

CHAPTER ONE

INTRODUCTION

1.0 INTRODUCTION

Every baby with or without Down Syndrome is a unique person. He will grow up having his own smile, his own laughter, his own distinctive habits, likes and dislikes. The development of his personality and of his physical and mental being will be determined by inherited genetic factors combined with cultural and environmental influences. All these factors make up a potential, that can be realized in time with growth and good health, with education and training, with a warm and happy environment.

It is a parent's challenge to seek out his child's capabilities and areas of possible development, to understand his limitations, both physical and mental, and to provide him with opportunities to grow and learn as he is able.

The child with Down Syndrome like other children, has a potential, but it is a limited one. It is limited even before the time of birth, from the very beginning of the mother's pregnancy. For, in the earliest stages of growth in the mother's uterus, the developing individual with Down Syndrome carries a genetic imbalance, that is by a simple mistake, he has an extra set of genes or an extra chromosome. This extra one is added to the usual number of 46 chromosomes which are found in every cell in his body. It is usually a perfectly normal chromosome, but the extra set of genes creates a fundamental genetic imbalance. This genetic imbalance causes the alterations of growth and development seen in the child with Down Syndrome and it is the most important factor in determining what his potential will be.

Down Syndrome is the most common serious problem in development seen in a newborn. It occurs more frequently than any other specific kind of mental deficiency or any single error in early development such as cleft lip or cleft foot. On the average, one in 640 babies has Down Syndrome.

A word is necessary regarding the term “Down Syndrome”. Down Syndrome (DS) was first described in 1866 by John Langdon Down. Nearly 100 years later, Jerome Lejeune and his associates showed that it is due to the presence of an extra copy of chromosome 21, and today the syndrome is the single most common genetic cause of moderate mental retardation. According to Langdon Down, “Syndrome,” in this context means a recognizable pattern of altered development.

Some people may feel “Down Syndrome is a rather stuffy, scientific name for the common old age problem of “mongolism”. But there are good reasons why “mongolism” deserves a new name and a fresh approach. There are few physical or mental conditions that are burdened with as many misconceptions as is “mongolism”. The very phrase “mongoloid child” suggests racial or physical reference to an Oriental people that is unsubstantiated in the past. “Mongoloids” were often believed to be hopelessly retarded and unmanageable, and were denied the understanding and simple training all children deserve. Today’s knowledge about the genetic and physical aspects of the syndrome and a new resolve to tackle the problems of mental deficiency have given children with Down Syndrome a somewhat brighter future. This study is an investigation into the communication disorders of Malaysian children with Down Syndrome.

1.1 STATEMENT OF THE PROBLEM

The problem of mental retardation is coming to the forefront in many societies today. In Malaysia, early intervention programmes, pre-school nurseries and integrated special education strategies have demonstrated that children with Down Syndrome can participate in many learning experiences which can positively influence their overall functioning. It is now well established that children with Down Syndrome are delayed in language acquisition. It also appears likely that they are weak specifically in syntactic development and perhaps in other language domains.

Research has shown that early intervention environmental enrichment and assistance to their families will result in progress that is usually not achieved by children who have not had such educational and stimulating experience and support. Speech and language represent a complex spectrum and thus present many challenges to the child with Down Syndrome.

The basis for communication is social interaction and conversational skills such as turn taking that can be developed at a young age. According to Kumin, Goodman and Council (1996:3), there are many pre language skills that can be given treatment before the child is able to talk, so they suggest therapy should begin as early as before the child speaks its first word. With the development of modern molecule technologies and the mapping of the human genome, communication disorders in Down Syndrome children can be identified and rectified.

1.2 RATIONALE OF THE STUDY

It can be regarded as a truism that all children with mental syndrome exhibit some form of impairment. Many children with Down Syndrome have been neglected in the past. With proper care and steps taken, these children can be taught to live their lives as normally as possible and be assimilated into the society. Because Down Syndrome is the most common chromosomal cause of retardation and because it can usually be identified from birth, this subgroup is the best studied of all subgroups of children with mental retardation. Many studies also indicate that children with Down's Syndrome are especially impaired in their development of language compared with other groups of children with mental retardation. They are consistently below the chronological age expectations and frequently show deficits that are incommensurate with other areas of development. To be sure, a major issue in research on children with Down Syndrome has become the extent to which some language domains (e.g. phonology, syntax and vocabulary) may be specifically impaired that is lower than mental age would predict.

