

## Understanding Cerebral Palsy

### Abstract

*Inclusion within sports, recreation, fitness and exercise is essential as every individual has the right to engage, participate in and have a choice of different sports, recreation, fitness and exercise activities. This is no different for individuals who have Cerebral Palsy. Although, in society, one of the main issues is how to make activities accessible and inclusive for individuals with disabilities. Additionally, within society there can be little understanding and appreciation of how different medical conditions can affect individuals and what this means when trying to engage in an activity. Therefore, the aim of this article is to give readers an understanding of Cerebral Palsy and how it can affect individuals. It will discuss the different types and forms of Cerebral Palsy, how it can affect individuals as well as the importance of recognising the individual even though they may have Cerebral Palsy.*

**Keywords:** *Cerebral Palsy, Functional Implications of Cerebral Palsy, Cerebral Palsy and Impairment, Individuals with Cerebral Palsy*

### Introduction

CPISRA (Cerebral Palsy International Sports and Recreation Association) is extending its activities to facilitate and promote research into exercise, sport and recreation for individuals with Cerebral Palsy and related conditions. This is in response to the increasing interest in sports, recreation, fitness and exercise for individuals with Cerebral Palsy and a demand for further research. In embarking on this activity, we at CPISRA quickly became aware the need to increase awareness and understand various sport and recreation participation aspects relating to individuals with Cerebral Palsy. Before understanding these various aspects though, there is firstly the need to have a critical understanding of Cerebral Palsy. As a result, this article will be based on understanding Cerebral Palsy. It will cover ‘what is Cerebral Palsy’, ‘the different effects of Cerebral Palsy’ and ‘the individual with Cerebral Palsy’. This will be the first of a series of articles.

## **Introducing disability and the individual**

Understanding disability, the fact that individuals have disabilities and that individuals with disabilities are still individuals, is important when understanding Cerebral Palsy and inclusive forms of sports, recreation, fitness and exercise. This is because previous research and literature notes that whilst having a disability does not make an individual ‘not normal’ and ‘unable’ as a human being (Goodley, 2011, 2013; Hughes et al, 2005), it can provide the individual with physical, emotional and psychological challenges. Whilst these challenges, such as other peoples' negative attitudes towards a person with a disability or inaccessible buildings, are not always something that is directly caused by an individual's medical condition. Challenges can act as barriers to participating in different activities and in the individual experiencing determination, autonomy, freedom, confidence and independence (Darcy et al, 2017; Dattilo, 2012; Henderson et al, 1994; Kleiber et al, 2002, 2011; Lumsdaine and Thurston, 2017; Tecklin, 2008; Thomas, 2007). Similarly, all type of barriers (whether linked to the individual's medical condition or not) can block or limit individuals chances of experiencing fun, enjoyment, positive health and ability (Dattilo, 2012; Devine and Mobily, 2017; Kuppan, 2017). Consequently, limiting their ability to experience their life to the optimum (Dattilo, 2012; Devine, 2003).

Understanding the diversity of impairments which individuals with Cerebral Palsy have and what their needs and requirements are is important. This is because individuals with Cerebral Palsy have a human right morally, and under UN international law, to a quality of life and to access to health, recreation, education and to different services (Singleton and Darcy, 2013; Stanton, 2002). Thus, it is essential to understand the individual's abilities and to work around and with them (Broach, 2016; Dattilo, 2012; Long, 2008; Short, 2016). For example, in terms strength and conditioning for sport performance and an athlete with Cerebral Palsy, it is important to recognise their possible physical difficulties (such as a lack of balance, a lack of fine motor control or poor coordination), and balance this up with the training needs of the athlete and what they desire to gain from strength and conditioning (Goosey-Tolfrey and Mason, 2017; Jeffreys and Moody, 2016; Short, 2016). Although, individuals are affected by Cerebral Palsy in different ways and their needs and requirements can vary greatly, which can therefore affect each of

their abilities and levels of engagement with different activities uniquely (Long, 2008; Stanton, 2002, 2012).

