A STUDY OF CORRELATES OF MENTAL HEALTH IN CHILDREN WITH CEREBRAL PALSY AND AUTISM

STUDENT RESEARCH PROJECT
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2020

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PREFACE

Disability is conceptualized as being a multidimensional experience for the person involved. There may be effects on organs or body parts as well as effects on a person's participation in areas of life. Correspondingly, three dimensions of disability are recognized in **ICF** (International Classification of Functioning, Disability and Health, 2001), which are, body structure and function (and impairment thereof), activity (and activity restrictions) and participation (and participation restrictions). The classification also recognizes the role of physical and social environmental factors in affecting disability outcomes. Since 'disability' is used as an umbrella term for all degrees of impairment, the distinction between different disabilities is often blurred. Thus, this study aims to compare and understand the differences between Cerebral Palsy and Autism; two disabilities which are very different in nature.

Chapter 1: Highlights the understanding of the basic concepts of Disability, Cerebral Palsy and Autism in association with different types of variables.

Chapter 2: Focuses on the literature survey of the selected variables of the study.

Chapter 3: Delineates the methodological plan and procedural details adopted for the present research work.

Chapter 4: Highlights the result section. Quantitative and Qualitative findings have been highlighted.

Chapter 5: Delineates all the relevant explanations and findings to the hypotheses of the present study, along with research evidence that support it.

Chapter 6: The conclusion of the study along with the limitations, originality of work, and areas of further research has been discussed.

Chapter 7: Provides the complete references of all different academic research articles cited in this study.

Chapter 8: Appendices

ACKNOWLEDGEMENT

The final materialization of this Research Project owes a great deal to the support and guidance of many significant individuals.

A sincere note of gratitude for Sister Christine Coutinho, Principal of Loreto College, for her support and encouragement in helping us give a meaningful outcome to our efforts.

We express our heartfelt gratitude to all the faculty members of the Research Cell of Loreto College for giving us this opportunity to complete our research work.

We are grateful to our supervisor Dr. Ranjita Dawn, Head, Department of Education, Loreto College and our Co-supervisor Dr. Sayantani Chatterjee, Head, Department of Psychology, Loreto College, for rendering their support and guidance throughout the tenure of this project.

We would also extend our gratitude towards Mrs. Ingrid Rozario, Ms. Donna Chung and Mr. Abdul Javed for their endless efforts to ensure that our project carries on smoothly.

Our sincere gratitude to the administrative members of Mentaid, Autism Society of West Bengal, Akshar School, Society of Indian Children’s Welfare and Asha School, Kolkata for granting us permission to interact and observe the children at their respective institutions.. We also got an opportunity to conduct surveys and have an interface meeting with the parents to gather personal information with regard to the child.

We are also very thankful to all the respondents, including subjects, parents of our subjects, caregivers and teachers of our subjects for providing us with data, without which our project would not be complete.

We express our gratitude to our respected parents and family for constant support throughout the research work.

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INTRODUCTION

1.1. WHAT IS DISABILITY?

A disability is defined as a condition or function judged to be significantly impaired relative to the usual standard of an individual or group. The term is used to refer to individual functioning, including physical impairment, sensory impairment, cognitive impairment, intellectual impairment, mental illness, and various types of chronic disease. (https://www.disabled-world.com/disability/types/)

Disability is an umbrella term that encompasses congenital and acquired impairments to body function or structure, activity limitations and participation restriction. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers. (https://www.disabled-world.com/definitions/disability-disabled.php)

People with disabilities have the same health needs as non-disabled people – for immunization, cancer screening etc. They also may experience a narrower margin of health, both because of poverty and social exclusion and also because they may be vulnerable to secondary conditions, such as pressure sores or urinary tract infections. Evidence suggests that people with disabilities face barriers in accessing the health and rehabilitation services they need in many settings. (https://www.who.int/topics/disabilities/en)

1.1.1.DEFINITION OF "DISABILITY"

The **Disability Discrimination Act, 1995 (DDA)** is an Act of the Parliament of the United Kingdom which has now been repealed and replaced by the Equality Act 2010, except in Northern Ireland where the Act still applies. It defines disability *as "a physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities"*. (https://www.rnib.org.uk/sight-loss-advice/equality-rights-and-employment/disability-discrimination-act-dda)

In **2001, the International Classification of Functioning, Disability and Health (ICF)** was officially endorsed by all 191 WHO Member States in the Fifty-fourth World Health Assembly. According to the ICF, 'disabilities' is, "*an umbrella term, covering impairments, activity limitations, and participation restrictions*" (https://www.who.int/news-room/fact-sheets/detail/disability-and-health). An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus, disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives. (https://www.who.int/classifications/icf/en/)

According to the **World Health Organization's (WHO) 'Convention on the Right of Persons with Disabilities: Roles and Responsibilities of the Health Sector', (2010)**, states that "*persons with disabilities include 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 on an equal basis with others*". (https://apps.who.int/iris/bitstream/handle/10665/204904/B4490.pdf?sequence=1&isAllowed=y)

In **1980, The International Classification of Impairments, Disabilities and Handicaps (ICIDH)**, provides a *conceptual framework* for disability which is described in three dimensions; impairment, disability and handicap. "Disablement" is sometimes used as an umbrella term covering all three dimensions.

a) Impairment: In the context of health experience an impairment is any loss or abnormality of psychological, physiological or anatomical structure or function. Impairment is considered to occur at the level of organ or system function. Disability is concerned with functional performance or activity, affecting the whole person.

b) Disability: In the context of health experience 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.

c) Handicap: In the context of health experience a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.

