dysfunction</td>
<td>Sensori-motor dysfunction</td>
</tr>
</tbody>
</table>

Boon also commented on how the number of descriptions has been too large and broad, some too vague or inaccurate such as minimal cerebral palsy. Moreover, she pointed out that some are now used to describe quite different areas of difficulty, for instance, ‘specific learning difficulties’ is a term now usually taken to mean ‘dyslexia’ or ‘dyscalculia’.
With hindsight, perhaps Alan's behaviour would have been better described as dyspraxic. A diagnosis would have meant the regular provision of occupational therapy until his discharge into the hands of the learning support teacher at school. It took six years of follow-up before one came to understand this child's difficulties and to finally say, despite normal Verbal IQ and a Full Scale IQ of more than 70, "not all is well”.

5.1.5 An ELBW child with behavioural & emotional problems

Marcus (not his real name) was the pride and joy of his parents when he survived his unexpected birth with an extremely low birth weight of 889 grams after a gestation period of 28 weeks. He was small for his gestational age. In spite of the rather precarious position he was in, he had relatively fewer common neonatal problems compared to those who were heavier at birth. Notwithstanding this, his pattern of development has been a cause for concern over the years of follow-up. The family was a typical Mandarin speaking family in Singapore. They were financially comfortable and he had his mother as his main caregiver in the early years. He also enjoyed the company of his older brother at home. A change in family circumstances, with his father being dismissed from his job, his mother returning to work and his brother going to school provides the back drop to this case study of an ELBW child with emotional and behavioural difficulties.

Both his parents came for his two year assessment during which he presented as an active child who could not "follow instructions very well". The psychologist attributed his poor performance to the overprotection of his parents who readily anticipated his needs. To the disappointment of his parents, his performance was assessed to be ‘Significantly Delayed’. Placement in a Child
Care or Playgroup setting was recommended for more opportunity to acquire the skills expected of children his age. Not wanting to miss other possible difficulties, another appointment was given for a re-assessment by the Psychologist a year later. At a non-scheduled visit to the hospital when he was three years old, Marcus was found to be functioning within the Low Average classification with weakness in oral vocabulary on the Stanford-Binet Intelligence Scale (SBIS). He struggled in naming some of the pictures or in giving an explanation for them and tended to shrug his shoulders with “don’t know” responses. His presenting weakness at that point appeared to be a lack of exposure or opportunity to acquire the kind of vocabulary expected of his age. The possibility of weakness in English as a second language could not be ruled out as he was from a predominantly Mandarin speaking background and the psychologist who assessed him at that time was non-Mandarin speaking. The paediatrician arranged for a half-yearly follow-up with him prior to the next scheduled assessment by a psychologist at five years old. Speech and language therapy was deemed unnecessary at this point of time as his weakness in oral vocabulary seemed to be linked to environmental factors largely explained by the issue of English as a second language and the lack of opportunity to acquire language and use that he already has. His parents were advised to provide a more linguistically stimulating environment for him. Subsequent follow-up sessions with the paediatrician found improvement in his speech and language skills but deterioration in his family circumstances. Citing financial constraints, his mother requested to return for only the psychologist’s appointment at five years old.

Marcus came with his mother a fortnight after his fifth birthday looking withdrawn but sulky. His mother explained that she had refused to buy
him a toy he wanted on their way to the hospital. She added that she was too stressed to explain to him why and had scolded him on the shuttle bus. In spite of age appropriate attention, Marcus took a while to cooperate on the Stanford-Binet Intelligence Scale. During the assessment, Marcus was occasionally tearful and displayed a deliberate refusal to look at his mother who was sitting behind the examiner (opposite him). He completed the assessment nevertheless and obtained an Average test composite or IQ of 94. His profile was fairly even and there were no clear difficulties as far as his ability was concerned. During feedback on his results, his mother disclosed that he was an aggressive child who constantly threw temper tantrums when he did not have his way. She likened his outbursts to an emotional rollercoaster. She revealed the financial hardships she and her husband were facing and said that she found it hard to explain to her children about the situation they were in, thinking they were too young to understand. Time did not permit further counselling but a referral was made to the medical social worker for this as well as financial assistance in follow-up. The paediatrician noted the results and endorsed the referral to the medical social worker. But due to time constraints again, little more was gleaned about Marcus’ emotional and behavioural problems. The next appointment was scheduled to be held at or after Marcus’ eighth birthday.

Eight year old Marcus was brought by his maternal aunt to the session. He presented as a handsome boy, a little small in size but looking as though he was ready for a fight. His demeanour was accompanied by some measure of silent defiance which the psychologist (the researcher) was uncomfortable with. This lessened after his aunt left the room and he warmed up to become interactive but outspoken even on the items of the Wechsler Intelligence Scale for Children (Third Edition) (WISC-III). On the WISC-III which was
administered in English, he obtained a Verbal IQ of 98, a Performance IQ of 112 and a Full Scale IQ of 105 which placed him within the Average classification. The latter indicated that he was better at solving nonverbal tasks via the manipulation of concrete materials or those that require nonverbal thinking than in expressing his ideas orally. Within the Performance Scale, Marcus' pattern of subtest scaled scores showed some variability. For example, the peak in his profile suggested excellent performance on a sub-test known as 'Coding' which measures sequential ability and psychomotor speed. He showed enthusiasm on this task transcribing written symbols at the speed and level beyond his age. During this task, he was observed to rely on his short-term visual memory, that is, he did not refer back to the 'key' throughout the tasks having memorised the pairs of symbols.

Although his Verbal IQ was well within the Average classification as portrayed by the individual sub-tests, some of his responses were unexpected. On Comprehension, for example, a sub-test that measures social judgment or knowledge of conventional standards of behaviour, a few of Marcus' answers were disconcerting. On "what is the thing to do if a boy (girl) much smaller than yourself starts to fight with you?", he aggressively responded along the lines of kicking, stabbing and letting him bleed to death! His verbal responses were accompanied by exaggerated gestures throughout.

Marcus was observed to resume his silent self when his aunt re-entered the room after the assessment. During the discussion, he appeared to be listening to the discussion which resulted in the adults moving to a corner of the room. His aunt reported that she was more worried about his behaviour than his poor academic performance comprising Band 4s in all three subjects, Mandarin, English and Maths. She revealed that the family situation had gone from bad to
worse with his father being unemployed and living away from home. His mother had returned to work and his older brother had the benefit of being able to go to a classmate's home after school. The family was reported to have adjusted to their new circumstances but not Marcus. In the midst of all this, he became a latch-key kid - often 'home alone' with little supervision. He would spend most of his time and savings at computer game arcades. This aunt tried to intervene initially but was unable to cope with his increasingly maladjusted behaviour. She believed that mixing with bad company at the arcades affected his behaviour. In addition, on nights when she had him staying with her, she found him sobbing quietly in bed on a few occasions. An interesting comment she made was, “I thought he was a fighter when he was born but not in this way”. His teacher reported daydreaming in class and aggression towards his classmates during recess time. He was in receipt of remedial help at school having been identified as an 'underachiever'. Marcus was not discharged in spite of his having fulfilled the criteria of the follow-up process. Intervention sessions with the psychologist were organised and the paediatrician was to continue monitoring his situation.

Marcus was evidently unable to cope with the many adverse events in his young life. This shows that being born with a very low birth weight may not be the main factor in a child's dysfunction. The changes in his family circumstances and its structure seemed to be important contributory factors to his difficulties. He was described as having emotional and behavioural problems at the point of his supposedly final assessment. Subsequent notes in the medical records showed that a referral to a community service for school-aged children, Student Care Services, had been made to ensure continuity of care after eventual discharge. Despite a normal IQ, not all was well with Marcus.
5.1.6 A VLBW child with speech and language difficulties

Anna (not her real name) was born with a very low birth weight of 1230 grams but was appropriate for her gestational age of 27 weeks. She had an uneventful neonatal history in spite of her prematurity and as far as her parents were concerned, she was just one of those infants who “couldn’t wait to get out to see the world”. They were equally pleased with her physical progress as she appeared to be catching up with her peers in height and size. Anna came from a low income, Mandarin speaking Singaporean family. Her parents were educated up to Primary school level. Her father worked as a welder and her mother was a housewife, looked after her and subsequently her younger brother at home. No concerns regarding her development were noted throughout her infant years, that is, prior to two years old. Her mother attended the follow-up assessments as a routine health check with little expectations that there would be problems.

When she was assessed at two years old, Anna presented as a sweet toddler who performed within normal limits on the Bayley Scales of Infant Development. Some concern was raised regarding the lack of a stimulating home environment for speech and language development. This was not, however, followed up by a referral for speech & language therapy at the time of this visit. The perception then was that Anna had little or no exposure to the English language and little opportunity to express herself in her Mother Tongue, Mandarin. The advice given at that point of time was enrolment in a playgroup through which Anna would develop more language by interacting with peers. Although she was concerned that there was some indication of weak language skills, her mother felt that she would grow out of it later on. The next appointment was scheduled to be carried out on or soon after her fifth birthday.
Anna’s presentation at five years old was recorded in the notes as a “pitiful sight”. She was a friendly child with excellent communicative intent but her verbalisation was garbled. It was difficult to understand what she was trying to say and her mother had to act as her interpreter. The Stanford-Binet Intelligence Scale was administered nevertheless. Anna was found to have a Test Composite of 73 which placed her within the Slow Learner classification of intelligence. Clinical observations by the psychologist suggested that this may not be truly representative of her overall functioning. Moreover, these supported her uneven profile in which there was a dip in her performance on the sub-tests measuring verbal reasoning skills. For example, whilst she was able to (non-verbally) point to different parts of a figure, for example, ‘thumb’, ‘chin’ etc., she had difficulty explaining why one would use umbrellas. Her mother reported that she would have known the answer but simply had difficulty “getting it out”. An expressive language delay label was used in this situation to describe Anna’s verbal difficulties. The paediatrician felt that the primary cause was the lack of stimulation within the home environment as well as bilingual issues in the sense that she had to cope with learning two languages at school even though she was struggling with just one. At the recommendation of the psychologist, she agreed to a referral to a speech and language therapist. Anna was already turning six and her next appointment with the psychologist was to be in two years’ time. During this period of time, her mother continued in her belief that Anna would grow out of her difficulties and did not approach the Unit for an earlier appointment. No tuition or help was deemed necessary and hence none arranged, in addition to her normal kindergarten education. Neither was there any mention of complaints by her teachers. This
could have been due to her presentation as a good, quiet child who followed instructions and coped with the curriculum reasonably well especially in Mandarin.