The majority of children with Down Syndrome have been deprived of a normal school environment by their parents. This is due to the ignorance of parents, the public and even some professionals. In most societies, including Malaysia, the problem has been largely neglected due to ignorance and poverty causing the children to be totally ignored. However, growing knowledge and improved orientation towards these problems are making professionals and the government to recognize and approach the problem in an increasingly systematic and comprehensive way.

Parents of children with intellectual disabilities think that they only need to be trained in self-help skills. Ignorance on the part of parents is the cause for this opinion. Limited facilities and training centers for such children further adds to the ignorance of the general public. At one time, there were only very limited facilities and training centers for such children. However now, in Malaysia the government has set up special centres in many schools to cater for mentally retarded children. Despite this, the general public tends to ignore these special children.

Most centres set up in schools provide various kinds of lessons and activities for children with Down Syndrome without actually understanding the actual type of communication disorders that they are facing. It is the duty of other citizens to help these unfortunate fellow citizens to attain and lead a life as normal and full as possible. It is necessary to explore into the field of mental deficiency before any step is taken for providing care for these intellectually challenged individuals in centres or schools.

This study will be a preliminary step, an investigation to achieve this aim.

1.3 OBJECTIVE OF THE STUDY

The Education ministry has set up centres for special children in many secondary and primary schools. These centres provide speech and language intervention through various programmes of direct therapy and coordination with educational programmes. Many parents just send their children to these centres without knowing the actual type of communication disorders faced by their children. The speech and language intervention

programmes provided in many of these centres are also designed without consideration of the actual type of communication disorders of the children.

The main goal of this study is to identify the communication abilities of children with Down Syndrome.

1.4 SIGNIFICANCE OF THE STUDY

The success of mastering a language rests on the personal dimension, that is the learner's attitudes, abilities, interests and exposure to the language and these should be considered with great attention. Most children with Down Syndrome face problems of language disorders and it is hoped that this study will help special school teachers to detect some of the language disorders before conducting lessons for them.

Many more children with Down Syndrome are now entering mainstream schools. Pressure from parents with support from voluntary organizations has led to the opening of centres to integrate children with special needs into mainstream schools if the parents so wished. Inevitably many teachers will find the idea of including children with Down Syndrome into their classrooms daunting and will initially be apprehensive. However, experience shows that most teachers do not have the skills to understand these children's particular individual needs in order to teach them effectively and sensitively.

A child with Down Syndrome should be given the opportunity to attend mainstream schools. Increasing amounts of research have been published enhancing knowledge about the capabilities of children with Down Syndrome and their potential to be successfully

included while parental awareness of the values and the benefits of inclusion in schools has grown.

It is hoped that this study will create awareness among parents of special children regarding the language disorders and communicative skills demonstrated by children with Down Syndrome.

1.5 RESEARCH QUESTIONS

- i. Do children with Down Syndrome respond to and initiate communication?
- ii. Which type of communicative skills are frequently used by Down Syndrome children?
- iii. How do the strengths and weaknesses in communication abilities vary among children with Down Syndrome?

1.6 DEFINITION OF KEY TERMS

- a) Communication - The ability to understand what one hears and the ability to express oneself in speaking and writing.(Valette 1973:25)
- b) Verbal Communication - A medium of oral communication that employs sounds, syllables, words, sentences and discourses of language.
- c) Non-Verbal Communication - Reciprocal interaction between 2 or more individuals without the use of oral language.
- d) Sign language - Means of communication in which gestures perform the function of words.

- e) Receptive Language - The ability to translate sound patterns into their Intended meanings.
- f) Expressive Language - Ability to use conventional symbols to communicate one's perceptions, ideas, feelings or intentions to others.
(Nicolosi, Harryman, E. and Kresheck, J, 1989:141, 142, 172 and 244)

1.7 LIMITATIONS OF STUDY

This small scale study may not reflect the general communication disorders faced by Down Syndrome children throughout Malaysia but it will provide a miniscule study of some of the communication disorders faced by a sampling of Down Syndrome children, as obtained in the group under study. The study is limited to identifying the communication abilities of a group of children with Down Syndrome. The findings may not be totally representative of the strengths and weaknesses of other children with Down Syndrome in other schools. The medical history of the children in this study is not known as it is not a criterion to be registered in this centre.