

## Chapter 90

# Living With Cerebral Palsy in Malaysia: Me, Myself, and Others

**Rajvin Kaur Randhawa**

*HELP University, Malaysia*

**Kiirtaara Aravindhan**

*HELP University, Malaysia*

### ABSTRACT

*The authors in this chapter highlights the reality of cerebral palsy in Malaysia. The chapter is a blend experiential account and factual details. The experiential fragment includes a personal case study, providing 32 years' worth of experience and first-hand details on the life of a cerebral palsy individual in Malaysia. The factual fragment provides researched information on the general reality of cerebral palsy in Malaysia, which includes regulations, existing services and support systems, ergonomics, awareness, and inclusion. This chapter also includes an interview with a fellow CP individual. The chapter ends with an interesting take-home message that aims to encourage and motivate those negatively affected.*

### WHAT IS CEREBRAL PALSY?

Most people are probably familiar with the term Cerebral Palsy (CP). However, not everyone is familiar with the etiological concept of CP and how an individual with CP is affected. Therefore before delving any further, let us begin by explaining what is CP all about.

Pathologically, cerebral palsy is defined as an abnormality of motor function. It refers to the inability to move and control movements or loss of muscle control due to damage on one or more parts of the brain (Richard & Malouin, 2013). Severity and the muscle affected is dependent on which part of the brain has a lesion. It is commonly acquired at the foetal or infant stage, causing issues of sensation, feeling, perception, cognition, communication, and behaviour (Richards & Malouin, 2013). Cerebral palsy is a non-progressive condition, meaning that it does not worsen or change over time.

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Classification of Cerebral Palsy varies. MyChild at Cerebralpalsy.org (n.d.) in their website provides excellent explanation on these classifications. According to their website, some are classified according to severity, topographical distribution, motor function and based on The Gross Motor Function Classification System (GMFCS). Topographical distribution in laymen terms can be described as which part of the body is affected.

It is important to understand that there are two different terms to describe how the body is affected; Plegia, meaning paralyzed; and Paresis, meaning weakened. If just one part of the body is affected, it is monoplegia or monoparesis. Diplegia or diparesis is when the legs are affected more than the arms. Quadriplegia or quadripareisis is when all four limbs are affected. There is also hemiplegia or hemiparesis, where a vertical half of the body, meaning the arm and leg on one side of the body is affected. Paraplegia or paraparesis describes the lower half of the body, which includes both legs affected (MyChild at Cerebralpalsy.org, n.d.).

Under motor functions, one can be spastic or non-spastic. Spastic CP is when there is an increase in muscle tone also known as hypertonia whereas non-spastic means muscle tonus fluctuates or decreases often referred to as hypotonia. Muscle tone is essential in contraction and relaxation of the muscles, for the muscles to work together. In spastic CP, the muscles are always contracting. Therefore, the limbs become tensed and resistant to movement. Even if there were movements, they are irregular and jerky (MyChild at Cerebralpalsy.org, n.d.).

## **CEREBRAL PALSY IN MALAYSIA: AN OVERVIEW**

### **Regulations**

Malaysia signed the Convention on the Rights of Persons with Disabilities (CRPD) on the 8th of April 2008 and later ratified the convention on the 19th of July 2010. The signing of the convention led to the establishment of The Persons with Disability Act 2008. The Persons with Disability Act 2008 is “an Act to provide for the registration, protection, rehabilitation, development and wellbeing of persons with disabilities, the establishment of the National Council for Persons with Disabilities (PWD), and for matters connected therewith” (Act 685, 2008). This act has since then provided the legal foundation for policies and legislations concerning disable individuals.

The act defines person with disability as “Those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society.” (Act 685, art. 2), therefore includes those with cerebral palsy.

### **Services and Support System**

There are various service and support systems for the disabled community in Malaysia be it governmental or non-governmental organisations.

#### **Governmental Support**

A national body, the National Council for Persons with Disabilities was formed in 200, in line with the implementation of PWD Act to oblige and oversee the policies implemented under the Act. The line

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