Anna’s eight year old appointment found her a quiet, bespectacled child with a mother who had become her spokeswoman. The test situation soon became a strain for everyone involved and her mother was requested to wait outside the room. Anna showed high anxiety after her mother had left the room. This was particularly evident on certain verbal items of the Wechsler Intelligence Scale for Children (Third Edition) (WISC-III). On this particular test administered in Mandarin, a language Anna was evidently comfortable with, she obtained a respectable Full Scale IQ of 106 that placed her within the Average classification. She achieved an Average Verbal IQ of 99 and a Performance IQ of 113, which is within the Above Average range. On the whole, she performed better when solving nonverbal items via the manipulation of concrete materials than when expressing herself orally and solving verbal problems. The variability in her verbal profile was too uneven to be ignored. The following excerpt from the Psychologist/researcher’s report explains the profile:

"Anna's Verbal subtest profile suggests that she performs better on tests that require minimal amount of verbal output, that is, less expressive language. Her eye contact with examiner was observed to become transient when she had to verbalise her responses more comprehensively......Anna could describe the common attributes of two objects on Similarities tasks. This subtest taps abstract reasoning reflected in the ability to form concepts and categorise them. Her performance on both this and the Comprehension subtest investigating social knowledge and understanding suggests average ability on auditory perception of simple verbal stimuli. These in turn required basic verbal responses e.g. single words or short phrases...Moreover, Anna performed better on those tasks
that demanded less verbal expression for success. She struggled on the *Vocabulary* tasks that involved considerable verbal expression. This subtest requires the definition of words. Whilst it is likely she did have the knowledge of some of the items she failed, Anna's difficulty in using the language she has to define words is believed to have affected her performance. In addition, she appeared to have some difficulty putting words together coherently on a few occasions...."

Although her Verbal IQ was within the Average range, Anna's profile meant difficulties with expressive language where narratives and elaboration were necessary. Her mother was ready to explain her daughter's difficulties as a second language issue, that is, she lacked practice in speaking English at home and this was acquired as a second language. However, Anna's mother began to realise that there could be a problem when it was explained to her that the WISC-III was conducted entirely in Mandarin. Clinical observations using picture sequencing revealed poor language structure and lack of coherence in storytelling as well as in relating her experiences. It also took an inordinate amount of time for her to answer open-ended questions such as "Tell me about your school?" An informal conversation may end up burdensome for her and she was noted to cope by short responses with increasing number of "I don't know" responses.

From the picture presented thus far, Anna continued to present with speech and language difficulties and would have benefited from regular therapy from the time she was two years old. As she was an older child, the heavy caseload at the hospital meant that she was not a priority. Her mother was asked to inform her teachers of her difficulties. The feedback prior to discharge was that she was
coping with academic work especially in Mandarin (Band 2) and her poorer performance (Band 3) in English and Mathematics (problem sums) was largely due to an English-as-second language problem. Unlike her neonatal history, Anna's later development has not been smooth sailing. The unevenness of her profile and her linguistic weakness do not convince one that her development was 'well' with a normal IQ. On the contrary, the findings indicate that not all was well with Anna.

5.1.7 A VLBW child who is “well”

Louise (not her real name) was born at 29 weeks gestation with a very low birth weight of 1330 grams via caesarean section. She was classified as 'appropriate for gestational age'. Her stay at the hospital lasted just over a month and she had a neonatal history that comprised 'only' retinopathy of prematurity. She comes from a middle class family and the main caregiver is her mother. Following her discharge from the ward and two years old onwards, Louise has been on follow-up at the Unit. The initial cause of concern in her toddler years was her being a fussy eater. This was subsequently resolved but her parents continued to attend as they saw the value of follow-up. Moreover, there is a history of intellectual deficiency in her mother's family and her parents wanted to be sure that she was developing 'normally'.

At two years old, Louise showed 'Accelerated Performance' in her Mental Development Index on the Bayley Scales. The paediatrician who examined her found no concerns especially as her feeding had improved. On the second assessment at five years old using the Stanford-Binet Intelligence Scale (Fourth Edition), Louise performed within the Average classification with an even profile. Her visual memory was described as good. Despite her normal scores, two
problems were reported by the psychologist who saw her at that point: sibling rivalry and obesity. Her mother reported that Louise felt inferior to her sister who was a year older and this problem was accentuated by the differences between her father and mother in their parenting styles. The former was said to be strict and the latter indulging. Her obesity could, in part, be explained by the lack of discipline within the home environment where she was able to help herself to snacks freely. Advice was given to the mother on the management of these problems without referrals to other services such as the dietician’s and the next psychological assessment was to be when Louise was eight years old.

It was an unexpected sight for the psychologist as eight-year-old Louise presented herself when her name was called out in the clinic. She appeared much bigger than her VLBW counterparts. She seemed embarrassed as she walked towards the assessment room. Throughout the session, she was relatively quiet, answering politely when spoken to but she did not initiate any conversation. Louise was comfortable with the WISC-III tasks. On the WISC-III which was administered in Mandarin, she achieved a verbal IQ of 100 that placed her verbal skills within the Average classification. Her Performance or non-verbal IQ score was also classified as Average (Performance IQ = 99). Her Full Scale IQ fell within the Average classification (FSIQ = 99). Notwithstanding her normal scaled scores, her profile showed some variation on tasks that measured nonverbal concept formation and problem solving approach. The weakness in the latter was described as “she tends to overlook details of the pattern but is able to correct herself when she realises her errors”. Her mother who was at the assessment interpreted this as carelessness but was not concerned. She was pleased that despite this tendency, she was able to score Band Is in all three subjects at school.
The paediatrician concluded that Louise was “well” but also added “obese”. She was discharged from the unit after her mother turned down a referral to the Dietician’s. She said that Louise was already in the ‘Tough Club programme’, a weight reduction programme at school and that she knew what she should be doing to lose some weight. Given her normal IQ scores, Louise was deemed “well” and “normal”. The question the reader might wish to pose here is, “was she really well and normal? ” given that the issue of obesity emerged in the course of one’s investigation.

5.2 Summary of qualitative findings

The case study reports presented sought to give the reader an insight into the process and realities of VLBW follow-up work as well as a better understanding of the children’s situation. Table 5.2 (page 111) summarises some of the salient points in the six case studies which reported difficulties and the seventh that was on a “well” child. Comparing the first six children with the case of Louise who seemed to have breezed through the follow-up the outcomes are sobering. It is of interest to note that at one point in this process, there was some concern with regards to areas such as feeding and this continued to the point of ‘obesity’. Yet this did not constitute a problem which leaves one to surmise that the absence of the type of difficulties that would have directly impacted on her educational performance and her average IQ scores led to the classification of “well”. This is but one possible reason why this particular VLBW has turned out well whilst her counterparts have not. A scrutiny of the data shows that some of them had more promising neonatal factors than her. Terence, for example, did not have any of the three listed common neonatal problems.
Table 5.2  An overview of the characteristics, outcomes and profile of the children depicted in the case studies

<table>
<thead>
<tr>
<th>Child Variables</th>
<th>Eddie</th>
<th>Jennifer</th>
<th>Terence</th>
<th>Alan</th>
<th>Marcus</th>
<th>Anna</th>
<th>Louise</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
<td>Male</td>
<td>Male</td>
<td>Female</td>
<td>Female</td>
</tr>
<tr>
<td>Birth weight classification</td>
<td>VLBW</td>
<td>VLBW</td>
<td>VLBW</td>
<td>ELBW</td>
<td>ELBW</td>
<td>VLBW</td>
<td>VLBW</td>
</tr>
<tr>
<td>Gestation age classification</td>
<td>SGA</td>
<td>SGA</td>
<td>AGA</td>
<td>SGA</td>
<td>SGA</td>
<td>AGA</td>
<td>AGA</td>
</tr>
<tr>
<td>School Bands Mandarin, Eng &amp; Maths</td>
<td>4, 4 &amp; 4</td>
<td>2, 3 &amp; 3</td>
<td>4, 3 &amp; 4</td>
<td>4 &amp; 4</td>
<td>4, 3 &amp; 3</td>
<td>1 &amp; 1</td>
<td></td>
</tr>
<tr>
<td>Two year old Assessment (BSID)</td>
<td>Mildly delayed performance</td>
<td>Within normal limits</td>
<td>Within normal limits</td>
<td>Not available</td>
<td>Significantly delayed performance</td>
<td>Within normal limits</td>
<td>Accelerated performance</td>
</tr>
<tr>
<td>Five year old Assessment (SBIS)</td>
<td>Average</td>
<td>Average</td>
<td>High Average</td>
<td>Low Average</td>
<td>Average</td>
<td>Low Average</td>
<td>Average</td>
</tr>
<tr>
<td>Eight yr old Assessment (Full Scale, Verbal and Performance IQs) (WISC-III)</td>
<td>FSIQ: Average</td>
<td>FSIQ: Average</td>
<td>FSIQ: Average</td>
<td>FSIQ: Low</td>
<td>FSIQ: Average</td>
<td>FSIQ: Average</td>
<td>FSIQ: Average</td>
</tr>
<tr>
<td>Related problem(s) identified prior to final appointment</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Diagnosis at eight years old</td>
<td>Specific Learning Difficulties</td>
<td>Autistic Spectrum Disorder</td>
<td>Attention Deficit Hyperactivity Disorder</td>
<td>Developmental Dyspraxia</td>
<td>Behavioural and emotional difficulties</td>
<td>Speech and language problems</td>
<td>Well</td>
</tr>
<tr>
<td>Discharged at eight year old appointment</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

The variables and their interaction considered here are in many ways inadequate in giving a comprehensive picture of a VLBW child. Suffice to say at this point, however, that what has been unearthed should serve to strengthen the call for change to the follow-up process of the Very Low Birth Weight children in Singapore.
Despite variances in the nature of studies on school aged VLBW children, findings in the literature (e.g. Aylward et al., 1989, Ornstein et al., 1991, The Scottish Low Birthweight Study group, 1992) seem to converge on the increased risk of problems in school performance, cognitive functioning, motor skills and behaviour. The presence of subtle or hidden impairments has been gradually gaining more attention (e.g. Zubrick et al., 1988, Pharaoh et al., 1994a and Hack et al., 1996). The findings of this study corroborate with the literature. The sample of 107 Singaporean Chinese VLBW children have been found to be overall at risk for difficulties in the areas investigated. The portraiture of the difficulties experienced by a sub-group of the sample illustrates the reality of the local situation. Notwithstanding the consensus of findings particularly in relation to European and North American studies, there exist a number of factors at play that are uniquely Singaporean. These add a local nuance to the outcomes and follow-up depicted in this thesis. This chapter aims to discuss the findings in the light of the literature reviewed in Chapter Two and the Singaporean factors which contributed to the outcomes.

6.1 Prevalence and profile

This section constitutes scrutiny of the findings in the light of the literature reviewed in Chapter Two and the research questions posed (Chapter One, 1.4., page 10).
6.1.1  Educational outcomes

Research findings (e.g. Saigal et al., 1992, Rickards et al., 1993, Hille et al., 1994, Hack et al., 1994, Horwood et al., 1998, Botting et al., 1998 and Taylor et al., 2000) support the contention that VLBW children perform less well than their normal birth weight peers at school and display an array of academically related difficulties. However, variation among the definitions adopted and in the standards of studies may have resulted in a somewhat arbitrary prevalence of academic difficulties. The quantitative findings based on the 'Band' system used by the Singapore education system demonstrate the uniqueness of local academic standards. However, they are unlikely to be of any meaningful comparison with the educational outcomes of other countries. This observation is supported by Lukeman and Melvin (1993) "Using academic standards as a means of comparison of outcome for different groups raises many problems. Not only are there international differences but there are regional variations within this country in criteria for school placement and measures of achievement" (page 837). The case study reports provide the opportunity to look beyond local academic standards in terms of Band categorisation. By giving detailed portraiture, they also give one an insight into how Singaporean parents and teachers view this area of outcomes. "More informative are profiles of outcomes, preferably in terms that provide some notion of the level of dysfunction associated with specific findings or scores" (McCormick, 1996, page 873).