Individuals with disabilities are also still individuals and have different human needs like anyone else such as the need to be self-fulfilled (Kuppan, 2017). As a result, as well as acknowledging individuals' needs and requirements, it is important to also acknowledge the individual behind the disability and their need to feel satisfied and happy in life (Dattilo, 2012; Devine and Piatt, 2013). Whilst standardising methods of inclusion can create a simpler way of creating inclusive environments, standardisation is not effective in providing individuals with Cerebral Palsy the optimum experience of a particular activity (Kunstler and Daly, 2010). Standardisation is more likely to provide individuals with limited choices in activities, which can risk participation to be unattractive to those with Cerebral Palsy (Dattilo, 2012; Kunstler and Daly, 2010). Additionally, if activities cannot appeal to individuals with Cerebral Palsy and / or that they are not accessible to individuals, this then limits further their ability to experience independence, personal enjoyment and some / total control of engaging in an activity (Dattilo, 2012, 2015, 2016; Kunstler and Daly, 2010; Long, 2008; Stanton, 2002). Working around and with what individuals can do can therefore enable the individual more to gain a better sense of determination, freedom, control and autonomy (Dattilo, 2012; Kleiber et al, 2008; Schleien et al, 2014). Hence, whilst the next section will explain 'what is Cerebral Palsy' and 'the nature of Cerebral Palsy', later on the author will then discuss Cerebral Palsy in relation to the individual.

### **What is Cerebral Palsy?**

The term Cerebral Palsy comes from the meaning of both cerebral and palsy, where cerebral means the brain and palsy means disorder of movements or posture (Porretta, 2017; Stanton, 2012). It is a neurological condition which can affect people in different ways, resulting in different types and levels of impairment(s). Cerebral Palsy may occur at birth where specific parts of the brain have been damaged as a result of a medical complication(s) (Foose and Ardivino, 2008; Swann-Guerrero and Mackey, 2008; Tecklin, 2008). However, Cerebral Palsy can occur

before or right after birth due to, for example, a brain haemorrhage, a tumor or an injury / trauma that damages the brain (Porretta, 2017). Similarly, as the brain communicates multiple messages to different parts of the body that performs different bodily functions (such as the movement of muscles, the processing of information and coordination), any damage to the brain can result in a range of different impairments depending upon which part of the brain has been effected. Therefore, regardless of whether the brain was damage before, during or right after birth, Cerebral Palsy can result in different levels of impairments and the individual having different needs and requirements to someone else with Cerebral Palsy or with another medical condition(s) (Porretta, 2017). This will be explained more in the next section.

### **Types and effects of Cerebral Palsy**

Due to the way in which the brain may be damaged, individuals with Cerebral Palsy will have a diverse range of impairments. Therefore, having Cerebral Palsy does not mean that the individual will have the exactly same impairments as to someone else with Cerebral Palsy (Lavay, 2017; Porretta, 2017; Tecklin, 2008). This is because brain's ability to process different pieces of information and to send signals and information around the body is important as it is a core component of how the body develops, moves and learns to interact with external environments such as the home, school, leisure and recreational spaces or sporting events (Kenney et al, 2015). As a result, any alteration and abnormal neurological activity (such as the delay of the brain processing information or the abnormal loosening of muscles), can have an impact unique on the individual's abilities for example to walk, speak, chew or to understand their spatial awareness (Lavay, 2017; Porretta, 2017; Tecklin, 2008). Therefore, Cerebral Palsy can affect each individual in different ways.

Under the umbrella of Cerebral Palsy, there are generally three main types of Cerebral Palsy - *Spastic*, *Athetoid* and *Ataxtic* (Foose and Ardovino, 2008). The reasons for these different types is because depending upon what parts of the brain has been damage, different levels / type of damage to the brain can result in different consequences to how the brain then communicates to different parts of

the body (Lavay, 2017; Porretta, 2017; Tecklin, 2008). Spastic, Athetoid and Ataxic have the following characteristics.

- Spastic Cerebral Palsy is where the condition has affected the tightness of the muscles and the mobility of the limbs. The tightness of the muscles, which is caused by the muscles constantly wanting to contract when they are stretched quickly, can cause discomfort for the individual and also alters the individual's physiological growth. In some cases, the individual can be prone to further medical complications. For example, an individual with high muscle tone in their legs can find it difficult to stretch out their legs leading to their legs being bent most of the time. If there is a high level of muscle tone or tightness within the legs, this could result in the individual finding it difficult to walk and balance unaided, where they may need surgery to lengthen the muscles (such as hamstrings) to prevent further reduction in the ability to walk and move. They may also require the use of a wheelchair for everyday living.
- Athetoid Cerebral Palsy is a type of Cerebral Palsy where the individual has low and/or fluctuating muscle tone. Whilst an individual with Athetoid Cerebral Palsy may be at low risk of muscle contractions and as a result the associated discomfort, individuals with Athetoid Cerebral Palsy have difficulty with maintaining body and/or head positions. This therefore can lead to poor posture and difficulty in controlling different fine movements which can include hand movements, but also chewing and speaking. Depending upon the level of Athetoid Cerebral Palsy, many individuals may face major challenges such as sitting independently, using an ordinary computer keyboard or doing an activity that requires fine motor skills.
- Ataxic Cerebral Palsy is the least common form of Cerebral Palsy, affecting around 5% to 10% of all people with Cerebral Palsy. It is a type of Cerebral Palsy that affects an individual's coordination and balance. Ataxic Cerebral Palsy is characterised by low muscle tone, coordination and balance difficulties, which can create difficulties in walking and daily living activities such as dressing, eating and speaking. Movements are characterised by

imprecision and instability, because Ataxia causes an interruption of muscle control. Ataxic Cerebral Palsy can also cause sensory difficulties and difficulties with motor control.