(https://www.dinf.ne.jp/doc/english/asia/resource/z00ap/001/z00ap00109.html#:~:text=For%20this%20purpose%20the%20International,to%20the%20consequences%20of%20diseases.&text=ICIDH%20consists%20of%20two%20parts%3A%20a%20conceptual%20model%20and%20three%20classifications.)

1.1.2.TYPES OF DISABILITIES

1.1.2.1. LEARNING DISABILITY

Children with learning disabilities are a heterogeneous group. These children are a diverse group of individuals, exhibiting potential difficulties in many different areas. For example, one child with a learning disability may experience significant reading problems, while another may experience no reading problems whatsoever, but has significant difficulties with written expression. (https://www.jstor.org/stable/1602494?seq=1#page_scan_tab_contents)

Generally, individuals with this kind of disability are seen to be unmotivated, disorganized, information is processed at a slow rate, they have difficulty in understanding spatial concepts, relationships, reading comprehension, language of math etc. Apart from all these, they usually have problems understanding their own self. They have inconsistency in their performance as they fail to repeat good scores.

(https://books.google.co.in/books?hl=en&lr=&id=RhpKDwAAQBAJ&oi=fnd&pg=PP1&dq=learning+disabilities+&ots=7KXaDljGwu&sig=IJVR70MzVpFE9WRqU8dmtzqUqOc#v=onepage&q=learning%20disabilities&f=false)

1.1.2.2. INTELLECTUAL DISABILITY

About 87% of people with intellectual disability will only be slower than average in learning new skills or information. The remaining 13% of the people with intellectual disability score below 50 in IQ tests. These people will have more difficulty in school, home, community etc. They need intensive support from their family members. Usually, individuals with Intellectual disabilities face trouble in speaking, remembering things, they fail to think logically, solve problems, understand or follow social rules etc.

People with intellectual disabilities comprise about 2% of the UK population. Demographics are, however, changing and the population of people with intellectual disabilities increased by 53% over the 35-year period 1960-95, which equals 1.2% per year. A further 11% increase is projected for the 10-year period 1998-2008. These changes are the result of improved socioeconomic conditions, intensive neonatal care, and increasing survival. The health needs of people with intellectual disabilities have an impact on primary healthcare services and all secondary healthcare specialties. (https://www.bmj.com/content/329/7463/414.full)

People with intellectual disabilities experience health inequalities compared with the general population. Although their life expectancy is increasing, it remains much lower than for the rest of the population. Over one million people across Europe, North America and Australia have a severe intellectual disability and also show additional problematic or challenging behaviours.

These include behaviours such as aggression, self-injury, destructiveness, over-activity, inappropriate social or sexual conduct, bizarre mannerisms etc. The combination of intellectual and behavioural disabilities can blight the lives of those affected and place the health, safety and welfare of those who care for them in jeopardy. (https://books.google.co.in/books?hl=en&lr=&id=uxCoJkKlCygC&oi=fnd&pg=PA1&dq=intellectual+disabilities&ots=q1YNJw65wJ&sig=HV1LVpR-dAM-4kJgjatN)

1.1.2.3. PHYSICAL DISABILITY

Individuals with physical disability have an acquired or congenital physical or motor impairment. The disability may interfere with the development or function of bones, muscles, joints and Central Nervous System.

Individuals with physical disabilities usually have an altered muscle tone, an unsteady gait, paralysis. They also face difficulties in using one or more limbs which results in difficulty in gross-motor skills like running or walking. They also face difficulty with fine-motor skills such as buttoning clothing or printing/writing etc.

One of the types of Physical disability is ***Cerebral Palsy*** which is associated with movement, muscle tone, and posture – 'Cerebral' refers to the brain and 'Palsy' means weakness or lack of muscle control.

Typically, it is due to an injury to the developing brain before or during birth, caused by a reduced blood supply and lack of oxygen to the brain. Illnesses during pregnancy such as rubella (the German measles), accidental injury to the brain, meningitis in young children, and premature birth can all be causes.

In Australia, over 90% of cerebral palsy was due to a brain injury while the mother was pregnant, or before one month of age, however, 10% of people develop the disability later in life, usually as a result of infections such as meningitis or encephalitis, stroke, or a severe head injury (Cerebral Palsy Alliance).