The educational outcomes in this study showed that most of the children investigated have at least an adequate grasp of the three subjects at Primary Two level. In terms of the different languages, most performed better in Mandarin than in English with more (69.2%) of the sample obtaining Band 1 or 2,
that is, 'Very good' or 'Good' in Mandarin compared with 51.4% in English. It would appear, in this case, that the educational outcomes from the sample are not as poor as depicted in the literature at large. It is of importance to note that whilst this may be true of the sample, the findings may not reflect the standards of school performance in the local VLBW population which includes children who have been brought up in English speaking homes as well as children of other races, primarily Malay and Indian. The latter group is made up of children with other Mother Tongues, Bahasa Melayu or Malay for the Malay children and Tamil for the Indian children. Predictably, when the sample's performance within each Band was analysed, many of the primarily Chinese speaking children in the sample were classified as having a mere 'Adequate grasp of the subject' in English. Interestingly, although more of these children had a 'Good' performance in their Mathematics, there were proportionately more who fared poorly on this as compared with the language subjects Mandarin and English. A possible reason for this is that the Mathematics curriculum at this level involves problem sums which rely on comprehension skills in English. A Mandarin speaking child who is good with numerical computation might therefore fare less well in Mathematics simply because he or she is comparatively weak in the English language. In a linguistically skewed situation such as this, the relatively high proportion of teacher complaints is likely to be more useful than Band categorisation in informing one how well these children are doing at school. The reason behind this supposition is that teachers tend not to complain unless a child is doing very poorly or failing in academic work, evidenced by the nature of comments on the children's report cards: "can do better in all subjects", "needs to improve on written English", "tend to be careless at Mathematics".
Another uniquely local finding among the educational outcomes is the dependence on home tuition regardless of whether the child fares badly or is doing well. This is believed to be a cultural factor as most school-aged children in Singapore are in receipt of tuition irregardless of whether they are VLBW children or not and, ironically, whether they are coping in school or not! The private tuition phenomenon simply reflects the demands of Singapore's education system and the expectations of local parents. The following quote from a letter entitled 'Where's the joy in learning?' by a Singaporean to a local newspaper on the Singaporean education system serves as an example. Among the writer's comments are, "I know families who spend one-third of their income on tuition for their children". He went on to state that, "'slow' students are 'forced' out of good schools by subtle pressure, so that they will not affect the schools' exam performance in the annual ranking. It is not uncommon for top schools to suggest that the slower charges need psychiatric attention for learning disabilities, and to ask them to switch to a neighbourhood school for his (or rather the school's) own good." (Today, 2002, page 8).

The quantitative outcomes in this study do not give one the impression that these children are performing poorly at school for the reasons given both in section 4.1.1.5 and the preceding paragraphs. On the other hand, data other than school performance Bands do suggest some evidence of learning deficiencies and underachievement. Again the large proportion of complaints from the school teachers as well as the high percentage of those in need of support services bear witness to this. Learning problems constitute the largest slice of the pie in the types of diagnoses at the eight year old assessment (Chapter four, Figure 8). One could also glean from these findings that, in reality, the school difficulties
local VLBWs experience go beyond being placed in low Band categories. If we focus on Eddie's Specific Learning Difficulties or Dyslexia for example, it can be seen that he was not only failing academically but was misunderstood both at school and home. His teachers labelled him as "a passive and slow learner" whilst his mother described him as "lazy" especially in the light of a normal IQ. Alan, on the other hand, was hampered in his school performance because of his motor difficulties which were subsequently diagnosed as Dyspraxia. He was chided by his teachers for his poor handwriting and laughed at by his peers for his poor motor coordination especially in Physical Education (PE) activities. Anna's WISC-III profile suggested normal intellectual functioning but her weak language skills, and therefore verbal communication, were impaired. For a long period of time, she had coped with her mother as her spokeswoman. Marcus' real problems were, in a way camouflaged by his doing reasonably well in the more 'routine' areas of his development. The lives of these children should lead one to see that any discussion of educational outcomes would be incomplete without looking at the psychological development of VLBW children.

6.1.2 Psychological outcomes

The areas discussed in this section are by no means exhaustive. In other words, there are many aspects to a child's psychological development and this study has sought to investigate three: cognitive ability, motor skills and behaviour.

6.1.2.1 Cognitive ability

This is possibly the most commonly investigated factor in VLBW research. The focus of this sub-section moves from a more general concern about the use of Intelligence Quotients or IQs as indicators of cognitive outcomes.
6.1.2.1.1 Using the IQ as an indicator of cognitive outcomes

The mean of the WISC-III IQ scores obtained at eight years old approximated that of the American norms which were used. Further details (Table 4.1.6) gave fairly extreme minimum and maximum scores under each scale, that is, the Full Scale IQ (FSIQ), Verbal IQ (VIQ) and Performance IQ (PIQ). For example, the minimum VIQ was an Intellectually Deficient score of 67 and the highest was a Very Superior score of 135! The mode, on the other hand, suggests a more common figure of 93. It suggests that the VIQ is Average albeit lower when compared to the norms. This may be more useful in unearthing the actual level of verbal cognitive functioning than the mean which suggests comparable VIQs. If the mode is indeed more representative of the cognitive functioning of the sample, then we are in agreement with the literature at large that VLBW children are at a disadvantage in terms of cognitive function. Rickard et al. (1993) looked further afield by stating that “although the difference in Intelligent Quotient (IQ) between VLBW and NBW children has been generally reported to be significant, most children score within one standard deviation of the test mean”. They went on to say that the “question arises whether statistically significant difference in IQ is of clinical importance” (page 363). The plight of the children depicted in the case studies tells us that the interpretation of the WISC-III profile should, in fact, go beyond the mere report of IQ scores. “One sensible approach is to begin with the most global score and work from the general to the specific until all meaningful hypotheses about the child’s abilities are unveiled.” (Kaufman, 1994, page 97). Kaufman went on to provide seven steps for interpreting the
profiles. These steps range from “the statistical treatment of the Full Scale IQ (Step 1) to the identification of significant strengths and weaknesses within the subtest profile (Step 7)”. It is unfortunate that this process is not always followed and that the IQ scores, rather than the profiles, have often been taken as a major if not an all encompassing indicator of the child's well-being. Moreover, any other indicators such as over activity or poor interaction with peers are usually treated as secondary concerns. As Sattler (1974) had forewarned, “cognitive acts require complex and multi-faceted behaviour. Reducing the act to a simple category name does not do justice to the psychological processes involved in the task” (in Fraser, 1984, page 154). Perhaps this holds the key to why those with whom 'not all is well' were overlooked in the follow-up process.

Notwithstanding the presence of an Average IQ classification, the proportion of learning problems and need for support services suggest that VLBW children may well have problems in their cognitive processing which in turn impact upon their learning efficiency. It is important to bear in mind that whilst the relationship between birth weight and cognitive ability appears linear, there will always be the interaction of these variables with factors such as family and school support. It is equally crucial to consider the factor of time, hence ‘maturation’, as difficulties arising from weakness in any areas of cognition often become apparent only after a child has entered primary school. Looking at it from a different angle, maturation of the children is an issue where there is little control. Often parents are likely to treat them differently and any changes or difficulties appear more pronounced than ‘normal’ children.

Aylward et al. (1989)’s review of outcome studies revealed normal albeit lower IQs. Most studies (e.g. Abel Smith & Knight Jones, 1990, Saigal et
al., 1991 & Dammann et al., 1996) confirmed the frequent occurrence of lower IQ scores. There are numerous areas in which the literature has differed. Some have sought to evaluate cognitive development in relation to perinatal characteristics such as gestational age, namely VLBWs who were born small for gestational age (SGA) (e.g. McCarton et al., 1996, Kok, et al., 1998, Stjernqvist & Svenningsen, 1999, Sommerfelt et al., 2000) and birth weight classifications, that is, ELBW (e.g. Hack et al. 1994, Halsey et al., 1996, Whitfield et al., 1997, Doyle et al., 2001). Other clinicians including those locally tend to examine the relationship between medical or specific neonatal problems and cognitive functioning (e.g. Whitehead, 1993, Dusick, 1997, Singer et al., 1997, Boyce et al., 1999, Ho, 2001). Yet others investigate social and family factors and their impact on the cognitive development of the VLBW child (e.g. Hunt et al., 1988, Dewey et al., 2000).

This study has sought to give a bird’s eye view encompassing some of the areas mentioned above. Whilst the differences between the AGA and SGA children in this study are, like the conflicting views in the general literature, less definite, differences in birth weight classification support those of the literature that ELBW children are at a greater disadvantage cognitively when compared with their heavier VLBW peers. In particular, the existence of a positive association between birth weight and the SBIS Test Composite, WISC-III Full Scale, Verbal and Performance IQs has been found. Of these the strongest relationship exists between birth weight and the Full Scale IQ score. This is in agreement with the findings of the literature, for example, Richards et al. (2001) regarding the upward trend of the relationship between birth weight and cognitive function.
6.1.2.1.2 Using the IQ as a predictor of educational outcomes

In spite of the consensus found between this study and others on IQ scores, evaluating an individually administered standardised WISC-III does not require the same type or degree of skills necessary for performance in a mainstream classroom setting. This may have led to inconsistencies in the findings between the educational and cognitive outcomes here. Leonard et al. (1990) warned that whilst cognitive testing at school age is a common measure of VLBW outcome, the test scores may not predict academic performance. Statements such as these should not surprise one as there exists contradicting situations where investigators have found no differences in IQ but a higher incidence of learning disabilities (e.g. Hunt, Cooper & Tooley, 1988). In the same year, Rickards et al. (1988) reported a positive relationship between their eight year measures which included IQ scores on an earlier version of the WISC-R or Wechsler Intelligence Scale for Children (WISC-Revised), and reading achievement and educational problems. They also found their eight year measures “useful predictors” (page 23). Five years on in a more detailed study, Rickards et al. (1993) disclosed that despite the majority of VLBW children having normal development and were “performing in most academic and social areas as well as NBW children…, (they) were significantly inferior to NBW children on tests of cognition, including tests of intelligence and visual memory, and on teacher’s reports of motor skills and initiative. In addition, proportionately more VLBW children (20.5%) than NBW children (5.9%) were reported by their parents to be not coping at school.” (page 363).

The use of the IQ tests in VLBW follow-up, though widespread, may not be a reliable indicator of outcomes. Revealingly entitled “The cognitive
outcome of very preterm infants may be poorer than often reported: an empirical investigation of how methodological issues make a big difference”, Wolke et al. (1994) spoke of the ‘outmoded tests’ used in measuring cognitive outcome. It was sobering to read of how their data on very preterm infants (VPI) indicated “...significant overestimation of the mean intellectual performance and large underestimation of cognitive retardation of VPI when compared to concurrent representative standards of infants of the same birth cohort or to a term group matched according to socio-economic indices” (page 911). However, in spite of its critics, IQ tests are still deemed useful as determinants of outcomes by VLBW investigators evidenced by the many studies cited in this respect.