(Foosse and Ardovino, 2008; Porretta, 2017; Tecklin, 2008).

As identified in the descriptions above, depending upon what type of Cerebral Palsy an individual has, this can affect their ability and determines how much support or adaptations they might need or want. However, individuals can have a mixture of different types of Cerebral Palsy (such as Spastic and Athetoid), which can make their conditions increasingly complex.

Along with Cerebral Palsy being able to be classified by type, Cerebral Palsy can also be understood according to topography classification or, in other words, which locations of the body have been affected. Equally, this can help us further to understand how Cerebral Palsy can affect function. From a generic perspective, Cerebral Palsy can affect individuals just in one limb, leg or arm, to affecting individuals in all four limbs, head, neck and trunk. In more detail, Porretta (2017: 272) explained that a topographic classification of Cerebral Palsy consists of six classifications which are:

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- *Monoplegia—any one body part involved*
- *Diplegia—major involvement of both lower limbs and minor involvement of both upper limbs*
- *Hemiplegia—involvement of one complete side of the body (arm and leg)*
- *Paraplegia—involvement of both lower limbs only*
- *Triplegia—any three limbs involved (a rare occurrence)*
- *Quadriplegia—total body involvement (all four limbs, head, neck, and trunk)”*

As can be seen above, Cerebral Palsy can affect individuals in numerous parts of the body and by effecting some of these locations, the effect in overall function may be varied and substantial (Porretta, 2017). For example, if an individual with Athetoid Cerebral Palsy was quadriplegic, the individual's Cerebral Palsy is likely to cause difficulty in the individual's ability to sit up unaided (due to affecting the trunk), cause difficulty in them controlling their arms and legs when performing a task such as walking, pushing or picking something up (due to affecting the arms and legs) and cause difficulty in them turning their head (due to affecting the neck) (Porretta, 2017).

From understanding the topographical classification of Cerebral Palsy, there is the additional ability to understand *how* and in *what way* Cerebral Palsy has affected a person. This is more commonly classified by using the Gross Motor Function Classification System, which categorises individuals' functions from 1 to 5 with 1 being those who are the most able to five being those with the most complex impairments (Palisano et al, 2007). Furthermore, the Gross Motor Function Classification System has been particularly useful in assisting professionals (such as physiotherapists) having an overall understanding of an individual's Cerebral Palsy and how their Cerebral Palsy has affected their function and what medical interventions that they may need if any (Alriksson-Schmidt et al, 2017; McCormick, 2017). However, despite this, it can also be argued that classifications of Cerebral Palsy can overlook the other possible effects has Cerebral Palsy can have on an individual such as speech difficulties or learning impairments (Stanton, 2012), as well as what an individual can do with assistance or by using a specific technique adaptation such as a roll-in shower.

### ***Critically thinking about Cerebral Palsy, function and the individual's abilities***

When we think about Cerebral Palsy and how Cerebral Palsy can affect different individuals, not only is it useful to understand the types of Cerebral Palsy as well as how it can affect different locations of the body, but it is also important to remember the element of function and how that can be affected. The saying that *"If you have 100 people with CP in a room, you won't find no two individuals that*

*the same*” is a really good example of this and how important the understanding of individual’s *own* function is when understanding the individual and their Cerebral Palsy. This is because mobility, flexibility, coordination, sensory and intellectual abilities plays a key role in function (Kenney et al, 2015; Lavay, 2017), where any alterations / impairment to any of those functions can interrupt / delay the development and abilities of the individual.