6.1.2.1.3 A Singaporean factor in cognitive outcomes

A Singaporean factor which could have contributed to inconsistencies, hence weak reliability needs further mention at this point of the discussion. This factor was the focus of an unpublished study entitled “The Psychological Assessment of Bilingual Children – a Dilemma” (Lee, 2000). As stated in 3.3.3, the researcher/psychologist was usually ‘assigned’ VLBWs from predominantly Mandarin speaking homes. Paradoxically, it turned out that these arrangements were likely to have affected the cognitive outcomes. In this particular study, the WISC-III performance of four pairs of identical VLBW twins assessed on the test in either Mandarin or English was analysed. The aims were to look firstly, at the effects of differences in test administration and secondly, the influence of code-mixing, where two or more languages are used in one utterance, on the scores of three WISC-III sub-tests. These were the Similarities, Vocabulary and Comprehension sub-tests. The following questions were asked: “1. Does using a different language, that is, Mandarin in test administration affect the Verbal IQ
scores? 2. Does code mixing elaborate one’s responses resulting in better scores?” (Page 3).

Despite the small number of children studied, there appeared to be a difference between the verbal performance of twins who were assessed in different languages. In other words, the ones who were assessed in a language more familiar to them did better on the verbal tasks and were observed to be more relaxed and confident in their test behaviour. The difference between those who code mixed and those who did not appear marginal. Scrutiny of the verbatim responses pointed to some effect on the quality of responses in the two sub-tests namely, Vocabulary and Comprehension. From the notes of the psychologist, the children used code mixing for three reasons: firstly, for clarification, secondly, to emphasise a particular point and thirdly, communication of a common identity possibly to ease one’s tension. This portion of the discussion may seem a diversion from the gist of the matter. However, with bilingualism being the norm in Singapore, there are necessarily important implications for future investigations into local outcomes as well as follow-up issues such as whether a bilingual child performs better with a similar bilingual tester than with a monolingual assessor. Cummins and Swain (1986) reported cases of children classified as of “low intelligence” based on a verbal IQ test in English the results of which were uncritically accepted, whatever the child’s language background. In some cases poor achievement on standardised tests was actually suggested to be due to the ‘negative influence’ of an English-as-a-second-language background. This may well be the case for the sample in this study.
6.1.2.2 Motor skills

The area of motor skills in VLBW children appears less controversial in the literature possibly due to the presence of concrete, neurological evidence with diagnoses such as 'Cerebral Palsy' and 'Minimal Neurological Dysfunction'. VLBW children have been consistently found to be weaker in the areas of visual motor and fine motor abilities when compared with their normal birth weight peers. Hall et al. (1995), for example, described the area of motor skills to be evidently weaker. More graphically, Sommerfelt et al. (1996) reported that motor clumsiness is twice as common as compared to the NBW children. Huddy et al. (2001) reported poor outcomes in their cohort with 32% poor in writing, 31% in fine motor skills and 12% in Physical Education. Keller et al. (1998) attributed reduced motor performance in their VLBW and ELBW sample to “be a reflection of impaired neuromotor control and motor development, rather than merely a small body or muscle size” (page 661). Then there are the studies (e.g. Losse et al., 1991, the Scottish Low Birthweight study group, 1992, Powls et al., 1995, Leonard & Peicuch, 1997) that looked at the pattern of development of such skills and the impact the deficits have on other areas of learning and psychological development of VLBW children. Hall spoke of the failures on motor tasks, “many of which are part of everyday life for children” (page 1045) and the adjective “distressing” was used by Losse et al. (1991) to describe the effect on the VLBW child. In referring to a group of children who were born prematurely and who were identified with subtle perceptual-motor difficulties, Jongmans et al. wrote, “although the motor difficulties are less severe than those of children with cerebral palsy, the ‘clumsiness’ experienced by these children affects progress in school and adjustment in many” (page F 9).
The present study shows that almost a quarter (23%) of the sample was noted by the team to have problems in the area of motor skills with 15.9% referred for either physiotherapy or occupational therapy in the course of follow-up. At the final eight year old assessment, 3.7% were diagnosed as having motor problems. Although a comparison group is absent in this study, it would not be unreasonable to surmise that the trend of findings follows that of the literature (e.g. Marlow et al., 1993, Pharaoh et al., 1994, Hall et al., 1995, Jongmans et al., 1998).

In the case study reports, Alan's motor difficulties illustrate the impact of these on educational and psychological outcomes in VLBW children. In the light of the findings, particularly Alan's situation, it is possible that the prevalence of the diagnosis of 'Dyspraxia', defined as "a delay or disorder of planning and/or execution of complex movements" (McKinlay, 1998, page 9) could have been higher, given that this same condition has been described in different ways by various professionals.

6.1.2.3 Behavioural difficulties

Behavioural and emotional problems are the most commonly noted problems in the course of this follow-up. As previously intimated, the other areas of concern such as learning problems could have surfaced later on as the children are subjected to formal schooling. Moreover, these other difficulties may have been deemed more manageable in the early stages of development and hence under-reported by the parents or not detected by the team. Close to a quarter (24.3%) of the sample was recorded as having behavioural problems. Although the definitions and reporting vary among the professionals as well as from one parent to another, this finding generally corroborates with those studies that investigate the behaviour of VLBW children over the past decade (e.g. Astbury et al., 1987,
Breslau, 1988, The Scottish Low Birth weight Study Group, 1992, Szatmari et al., 1993, Botting et al., 1997, Sykes, 1997). Notwithstanding this, the inherent problems of investigating behavioural difficulties are not to be downplayed. Section 2.2.2.4 discusses the variegated definitions of behavioural difficulties, for example, whether inattention and overactivity are to be categorised similarly or separately. This study has not distinguished the severity or types of behaviour or emotional difficulties reported. One could infer from this that the report of any problems might have encompassed a wide range of behaviour and degree of severity. One could speculate that this also depended on the threshold of tolerance, or accommodation, of behavioural problems depending on the family and even culture. The latter point can be refuted by a recent cross-cultural study (Hille et al., 2001) that found similar behavioural problems in four countries and therefore suggested that “biological mechanisms contribute to behavioural problems in ELBW studies” (page 1641) as opposed to cultural events.

Supported largely by other investigations, the quantitative findings in this study give an overall profile of VLBW children being at risk for difficulties other than major neurological or disabling conditions. The evidence of academic, cognitive, motor and behaviour difficulties is reinforced by the qualitative findings in Chapter Five.

6.1.3 Subtlety in the outcomes

In spite of distinctly Singaporean contributory factors to the educational and psychological outcomes in the study, the picture that emerges is one of general conformity to the outcomes of studies in other countries. Furthermore, the issue of hidden handicap warrants attention in this discussion and
this is where the case study reports direct one to the reality of prevailing subtleties in VLBW outcomes.

The case study method has been instrumental in exemplifying salient points in the process of VLBW follow-up, which will be addressed in the next section. Its basic aim was to assist the reader to gain a better understanding of the children's hidden difficulties by adding substance to the outline presented by the quantitative findings. One would also note from the case study reports that it was often when a child was due for discharge from the follow-up programme at eight years old that hidden difficulties became a cause for concern and action such as arrangements for further assessments or investigations. It could be argued that many of these difficulties do not manifest themselves until the child has entered primary school and is subject to greater demands on their skills (e.g. Den Ouden et al., 1993). Along similar lines, Sykes et al. (1997) stated that "the more subtle the dysfunction, the less likely it is to be apparent in the short-term. Rather, it may be expressed only at an age and within a context that stretches the child. The earliest such age is typically school-age, with the context being the relatively high demands for behavioural adaptation placed on children within educational settings." (Pages 315-316). Yet there are other authors who point out that minor difficulties will remain hidden as long as one focuses on the absence of major neurological impairment or disabling conditions (Zubrick et al., 1988, Schendel et al., 1997). Whilst it is conceivably more difficult for one to appreciate how obscure the problems can be even during the pre-primary or kindergarten years, it is important to, as it were, carry out an examination on what has taken place in the lives of these children.
Notwithstanding their normal IQs at eight years old, dissecting more minutely the details of the children's lives revealed symptoms which were missed or dismissed by either professionals or parents in the early stages of follow-up. For example, Eddie, the child with Specific Learning Difficulties, had speech delay at two years old and poor fine motor skills at five years old. He could have been labelled to be at high risk for learning problems by five and followed up more closely with intervention. Eventually diagnosed as a child with an Autistic Spectrum disorder, Jennifer's had problems that were more subtle as she could have easily been passed off as a very shy child. However, if the 'difficult' behaviour reported and observed during the earlier assessments had been explored in greater detail, her impairments in social communication, interaction and imagination could have been addressed earlier. Similarly, Terence who has Attention Deficit Hyperactivity Disorder, had shown some signs of overactivity earlier on in his life and should have been closely monitored and 'treated' prior to primary school admission. Despite concerns about his motor skills when he was two, resulting in a non-scheduled appointment at three years of age, Alan's weaker attention span was subtly and selectively manifested on visual-motor and perceptual tasks. Until his assessment at eight years of age, he was viewed as a slower child when in effect he was quite average on his verbal skills. Marcus had a promising start even as an ELBW but less emphasis was placed on the emotional struggles he was having within as he manifested behaviour problems without. Anna’s language difficulties were largely camouflaged by her average IQ scores and explained away as a problem of English as a second language throughout the follow-up process. She was a child who could have safely benefited from intervention in the form of speech and language therapy during her early years.
Whilst the selection of the six children for case study is not necessarily applicable to the wider population of VLBW children, these give examples of existing difficulties and should lead to better informed decisions about the areas investigated, namely, the hidden difficulties and the follow-up process.

6.2 A critical evaluation of research issues in VLBW follow-up

The discussion of the findings thus far depicts a maze of complexities of VLBW follow-up. It can be likened to a journey often fraught with danger and obstacles along the way. Literature evaluating issues on follow-up attempts to categorise these difficulties as the subjects studied and methods used, environmental factors and outcome measurement. Among these are listed "inadequate description of subject population, perinatal course not considered, single-hospital samples, lack of appropriate comparison groups, excessively high dropout, no assessment or control for environment, too short duration of follow-up, global or vague outcome measures, variability in diagnostic criteria, inclusion of severely handicapped children in mean scores and no consensus on correction for prematurity" (Aylward et al., page 516). Many of the issues have been lamented by a number of researchers in their discussions and recommendations (e.g. McCormick, 1996, Bregman, 1998). McCormick goes to the extent of questioning if one is indeed asking the right questions. A comprehensive picture that includes cognitive development, school achievements, medical and behavioural difficulties and relating these outcomes to perinatal, social and environmental data would appear ideal. We shall see one such proposition in the next chapter.
6.2.1 The sample

Despite the adoption of 'convenience sampling' in this study, where information on the VLBW children was readily available to the researcher since she was part of the multi-disciplinary follow-up team, the group sampled was further refined with pre-set criteria. Some bias may have therefore existed in the selection of children. In more technical terms, differential selection where there is a lack of randomised selection poses a threat to internal validity. This is believed to have led to the atypical variation in the sample's performance in their academic subjects. One could also argue that the researcher has been subjective in her accounts of these children, that is, she has been so immersed in the cases that the reported findings are biased. This is a possibility as the researcher was not blind to the status of the children in the first place. Moreover, she was working in a different capacity as a psychologist as she recorded information on children who came for the assessments. This leads to another shortcoming of this study, namely, missing data. In terms of the follow-up process itself, the children who follow through with all the psychological assessments from ages two to eight may be different from those who do not continue with the follow-up programme, for example, in socio-economic status. Again, those who eventually come and are assessed may differ in their home languages and the language used in the assessment.

6.2.2 Defaulters or difficult-to-follow-up VLBWs

The research evidence directs the VLBW investigator to look further at those who are not followed up either without difficulty or not followed up at all. Another way of describing this phenomenon would be the investigation of 'dropouts' as well as those who did not cooperate with assessments. In a
letter written to The Lancet as early as 1989, Wariyar & Richmond stated that “parents who have not come to terms with their child’s disability may tend to avoid situations where that disability is highlighted, and in any follow-up of preterm infants, we would expect to find a higher disability rate amongst those children who were difficult to review than among those reviewed more easily.” (page 387).

Unstructured clinical observations recorded in the medical reports may shed some light on this point. Alan’s behaviour at the two year old assessment was likened to that of a baby with his mouthing and banging of objects in addition to gross and fine motor delay. Although he was already reported to be developmentally delayed, a score was not given as testing was abandoned after he refused to cooperate on most of the items. Anna’s verbal skills at five years old were recorded as “a pitiful sight”. The psychologist found assessing her difficult as she could not understand what the child was trying to say and her mother acted as her interpreter. These findings are in line with those of more recent findings such as those of Wocadlo and Rieger (2000) who investigated a group of children who attended follow-up but exhibited uncooperative behaviour. In summary, both quantitative and qualitative findings particularly in terms of parental description of difficulties and need for services testify to the stance of the literature. In layman’s terms, difficult early test behaviour can be tell-tale signs of what is to come at school age. With regard to those who are not followed-up at all, Wolke et al. (1995) maintained in their writings that data defaulters or ‘dropouts’ are the key in one’s investigation into outcomes. It is unfortunate that little more can be gleaned about the group of defaulters within this particular study. It is now recognised that this would have had an impact on generalisability in addition to the possible injection of bias into the findings.
6.2.3 Birth weight and gestational age groups

It has to be borne in mind that within these groups, heterogeneity rather than homogeneity usually exists. In other words, despite the fact that low birth weight can be reliably quantified, it does not represent a homogeneous condition. It was stated at the outset of this thesis that ELBW children come under the umbrella term of VLBW. The findings revealed that only 37.4% of the sample came under the Appropriate for Gestational Age or AGA classification. Most (62.6%) were SGAs. In short, our sample had a mixture of VLBW children who may have had a birth weight appropriate for their gestational age (AGA) whilst others may be small for their gestational age (SGA). On assessing cognitive ability, as measured by IQ and reading comprehension, among other functions in school aged SGA premature children, Hutton et al. (1997) found cognitive ability to correlate with the degree of fetal growth retardation. They concluded that infants born too early and too small are at an even higher risk for cognitive deficits than appropriate for gestational age infants. Our analyses of the outcomes in Chapter Four suggest that the lack of differentiation between the groups in this study could have contributed to the inconsistencies in the findings. The hypothesis is that a more uniformed sample would have given more of an insight into the relationships between birth weight, gestational age and the variables on outcomes.

6.2.4 The follow-up

This section evaluates the process of follow-up primarily in terms of methodological issues. It commences with a critique of the design followed by a scrutiny of the methods adopted. It then progresses to discuss an important but largely neglected factor, the involvement of parents and teachers.
6.2.4.1 A word of caution about the design

A quick recapitulation tells us that the ex post facto design was chosen primarily because of its flexibility in retrospective clinical data collection and analysis within a specific population of children. This same flexibility is however, often viewed as one of the greatest weaknesses of the design. Cohen and Manion summed up the limitations and weaknesses of this design many of which have been stated in previous sections: "The problem of lack of control in that the researcher is unable to manipulate the independent variable or randomize her subjects" as seen in how little control there is in the sample and sampling in this study; "it often bases its conclusions on too limited a sample or number of occurrences" reflected in the difficulties the researcher has had in drawing conclusions that are commensurate with the literature at large and "as a method, it is regarded by some as too flexible" (page 153).

Accentuating the weaknesses in the adoption of this design is the fact that the data were confined to one particular hospital. This implied restricted variability in environmental factors and high variability in medical procedures and management when compared with other centres even within a tiny island state like Singapore. Generalisability to other groups of VLBWs in Singapore is therefore questionable. In addition, it is the author's convictions that these limitations are highly likely to have resulted in an underestimation of the prevalence of developmental deficits let alone the hidden ones.

6.2.4.2 Evaluation of the methods used

Although methodological triangulation which in this case is essentially the use of "different methods on the same object of study" (Cohen and Manion, 1994, page 236) has been adopted, it is clear that the secondary means of
consolidating the data is on its own inadequate given the potential weakness of the ex post facto design. From the limitations cited in the preceding section, one also can see the tension between choosing a research tool that gives the flexibility in data collection and one that gives better validity albeit with more time and costs incurred. This section seeks to evaluate the quantitative and qualitative approaches used in order to draw out about the prevalence, profile as well as pitfalls in VLBW follow-up. Neuman (1997, page 329) summarised the difference between these two approaches:

Table 6.2.1 Differences between quantitative and qualitative research

<table>
<thead>
<tr>
<th>Quantitative</th>
<th>Qualitative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Test hypothesis that the researcher begins with</td>
<td>Capture and discover meaning once the researcher becomes immersed in the data</td>
</tr>
<tr>
<td>Concepts are in the form of distinct variables</td>
<td>Concepts are in the form of themes, motifs, generalizations and taxonomies</td>
</tr>
<tr>
<td>Measures are systematically created before data collection and are standardised</td>
<td>Measures are created in an ad hoc manner and are often specific to the individual setting or researcher</td>
</tr>
<tr>
<td>Data are in the form of numbers from precise measurement</td>
<td>Data are in the form of words from documents, observations, transcripts</td>
</tr>
<tr>
<td>Theory is largely causal and is deductive</td>
<td>Theory can be causal or non-causal and is often inductive</td>
</tr>
<tr>
<td>Procedures are standard, and replication is assumed</td>
<td>Research procedures are particular, and replication is very rare</td>
</tr>
<tr>
<td>Analysis proceeds by using statistics, tables or charts and discussing how what they show relate to hypotheses</td>
<td>Analysis proceeds by extracting themes or generalizations form evidence and organising data to present a coherent, consistent picture</td>
</tr>
</tbody>
</table>

This table suggests that a qualitative research orientation follows a cyclical path unlike the relatively linear route taken by quantitative researchers. It also appears that with each cycle or spiral, new knowledge and data are obtained. Data analysis is an ongoing activity and may even take place concurrently with data
collection. Examples taken from Chapters Four and Five illustrate the difference between these approaches:

**Table 6.2.2  Examples of quantitative and qualitative descriptions**

<table>
<thead>
<tr>
<th>Quantitative subject description</th>
<th>Qualitative subject description</th>
</tr>
</thead>
</table>
| "The value of the Pearson correlation coefficient (r) for birth weight and WISC-III Full Scale IQ was highly significant at 0.01 level (99% confidence level). These suggest the existence of a positive association between birth weight and the SBIS Test Composite, WISC-III Full Scale, Verbal and Performance IQs. Furthermore, a strong relationship exists between birth weight and the Full Scale IQ score" (page 73) | "At a chronological age of eight years old, Eddie achieved an overall Average IQ score of 102 on the Wechsler Intelligence Scale for Children - Third Edition. (WISC-III) (Wechsler, 1991). Classified as 'High Average' (Performance IQ = 113), his performance or non-verbal ability was stronger than his verbal skills which was Average (Verbal IQ = 92). Overall, his profile was fairly even between and within each scale. During the session, he was observed to be relatively weak on tasks that required him to describe a word or relate an event in a sequence, for example, on the WISC-III's vocabulary sub-test that required word definition. A quick informal assessment on basic spelling and reading in English found him to have some difficulty in deciphering sounds as he attempted to read and spell. As the results were discussed with Eddie's mother, she repeatedly questioned, "Why is he failing in all his subjects if he isn't stupid (meaning that he has an overall average IQ)? He must be lazy!" (pages 84-85).
This example leads us to understand why both approaches were adopted as one is confronted with the task of investigating the prevalence of difficulties and the profile of outcomes in VLBW children. The approaches here appear to be in a collaborative relationship. The common ground they share is that they involve inference from the data obtained. One might, on the other hand, wish to take a step further to ask if the methods used were adequate for the purposes of this study. "In qualitative research, adequacy refers to the amount of data collected, rather than to the number of subjects as in quantitative research. Adequacy is attained when sufficient data has been collected that saturation occurs" (Morse, 1994, page 230).

6.2.4.2.1 Appraisal of the interview

As stated under 3.3 Methods, data collection was through interviews with parents and if available, school reports, formal psychological tests as well as gleanings from the paediatricians' and psychologists' notes in the case studies. Primarily in view of limitations of time, the survey method was adopted simply because it gave the team the opportunity to obtain as much 'up-to-date' information as possible within the shortest space of time when a VLBW child came for the scheduled assessments. A standard form was constructed for this purpose. This served to standardise the interview and its reliability was enhanced by the training of the staff to use it. Additionally, a copy of the latest school report from the parents would have been obtained at the eight year old assessment. There were occasions when this was unavailable and school achievement, in the form of bands was verbally reported by the parents. Further, any comments from parents and/or 'complaints' from the teachers concerning the child were recorded. The goal of the interview was therefore to obtain a fair description of the child in his or
her current situation as quickly as possible. The question remains, was this goal achieved? Validity basically informs us of the extent to which an item or data collection procedures measure what it is supposed to measure. Whilst it is evident that in practice, the structured format was instrumental in obtaining the bulk of the data within a short space of time, the content was inadequate for the purpose of this research. In a way, this is to be expected as the format was not specifically designed with the research questions in mind. It has to be borne in mind that this is a piece of ex post facto research and the interview was used primarily as a tool for a VLBW follow-up service. It is likely that its adaptability which allow for the interviewer to probe further into and follow up on the responses of the parents made it an ideal tool for VLBW research. Bell (1993), on the other hand, warned of bias in the interview. Citing Borg (1981, page 87), she pointed out that “many factors can influence responses, one way or another. Borg draws attention to a few of the problems that may occur:

“eagerness of the respondent to please the interviewer, a vague antagonism that sometimes arises between interviewer and respondent, or the tendency of the interviewer to seek out the answers that support his preconceived notions are but few of the factors that may contribute to biasing of data obtained from the interview. These factors are called response effect by survey researchers.”......The same question posed by two people, but with different emphasis and in a different tone of voice, can produce very different responses, complete objectivity is the aim.” (pages 95-96).

In view of what researchers have said about the use of the interview for data collection, some observations concerning bias in the VLBW interviews are
retrospectively made. There was, for example, resentment about having to disclose one’s income or embarrassment in having to report financial difficulties, hesitation in revealing their children’s problems or venting their frustration about these during the interview session. Despite being trained to conduct the interview, space and time constraints were likely to have caused the nurses to carry out an entirely structured interview which in turn eliminated some details that may have produced alternative responses or opportunities to delve more deeply into problems. Paradoxically, the depth of information required in a case study approach meant that breadth had to be compromised, for example, investigations into the influence of social or medical factors were avoided as it would have meant a diversion from the course of study.

6.2.4.2.2 The role of the case study

The case study was adopted as a complementary approach to the survey. As a qualitative method, its accessibility in terms of showing the unique features and enabling the reader to understand the real-life examples of the VLBW children made it a choice tool in this study. The following conditions under which qualitative methods are deemed suitable were suggested by Patton (1990), quoted in Mertens and McLaughlin (1995):

“1. the programme emphasises individual outcomes
2. detailed in-depth information is needed about certain clients or programs
3. the focus is on diversity among, idiosyncrasies of, and unique qualities exhibited by individuals
4. no standardised instrument is available that can validly and reliably measure program outcomes” (pages 45 to 46).
These criteria support the appropriateness for the choice of a qualitative method like the case study. Specific issues in Chapter Five would not have surfaced if a single quantitative approach had been adopted.