Lavay (2017) explained that medical conditions (particularly developmental conditions such as Cerebral Palsy) can delay or alter an individual’s development and this can provide implications to the development of their learning and/or sensory skills. Additionally, Foose and Ardovino (2008) highlighted that if a medical condition impairs a specific part of a person’s cognitive, physical, personal or social development, or that the person faces barriers (such as stairs, negative attitudes or poor delivery in education), then that person’s development can be slower. Consequently, depending upon the nature of the Cerebral Palsy which an individual has, Cerebral Palsy can result in mild to severe developmental delay and can cause individuals to have additional difficulties (for example difficulties in learning), which can alter their everyday life (Lavay, 2017; Porretta, 2017; Stanton, 2002, 2012). Although, also depending upon the developmental delay, this can also affect their overall level of impairment further regardless of whether for example they are quadriplegic or has Spastic Cerebral Palsy (Lavay, 2017). However, this does not stop the individual from developing or having the ability to learn new skills and to develop old ones (Dattilo, 2015, 2016). This is because from individuals experiencing different situations, engaging in different activities and learning about different ways in which they can do things whether with or without assistance, individuals with Cerebral Palsy can develop ways of overcoming challenges (Dattilo, 2012, 2016; Lavay, 2017). Therefore, as Tecklin (2008) explains, when understanding an individual’s Cerebral Palsy it is important to understand the full extent of an individual’s abilities and difficulties. However, as mentioned earlier, it is also important to remember about the individual behind the Cerebral Palsy.

## The individual behind the Cerebral Palsy

Medical conditions such as Cerebral Palsy can provide individuals with impairments which can limit or prevent individuals from doing certain activities, and together with negative social attitudes and a lack of inclusion in society, such conditions can make life challenging for the individual (Sparkes and Smith, 2002; Thomas, 2007). However, the idea of ‘having a disability’ does not mean that individuals stop having an identity or are not able to enjoy life (Hutchinson et al., 2003). This is because whilst medical conditions such as Cerebral Palsy affects function, individuals are still individuals with emotions, wants and desires (Henderson et al, 1994). They still are able to experience life, want to do specific things and have specific goals and aims in life, as well as the ability to want to control or influence what they experience and feel in everyday life (Devine, 2003; Goodley, 2011). Similarly, an individual with a disability is still a person with a personality, emotions, feelings, and someone who has desires (Hutchinson et al., 2003; Sparkes and Smith, 2002).

In their study of women’s with disabilities leisure experiences and their self-identity, Henderson et al (1994: 83) evaluated that:

*“The psychosocial impact of disability on self-identity and leisure depended on the nature of the disability, extent to which the woman had ascribed to traditional roles, and the reactions of others as social stigma”*

Whilst this is concerning women with different types of disabilities, such a statement is equally relevant to all types of individuals with disabilities and all types of individuals with Cerebral Palsy. This is because while conditions such as Cerebral Palsy do effect individuals (Hughes, 2014), medical conditions do not alter the individual’s ability to experience, have personal desires or to want many different things (Dattilo, 2012; Goodley, 2011; Hughes, 2014; Kuppan, 2017). As a result, even though it is important to understand the effects of the individual’s condition(s), is it also critically important to understand that the individual is still an individual and has different human needs as a person (Dattilo, 2012, 2016; Goodley, 2011; Kuppan, 2017). Similarly, both Goodley (2011) as well as Henderson et al (1994) states how the condition, negative attitudes of wider society and an inaccessible environment can affect the individual’s experiences of everyday life.

## Summary

The main aim of this article was to give readers some understanding of Cerebral Palsy and how it can affect individuals. It also highlighted the individual behind the condition of Cerebral Palsy and the importance of acknowledging their individuality.

Cerebral Palsy can be a complex condition, affecting individuals in different ways depending upon type and severity. It can cause individuals to have different levels of function and different needs. The effect of the condition can have implications for movement and other functions such as speech and learning, consequently affecting individuals' everyday lives. Modifications and different types of therapies and medical interventions are therefore important. In the context of sport, recreation, fitness and exercise, this is very important to note as making modifications can reduce barriers (such as stairs into a sport centre) or unnecessary hurdles (such as competition rules that do not consider that some athletes with Cerebral Palsy have involuntary movements or spasms), that can prevent, limit or put individuals with Cerebral Palsy at an unfair disadvantage. Equally, understanding Cerebral Palsy, how it can affect individuals as well as understanding what individuals' can and cannot do, helps to create activities and experiences that allows for maximal engagement and, subsequently, allows the individual to experience, enjoy or perform (in the case of sports performance) the activity effectively.

Along with understanding the condition of Cerebral Palsy and how it might affect people, it is important to acknowledge and see those with Cerebral Palsy as individuals with desires, wants and needs. Despite some individuals having medical conditions which affects their function, individuals are still individuals with emotions, wants, needs and desires, who are still able to experience everyday life. As a result, this means that they still have the human need to be fulfilled where they can also experience distress. Consequently, individuals with Cerebral Palsy still have the ability to feel, meaning that just objectifying who they are and what they want, overlooks them as people and individuality.

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