In spite of its qualities, the case study has been criticised because it is time consuming, lacks generalisability and perhaps most frequently, is subjective or biased especially when the researcher becomes so involved in the case. An example of this can be seen from the researcher’s description of one of the case study reports: “Anna’s presentation at five years old was a pitiful sight. She was a friendly child with excellent communicative intent but her verbalisation was garbled. It was difficult to understand what she was trying to say and her mother had to act as her interpreter.” On reading this, one would sense the emotions of the researcher at play as she described the child’s difficulties. Furthermore, underlying the criticisms of the case study are the notions of validity and reliability, that is, the degree of consistency in the process of investigation. Attempts were made in this study to maximize the latter in the use of triangulation succinctly described by Edwards and Talbot (1994) as involving “taking more than one, and usually three, perspectives on a phenomenon. Triangulation usually occurs in practitioner research through the use of more than one research method or more than one researcher or a mixture of these.” (Page 161). Applying this to the VLBW situation diagrammatically, we have a combination of investigator and methodological triangulation (Figure 9):

```
Nurses’ interviews → VLBW follow-up ← Paediatricians’ notes
                        ↑
Psychologists’ assessments
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Triangulation, to some degree, would have reduced subjectivity and enhanced consistency in using the case study in VLBW follow-up.

6.2.4.2.3 Some comments on formal assessments

Instrumentation is another major threat to reliability and validity in this study. Two different IQ tests (S-BIS and WISC III) were used three years apart by different psychologists. Irrespective of how standardised the test administration could have been among the psychologists, the results varied and any retrospective analysis of scores is likely to differ. This brings in the question of inter-rater reliability. The testing situation is often an artificial one where little preparation is needed as compared to school performance. With regard to the latter, there is variation in the amount of input such as in private tuition. Moreover, there is usually different test behaviour exhibited by the child depending on whether parents sit in the assessment session. Children’s actual performance on tests could also be affected either adversely or positively by their parents’ presence. The psychologist unfortunately has little control over this situation. The same is true as to the variety of instruments and norms used in the assessment or evaluation of outcomes. Dammann et al. (1996), for example, relied on standardised assessment norms as a basis of comparison while other studies used standardised parents’ reports (e.g. Schmit, 1990). In this scenario, the norms used were American as local norms were not present at the time of assessing this group of VLBW children. Of even greater concern would be the differences in the languages used in test administration. The American Psychological Association’s Standards for Educational and Psychological testing (1985) has identified problems pertaining to the effects of any form of test modification on their technical adequacy: “When a test user makes a substantial change in test format, mode of
administration, instruction, language or content, the user should revalidate the use of the test for the changed conditions or have a rationale supporting the claims that additional validation is not necessary or possible.” (APA, Standard 6.2, page 41).

The absence of a local control group such as NBW children in the assessments adds to the weakness of this study by threatening its validity, “If we are to understand the effects of prematurity per se, versus multiple other factors impacting on outcome, then comparison groups varying by birth weight and gestational age, with comparable or contrasting demographics are necessary.” (Bregman, 1998, page 674). In view of these threats to validity, one cannot be certain about how generalisable the findings are to the rest of the population. In other words, the sample is a poor representative of the population of VLBW children in Singapore. The researcher will need to adopt measures to overcome some of the difficulties encountered.

### 6.2.4.2.4 A word about parents’ and teachers’ involvement

Though not systematically documented, a by-product of the assessment is that parents’ perception, hence concerns, varied according to their expectations and tended to focus more on school performance than in terms of their cognitive profile especially when the latter were within normal classifications. In 1990, Schmidt and Wedig used a mail survey to investigate parental perception at school age (6 to 10 years old) of VLBW infants. They asked the question, “how valid are parents’ perceptions of their children’s classroom performance?” and suggested that the parents in their study “may have over, or just as likely, underestimated their children’s performance”. Ten years on, Heiser et al. (2000) sought to investigate whether parents of VLBW infants underestimated their infants’ development more frequently than parents of term children. They found
evidence that parents of VLBW children tended to underestimate their infants' development. Looking at behavioural problems in ELBW children in four countries, Hille et al. (2001) suggested that

"the immature behavioural organisation of the preterm infant could provide more challenges to parental behaviour and to parent-child interaction. Life-threatening events in the perinatal period might induce overprotective parental behaviour, which leads to differences in parental perception of the child's behaviour, and to inadequate socioemotional behavioural adjustment in the child." (page 1643)

The importance of the responses of parents to their VLBW children cannot be underestimated. In summarising research findings from over two decades of research, Miles and Holditch-Davis (1997) propounded that "mothers also need ongoing assistance and guidance in dealing with the parenting of these children, particularly issues related to compensation, normalization, stimulation, attention, overprotection, discipline, and the impact on the family." (page 263). They cited the findings of an earlier study (Miles & Holditch-Davis, 1995) which found that the mothers of three year old VLBWs viewed their children as both 'special' and 'normal'. They suggested that the parenting style adopted by these mothers to compensate the child for the neonatal experience, was a way of resolving these apparently conflicting views. They also found that "the mothers in their study viewed the characteristics of a typical, prematurely born child as less positive than those of the average child" (page 258). Interestingly, their perception did not apply to their own child! They added, "instead, they viewed their own child as an exception to the stereotype. Prematurity stereotyping...appears to confirm the mother's belief that their child is normal". Based on their research, the
authors went on to present a framework on what they described as 'pathways of influence in parenting prematurely born children' (page 258).

Paradoxically, in the course of her work with VLBW children, the researcher did find that many of the parents held the view that their children would grow up and hence 'out' of the problems VLBW children have. Most did not think of informing the primary schools of their children's early setbacks. Many teachers, on the other hand sought explanations for the problems they found in these children and most would accept very low birth weight as a reason. In this process of follow-up, it is deemed unfortunate that mainstream school teachers were consulted only when more information on a particular VLBW child was required. The overall impression is that the contribution of teachers has been grossly underestimated in the follow-up of VLBW children in Singapore given that

"the teacher's daily interaction with the child over a school year places that professional in a position to closely observe problems and strengths of the child, in terms of academic and social learning, peer relationships, temperament, and general health. The teacher's observation over a sustained period of time of a child's individual patterns of development and performance across various dimensions in the classroom context and in the school culture provides a rich source of information for the whole assessment team. In particular, the teacher's academic training and professional experience position him or her well for comparing and contrasting the child's progress with peers - a perspective that parents and other team members may well lack." Cooper and Ideus (1996, page 30-31).
6.3 **Summary of discussion**

This chapter has attempted, firstly, to discuss the prevalence and profile of the educational and psychological outcomes in detail and secondly, to critically evaluate the issues involved in VLBW follow-up. In the first part, the use of the IQ as the primary indicator and predictor of cognitive ability and educational performance respectively was scrutinized. This was followed by the possible influence exerted by Singaporean factors on the quality of such outcomes. The case study reports incorporated in this study became invaluable in substantiating some of the findings especially in providing information lacking in the quantitative arena.

With respect to follow-up issues, however, this study has many of the limitations raised in the literature, for example, a control group and local norms are lacking. The hospital based population had thus far been viewed as homogenous when in reality there are a number of sub-populations whose outcomes differ and therefore need to be either addressed separately or viewed as a spectrum.

The process of follow-up seems to take a complicated albeit linear route. Whilst the term 'multidisciplinary team' is used, communication among professionals appears minimal and the making of decisions individualistic in nature. In addition, parents and teachers who interact and know the child far more than the professionals are often marginalised in the whole process.
Chapter Seven

CONCLUSION AND RECOMMENDATIONS

7.1 The situation thus far

The VLBW child starts life in a unique situation of being born with a very low birth weight and many uncertainties ahead of him or her. A growing body of research evidence around the world suggests that these children are at risk of long-term problems in areas of child development. It also intimates that these problems do exist in the absence of major handicaps and are present in a subtle or obscure manner. Within the Singaporean context, little is documented on how well or poorly this group of children is doing especially in mainstream primary schools.

Working as a psychologist involved in the follow-up assessments of VLBW children has given the researcher the opportunity to gather information on a sub-group of such children who were followed up from ages two to eight years old when they are normally discharged from the follow-up programme. Underlying this study has been the concern that VLBW children are all too often discharged from follow-up as “well” when, at some point of the follow-up, red flags were present. This concern has increased given that there is now more evidence (Kaplan & Mayes, 1997) that functional impairments may appear only when a child is older and faces greater demands of complexities in given tasks. This study has set out firstly, to give an overall group picture of how Singaporean Chinese VLBW children are performing at primary school. Secondly, it sought to investigate their levels of cognitive functioning and their overall development with in-depth profiles drawn by the case study reports of selected individuals. The third
aim was to identify and address issues in the process of follow up. Based on these aims, the research questions that needed answering were:

1 a. How are Singaporean Chinese VLBW children performing academically, that is, in their Mother Tongue (Mandarin), English and Mathematics?

b. What is the status of their psychological development in the domains of cognitive ability and overall functioning?

2. What is the prevalence and profile of needs and impairments in this group of children?

3. What are the issues involved in the process of VLBW follow-up in Singapore?

The quantitative findings in this study on educational outcomes show that more children in the sample performed better in Mandarin than in English. Selection bias in the sampling process may offer an explanation for this phenomenon as the researcher/psychologist 'normally' assessed predominantly Mandarin speaking VLBWs. Although more (31.8%) achieved a 'Good' performance standard in their Mathematics, there were proportionately more children who fared poorly when this was compared with the subjects Mandarin and English. This was in part explained by the fact that problem sums were a part of the Mathematics curriculum for the eight year olds. Solving these problems required substantial comprehension of the mathematical questions posed in English. It therefore places a bilingual child whose first language is Mandarin in a disadvantaged position even though he or she may be good at mathematical computation.

A comparison of school performance between ELBWs and VLBWs showed findings at variance with the literature (e.g. Hack et al, 1994). No
significant differences were detected between the two birth weight classifications in their school performance within this sample although it must be pointed out that the correlation between the two groups seem to support the general view that heavier birth weights are linked to better academic performance in VLBW children. In spite of missing data, the available information on privately arranged tuition and teachers’ complaints reported by parents or via the children’s school report cards indicate that this group of Singaporean Chinese VLBW children are not performing as well as one would expect and that they do experience difficulties academically.

Encouragingly, positive relationships among the Bayley’s MDI, SBIS test composite and WISC-III IQs were found. In other words, a higher MDI obtained on the BSID-II when a child is two years old tended to correspond with a higher test composite on the SBIS-IV at five as well as WISC-III IQs at eight years old. These have pragmatic implications on the follow-up process as one would then look for some predictability between test scores and from one test to another. With respect to the lack of significant findings between the Bayley’s Mental Development Index and the variables investigated, one might do well to remember that studies (e.g. Bowen et al, 1996) have shown that developmental tests administered during early childhood have significant limitations in their predictive validity.

Although the mental and cognitive outcomes of the sample tell us that this group of VLBW children is average in their ability, further investigations show variance in the strength of relationships among the variables investigated. The relationship between the Mental Development Index on the Bayley Infant Development Scales (BSID) and birth weight, for example, was not significant.
On the other hand, the relationship between the Full Scale IQ on the Wechsler Intelligence Scales for Children (Third Edition) (WISC-III) and birth weight was strong. The outcomes of the assessments at the older age groups, that is, five and eight appear to be in greater agreement with the findings of Richard et al (2001) on the upward trend of the relationship between birth weight and cognitive function. Further dissection of the sample into their birth weight categories, ELBW and VLBW yielded similar but more informative results which basically confirmed those of the literature that ELBWs do not perform as well as the heavier VLBWs in terms of cognitive outcomes.

Another comparison between that of gestational age and cognitive test scores was made and this time significant association was found between gestational age and the WISC-III Full Scale IQs. Again, this is in general agreement with the studies at large. (e.g. Sommerfelt et al, 2000, Larroque et al, 2001, Ho, 2001 [for the Malaysian Very Low Birth Weight Study Group]).

Suffice to say at this point that the overall picture of cognitive outcomes is an average one, and is dependent on multiple factors such as birth weight and gestational age classifications. Interaction among factors not considered in this study is likely to have affected the outcomes and will be addressed under the section on the limitations of this study.

The prevalence and profile of difficulties and needs of the sample are characterised by the common occurrence of behavioural problems even at the early stages of follow-up. The other areas of concern, for example, learning problems are more evident later when the children have started formal schooling. Certain problems such as speech and language deficits may have already been in existence in the early days but could have been deemed more manageable hence
under reported by the parents or not detected by the team. Again the proportion of the types of problems and intervention as well as the diagnoses conspire to give a more accurate profile and prevalence of the children's needs and difficulties. It was, in a way, expected that by the time the child was followed up until eight years old, any existing problem would have been identified and defined. However, the case study reports suggest that this was not always the situation during the process and period of follow-up.

7.2 Limitations of this study

The limitations of this study are many. To begin with, the sample itself was not representative of the VLBW population given that most of these were Mandarin speaking children of ethnic Chinese origin. The educational outcomes have been found to be skewed with most of the sample performing well in Mandarin and less so in English. In addition, the depressed performance in Mathematics could have been due in part, to weakness in English rather than poor mathematical ability. Given the bias, the findings from this sample are unlikely to be generalisable to the VLBW population in Singapore much less to those worldwide. It may be more accurate to say that it better describes the sub-group of Singaporean Chinese VLBW children. Unfortunately, homogeneity in this case has not helped. Paradoxically, a heterogeneous sample where ELBW children are included under the larger group of VLBW as well as placing AGA together with SGA is likely to have depressed the findings. On the whole, the literature has suggested that the groups of ELBWs and SGAs, particularly the former, do not develop as well as their heavier counterparts. It has to be borne in mind that despite the fact that low birth weight can be reliably quantified, it does not
represent a homogeneous condition. The qualitative findings are not exempted from the issue of bias. By looking at the case studies, one would realise that objectivity issues would have crept in simply because “the case...neatly fits the researcher’s preconceptions” (Isaac & Michael, 1987, page 48).

Recent research (Wolke, 1995, Wocadlo & Reiger, 2000) has emphasised the importance of investigating VLBW children who are defaulters or uncooperative in follow-up. This study lacks information on this group of children and implies further bias in the findings.

The absence of a control group of the same number of normal birth weight children comparable in socio-economic variables is another notable weakness in this study. One could only search out relationships among the variables within the sample and a means of comparison is lacking. Moreover, in terms of the formal IQ tests administered, locally standardised norms are absent at the point of study and this would have introduced error into the measurement and therefore the findings. The children investigated in this study are assessed at different points of times by different professionals using different tests. Furthermore, at least two different languages used at different times of testing would have increased the complexities of cognitive outcomes.

In reporting the details of other areas of functioning such as behaviour and motor skills, the lack of clarity or variation in definitions especially in what constitutes a problem would have meant differences in perception among professionals and parents. Inattention or emotional fluctuations, for example may not be included in the category of behavioural problems. Parents, such as Terence’s, had “always accepted his overactivity as the liveliness of a young boy”.

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Those who are able to cope with such behaviour may therefore under-report the severity of it.

Adding to this perplexing picture is the contrast in perception among professionals and parents. This seems to be a phenomenon that goes beyond the shores of this island state. This difference in perception can be evident right from the birth of the child. Two letters written to the Editor of the journal Birth in response to the comments on the follow-up of a tiny baby (who weighed 345 grams or just over 10 ounces at birth) serve to highlight this point. The first letter was written from a professional's perspective. Merzbach and Phelps (1996, page 51) gave a summary of a child's outcomes and services she had up till six and a half years old. They concluded that,

"certainly, looking at this child and seeing that, with special services, she is able to function in school and is part of her family and our society, one cannot help but agree with Dr Mercier" who had earlier commented that 'undeniably, cost and cost limitations are important issues in neonatal intensive care. However, I am unsure if their importance implies a public desire for physicians to decide when and if an individual child's life is too costly to save. Furthermore, it would seem more appropriate for cost control considerations to be addressed in the larger social context rather than in individual cases at the bedside’.

The second letter, written by a parent (Harrison, 1996) gave a different perspective: "Merzbach and Phelps consider this child's outcome to be positive, and it is in the sense that it could have been much worse. As an experienced parent, however, I see the child's current condition with less optimism". She then gave a similar description of the services her son had received when he was six and a half years old but poignantly concluded that the
problems he has had in his development made "it impossible for him ever to live independently." (Page 179). Whilst the children in these letters are those with clear difficulties, professionals and parents, as suggested earlier, have different perspectives of the needs and predicament of VLBW children. This leads one to a minefield of moral issues and medical ethics where neonatologists have the unenviable task of making difficult treatment decisions particularly for very premature ELBW's. Whilst the area of treatment or intervention decisions is beyond the scope of this thesis, one has to be constantly reminded that the reality of follow-up is that parents and professionals do not always agree. This makes the collation of data that is fully representative of a VLBW child's functioning difficult. The impact of having to bring up a VLBW child cannot be underestimated. Whilst self-help and support groups like the 'lightweight clubs' especially for 'newer' parents of VLBWs now exist, it is equally important that these parents be given information and help about later outcomes. One of the best opportunities to do so would be during the follow-up consultations and assessments. Bregman (1998, page 674) succinctly sums up the situation as:

"Finally, the scope of outcome studies has been traditionally narrow, focusing on presence or absence of significant impairment and integrity of intellectual and academic functioning, without addressing socioeconomic functioning, quality of life, or impact on the family of caring or raising an extremely prematurely born infant. Whilst the former information is important and useful, it does not tell the whole story, and as clinicians can attest, a score on a global test may not adequately affect the integrity of an individual child, nor does such a narrow focus elucidate which specific factors directly affect such outcomes. Studies published recently seem to be
addressing these criticisms and are beginning to augment our understanding of outcome in the VLBW infant”.

7.3 Where do we go from here

O’Shea (2001) has summarised changes in research methods in follow-up studies during the 20th century:

“Based on epidemiological principles, Kiely and Paneth offered the following suggestions for improving neonatal follow-up studies: 1) use of population-based rather than hospital-based samples for prevalence studies; 2) inclusion of appropriate controls; 3) assessment of confounding due to social class; and 4) minimizing lost-to-follow-up rates. In addition, they commented on issues specific to neonatal follow-up, including: 1) continued follow-up of subjects to school age; 2) reporting of mortality rates as well as morbidity; 3) reporting of birth-weight-specific data; and 4) more detailed reporting of the co-occurrence of impairments. To these considerations, Mutch et al added: 1) prospective consideration of sample size and study power; 2) efforts to reduce inter-observer variation in outcome assessments; and 3) use of the International Classification of Impairments, Disabilities, and Handicaps to describe outcomes. In another commentary, McCormick suggested that investigators: 1) aim to describe children’s functional level across multiple domains, rather than emphasizing handicapping neurodevelopmental outcomes; and 2) specify explicit conceptual models of probable links between risk factors and outcomes. Among neonatal follow-up studies, the adherence to the foregoing methodologic guidelines generally has increased over time.” (page e249)

Applying these observations and recommendations to the local scene, it is recommended that future studies include not only a control group of
full term, normal birth weight children but one that is controlled for variables that are known to affect a child's development such as social factors. The sample should be larger and randomly selected so that it could be more easily generalisable to the population. Greater efforts should be made to ensure a more homogenous sample. In the event that it is logistically difficult to obtain a control group, one could divide the sample into two matched groups e.g. one with good school performance (bands 1 & 2) versus another with poor school performance (bands 3 & 4). These children could be matched on variables known to affect school performance or cognition, for example, socio-economic status. There should thus be less interaction as it were, with the test scores and one could then be more confident of the relationship which may or may not exist.

Although triangulation is adopted in this study by way of different methods being used in the data collection (for example, interviews, school reports and formal psychological tests), it is clear that the secondary means of consolidating the data is on its own inadequate given the inherent weaknesses of the ex post facto design. It is believed that more contrasting methods need to be incorporated into this design. Qualitative data via telephone interviews with teachers for instance, may provide a clearer picture of how the VLBW child is faring not only academically but in other areas of development for example, attention and social areas. Post test interviews with parents and child as to how they perceive the session of formal psychological testing may also give the researcher a fuller idea of how representative a child's performance is. The tests used for the different age groups may need to be revised in terms of seeking stronger correlation between findings at different ages. If further evidence stemming from on-going research come to some fruition, the Wechsler Preschool
and Primary Scale of Intelligence (Revised) or WPPSI-R may be more appropriate than the Stanford-Binet Intelligence Scale (Fourth Edition) for the psychological assessment at five years old. As it is, sharing similar main dimensions with the WISC-III which is used for the psychological assessment at eight years old, comparison studies have demonstrated high correlations between the two tests (Wechsler, 1992). As for the relationship between the Bayley Scales and the WPPSI-R, the comments are also promising: "overall, the pattern of correlations and the mean differences between the two scales suggest that in the 36-42 age month range the Mental Scale of the BSID-II and the FSIQ (Full Scale IQ) and VIQ (Verbal IQ) of the WPPSI-R assess a similar construct" (P 218, BSID-II Manual).

Interview schedules on social maturity or adaptive ability such as the Vineland Adaptive Behaviour Scales (VABS) could be included in the battery of tests to assess a child's functioning in several dimensions related to daily life. This Scale has been inconsistently used by different assessors throughout the course of follow-up. Interestingly, Rosenbaum et al (1995) reported that the Vineland Adaptive Behaviour Scales has been found to be more informative as a global indicator of a child's functioning than is a list of his specific impairments! A children's self-esteem scale may be useful when the child is older to see whether his perception of being born a VLBW affects a child's overall performance both cognitively and academically. These are but some means of increasing information which will in turn support or refute the initial findings of the existing data. In other words, existing data that is utilised through the ex post facto approach could be supplemented by a new set of data based on the above measures. This set of data would be from a different group of eight year old
children and efforts would have to be made to keep these as close as possible to the 'retrospective' group so that meaningful comparisons could be made. Furthermore, it may be both enlightening and interesting that future studies involve VLBWs at twelve years of age since this is the time they sit for their Primary School Leaving Examination (PSLE). This situation will certainly provide national norms!

Much work needs to be done in overcoming the weaknesses found in this study. It is recognised firstly that certain assumptions have been made here about the reliability and validity of the design. There is also the temptation of weakening the design in order to make data collection easier. In addition, there is the ethical dilemma of placing the targets of the study before the needs of the child and his parents as well as the tension in being both researcher and psychologist in data collection.

As seen in this study, the nature of VLBW data is such that both qualitative and quantitative approaches can be readily used in investigating outcomes, that is, methodological triangulation. This and investigator triangulation are the more commonly used types. Applying the latter method to future studies of VLBW children, teachers' contributions via rating scales will be invaluable as this provides a different perspective to the child and his situation. Prospective studies on local VLBW children should also attempt to adopt other types of triangulation such as time triangulation which involves looking at the same events over a period of time.

In McCormick's (1996) article "The outcomes of very low birth weight infants: are we asking the right questions", she pointed out that current follow-up studies "tend to ignore the theoretical and empirical experience of
factors influencing child health and development” (Page 872). She presented the underlying model in most studies as:

**Figure 10** Conceptualisation of current follow-up studies:

Very Low Birth Weight/ Premature → Neuro-developmental outcomes

To illustrate her point, she carried out multiple regression analyses on five outcomes of children assessed at school age: limitations in usual activities due to health, maternal ratings, behaviour problems, social competence and cognition (I.Q.) and factors such as neonatal stay, maternal education and mental health. Reporting significant influence of some of the factors on outcome, she concluded that “these findings could be predicted from the literature on each of these individual outcomes, and suggest a far more complex situation than the simple paradigm of causality underlying most follow-up studies”. (Page 873). This situation is represented by:

**Figure 11** Conceptualisation of future studies

Risk Factor → Post-discharge Environment → Outcomes

Neonatal Status
Specific Anatomic, or Physiologic, or Maturational Event

Outcomes
Morbidity
Functional status
Behaviour
Affect
Cognition
Self-esteem
Physical growth
A comparison of the above models brings one to a realisation that there is so much more than meets the eye in VLBW follow-up. A closer look at the earlier model (Figure 10) seems to suggest a unilateral relationship involving two broad areas of concern whilst the latter (Figure 11) advocates an intricate relationship comprising interaction among a number of variables. The researcher's interpretation of the models is that the first describes a relatively 'simplistic' view of follow-up as a *product* whilst the latter depicts a more realistic picture of it as a *process*. It is possible that whilst McCormick (1996) presented the first model as underlying most VLBW studies, there could have been some who, by way of recommending *continued* follow-up, recognised the underlying *process* instrumental in revealing increased difficulties with time.

Although it is clear that more needs to be done in proposing a model for effective follow-up within the Singaporean context, this study suggests that it is time for all those involved in working with VLBWs to look anew at follow-up as a process together with its surrounding influences. To begin with, teachers could be empowered by the knowledge that a child was born with a very low birth weight and is therefore at risk for subtle difficulties within a mainstream setting. Quoting Yssledyke and Thurlow's work (1984), O'Callaghan et al (1996) wrote: "Teachers familiar with the child's classroom performance are reliably able to identify children who are struggling with their learning". They added, "The advantage of teacher reports is that detailed assessments of multiple academic areas are possible by a person familiar with the child's performance over time." (page 923). Presently, the key area of teachers' contribution to the lives of local VLBW children in mainstream schools tends to be viewed as 'good to have' but optional. It must be said that on this basis, the teachers who were informed by parents of
their child’s VLBW history or contacted by the psychologist over his or her difficulties in the course of follow-up have thus far been appreciative of the information. One teacher was recorded in a child’s medical records as wishing that someone had told her about earlier about VLBWs and their being at risk for problems as she would have understood and therefore worked with him differently.

Further research in ascertaining the importance of this contribution followed by evidence-based recommendations to the local educational authorities is encouraged. Enhanced understanding of the consequences of being an apparently normal VLBW child by the educationalists will go a long way in their accommodation of subtle difficulties and their assistance in fulfilling the learning needs of these mainstream albeit special children.

Changes in one’s perception of what it means to born with a very low birth weight and what it takes to monitor these children are crucial in order for progress to be made in VLBW research. Cited at the outset of this thesis (page 2), Barsky and Siegel’s decade-old quotation still holds true: “the previous struggle for maintaining the survival of VLBW infants is giving way to determining what the possible sequelae for these infants in terms of long range functioning are. The subsequent development of the VLBW infant is a question that concerns both parents and the professionals who work with them” (page 275).

To conclude, this study has aimed at investigating the school performance and psychological functioning, that is, cognitive ability, behaviour and motor skills in a sub-group of VLBW children of ethnic Chinese origin in mainstream schools. It also sought to identify issues pertaining to the follow-up work that is ongoing. This work simply represents the efforts of a hard pressed researcher wanting to make an educational difference in a clinical setting.
REFERENCES


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Yeo & Ho (1996) ‘Clinical factors associated with adverse outcome in babies weighing less than 1500 grams at birth’. Singapore Paediatric Journal. 38, 1, 6 - 10.


APPENDIX 1

Structured form used by the multi-disciplinary team for VLBW follow-up
CONFIDENTIAL

PERSONAL PARTICULARS

CHILD

Drug Allergy: Yes / No
Birth Wt ____________ gm (AGA, SGA, LGA)
Gestation: ____________ (Date)
______________ (Scoring)

Place of Birth: ____________________________

Date of Assessment: ____________
Date of Birth: ____________
Chronological Age: ____________
Adjustment For Prematurity: ____________
Corrected Age: ____________

Child accompanied to assessment by:
1. Mother
2. Father
3. Grandparents
4. Baby Sitter
5. Maid
6. Others (specify):

Child fostered out: Yes / No

Care-Giver:
1. Mother / Father
2. Grandparents
3. Baby Sitter
4. Child Care Centre
5. Maid
6. Others (specify):

Diet: Formula:
Solids:

FAMILY HISTORY

1. Mental retardation
2. Chromosomal disorder
3. Dysmorphic
4. Seizures

SPoken LANGUAGE AT HOME

1. English
2. Mandarin
3. Chinese dialect (specify)
4. Malay
5. Tamil
6. Others (specify)

Tel No.: ____________ (H) ____________ (O)
Other Contact No.: ____________________________

MOTHER

Name: ____________________________
Age: ____________________________
Education: ____________________________
Occupation: ____________________________

FATHER

Name: ____________________________
Age: ____________________________
Education: ____________________________
Occupation: ____________________________
Family Composition:

Combined Family Income:

Type of Housing:

Social/Financial Problem: Yes / No
Specify:

EDUCATION

Attending: □ Nursery □ K1 □ K2 Primary □ Others

School: ____________________________________________

Teacher’s Name & Contact: ________________________________________

Results

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<th>2nd Language</th>
<th>English</th>
<th>Maths</th>
<th>Overall</th>
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<td></td>
<td></td>
</tr>
<tr>
<td>P2</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Completed Immunisations: Yes / No

Any hospitalization: Yes / No

If yes, specify:

No: Duration

Illness:

Childhood illness: Yes / No
Non-febrile seizures: Yes / No
Urinary tract infection: Yes / No
Hydrocephalus: Yes / No
If yes, any VP shunt?

Family history of psychiatric disorders: Yes / No
Family history of developmental problems: Yes / No
If yes, specify:

Cardiac problems: Yes / No

If yes, specify:

Acute bronchitis / bronchiolities: Yes / No
Bronchial asthma: Yes / No
Pneumonia: Yes / No
Gastroenteritis: Yes / No
Food allergies: Yes / No
Surgical procedures: Yes / No
Any visible scars: Yes / No
### DEVELOPMENTAL MILESTONES AT CORRECTED AGE

1. **GROSS MOTOR:**
   - 

2. **FINE MOTOR:**
   - 

3. **LANGUAGE:**
   - 

4. **SOCIAL:**
   - 

### CLINICAL EXAMINATION

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<th>Height: (percentile)</th>
<th>OFC: (percentile)</th>
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<td>Teeth:</td>
<td>Blood Pressure:</td>
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<td>Nodes:</td>
<td>Genitalia:</td>
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<tr>
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<td>Thoracic cage:</td>
<td>Spine:</td>
</tr>
<tr>
<td>Nose:</td>
<td>Lungs:</td>
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<td>Heart / Pulses:</td>
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### SPECIFIC PROBLEMS

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<td>0. Nil</td>
</tr>
<tr>
<td>1. Spastic diplegia</td>
<td>1. Hypotonic upper limbs</td>
</tr>
<tr>
<td>2. Spastic hemiplegia</td>
<td>2. Hypotonic lower limbs</td>
</tr>
<tr>
<td>3. Spastic quadriplegia</td>
<td>3. Hypotonic trunk</td>
</tr>
<tr>
<td>4. Athetoid CP</td>
<td>4. Hypertonic upper limbs</td>
</tr>
<tr>
<td>5. Ataxic CP</td>
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<th>Wear glasses: Yes / No</th>
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<td>2. Amblyopia</td>
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<tr>
<td>3. Squints</td>
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</tr>
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<td>4. Others, specify:</td>
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<table>
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<th>Hearing disorder: Yes / No</th>
<th>Uses hearing aid: Yes / No</th>
</tr>
</thead>
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<tr>
<td></td>
<td>If abnormal, history follow-up:</td>
</tr>
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<table>
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<td>2. Abnormal, specify:</td>
<td>If abnormal, history follow-up:</td>
</tr>
<tr>
<td>3. Not done</td>
<td></td>
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</table>

Page 3
PSYCHOLOGICAL ASSESSMENT

TESTS GIVEN
- Bayley Scales of Infant Development (2nd Ed.)
- Vineland Adaptive Behaviour Scales
- Stanford-Binet Intelligence Scale (4th Ed.)
- Leiter International Performance Scales
- Wechsler Intelligence Scale for Children (3rd Ed.)

TEST BEHAVIOUR (Child was accompanied by ______________________ / on own during the session)

1. REACTION DURING TEST PERFORMANCE
- Normal activity level
- Initiates activity
- Quick to respond
- Hyperactive / active / depressed / restless
- Waits to be told
- Urging needed

2. EMOTIONAL INDEPENDENCE
- Socially confident
- Realistically self-confident
- Comfortable in adult company
- Assured
- Shy, reserved
- Distrust own confidence / overconfident
- Ill-at-ease
- Anxious about success

3. PROBLEM SOLVING BEHAVIOUR
- Persistent
- Eager to continue
- Challenged by hard tasks
- Gives up easily
- Seeks to terminate
- Prefers only easy ones

4. INDEPENDENCE OF EXAMINER / ADULT SUPPORT
- Needs minimum of commendation
- Needs constant praise

5. OTHERS:
   (a) Attention span: Stage 1 2 3 4 5 6
   (b) Level of energy: Low 1 2 3 4 5 6 High

GROSS MOTOR FUNCTION
- Smooth functioning 1 2 3 4 5 6 Poor coordination
- Remarks: Walked at

FINE MOTOR FUNCTION
- Smooth functioning 1 2 3 4 5 6 Poor Coordination
- Hand preference L R
- Prehension
- Remarks:

LANGUAGE FUNCTION
- English / Mandarin / Malay / Tamil / Others:
- Longest phrase / sentence heard / reported:
- Remarks: Talked at
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<th>RESULTS</th>
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<td>□ Intervention</td>
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Re-assessment in _________ months / years / Review _________ progress / discharge.

Psychologist: __________________________