People with Cerebral palsy may experience epilepsy, and may have difficulty with awareness and comprehension. (https://www.hwns.com.au/about-us/about-disability/types-of-disabilities/types-of-physical-disabilities/)

1.1.2.4. MULTIPLE DISABILITIES

“Multiple disabilities” is a term for a person with several disabilities, such as a sensory disability associated with a motor disability. If an individual has a developmental disability, emotional disabilities, and a visual impairment together, they may be classified as having multiple disabilities. (https://www.news-medical.net/health/Types-of-visual-impairment.aspx)

In other words, a student whose special needs are categorized under multiple disabilities requires coinciding adaptation for more than one disability.

Individuals with this kind may show extreme variations in their behaviour. They may be clumsy and physically awkward, and may display immature behaviour inconsistent with their chronological age. They may have difficulty forming interpersonal relationships. Students with multiple disabilities may become fearful, angry, and upset in the face of forced or unexpected changes. They may have a tendency to withdraw from society. (https://www.coavision.org/m/pages.cfm?pageid=3625)

1.2. AUTISM

Autism, or autism spectrum disorder (ASD), refers to a range of conditions characterized by challenges with social skills, repetitive behaviours, speech and non-verbal communication, as well as by unique strengths and differences. The term “spectrum” reflects the wide variation in challenges and strengths possessed by each person with autism.

Autism’s most obvious signs tend to appear between two and three years of age. In some cases, it can be diagnosed as early as eighteen months. Some developmental delays associated with autism can be identified and addressed even earlier. These signs often develop gradually, though some children with autism reach their developmental milestones at a normal pace and then worsen.

Autism is caused by a combination of genetic and environmental factors. Risk factors include certain infections during pregnancy such as rubella as well as valproic acid, alcohol or cocaine use during pregnancy. Autism affects information processing in the brain by altering how nerve cells and their synapses connect and organize. In theDSM-5, autism is included within the autism spectrum disorders (ASDs).

Early speech or behavioural interventions can help children with autism gain self-care, social and communication skills. Although there is no known cure, there have been cases of children who have recovered from the condition. Not many children with autism live independently after reaching adulthood, though some are successful. An autistic culture has developed, with some individuals seeking a cure and others believing autism should be accepted as a difference and not treated as a disorder. **(**https://www.autismspeaks.org/what-autism)

1.2.1. CHARACTERISTICS OR SYMPTOMS

The characteristics of autism vary from one person to another, but in order for a diagnosis to be made, a person will usually be assessed as having had persistent difficulties with social communication and social interaction and restricted and repetitive patterns of behaviours, activities or interests since early childhood, to the extent that these "limit and impair everyday functioning". (http://www.autism.org.uk/about/what-is/asd.aspx)

1.2.1.1. Social Communication and Social Interaction Difficulties

Autistic people have difficulties with interpreting both verbal and non-verbal language like gestures or tone of voice. Many have a very literal understanding of language, and think people always mean exactly what they say. They may find it difficult to use or understand:

- facial expressions
- tone of voice
- jokes and sarcasm.

Some may not speak, or have fairly limited speech. They will often understand more of what other people say to them than they are able to express, yet may struggle with vagueness or abstract concepts. Some autistic people benefit from using, or prefer to use, alternative means of communication, such as sign language or visual symbols. Some are able to communicate very effectively without speech.

Others have good language skills, but they may still find it hard to understand the expectations of others within conversations, perhaps repeating what the other person has just said, called echolalia or talking at length about their own interests.

Autistic people often have difficulty 'reading' other people - recognizing or understanding others' feelings and intentions - and expressing their own emotions. This can make it very hard for them to navigate the social world. They may:

- appear to be insensitive
- seek out time alone when overloaded by other people
- not seek comfort from other people
- appear to behave 'strangely' or in a way thought to be socially inappropriate.

1.2.1.2. Repetitive Behaviour and Routines

The world can seem a very unpredictable and confusing place to autistic people, who often prefer to have a daily routine so that they know what is going to happen every day. They may want to always travel the same way to and from school or work, or eat exactly the same food for breakfast.

The use of rules can also be important. It may be difficult for an autistic person to take a different approach to something once they have been taught the 'right' way to do it. People on the autism spectrum may not be comfortable with the idea of change, but may be able to cope better if they can prepare for changes in advance.

1.2.1.3. Highly Focused Interest

Many autistic people have intense and highly-focused interests, often from a fairly young age. These can change over time or be lifelong, and can be anything from art or music, to trains or computers. Many channelize their interest into studying, paid work, volunteering, or other meaningful occupation. Autistic people often report that the pursuit of such interests is fundamental to their wellbeing and happiness.

1.2.1.4. Sensory problems

Many children with autism spectrum disorder (ASD) either overreact or underreact to certain sights, sounds, smells, textures, and tastes. For example, some may: dislike or show discomfort from a light touch or the feel of clothes on their skin, experience pain from certain sounds, like a vacuum cleaner, a ringing telephone, or a sudden storm; sometimes they will cover their ears and scream and have no reaction to intense cold or pain. Researchers are trying to determine if these unusual reactions are related to differences in integrating multiple types of information from the senses.

1.2.1.5. Sleep problems

Children with ASD tend to have problems falling asleep or staying asleep, or have other sleep problems. These problems make it harder for them to pay attention, reduce their ability to function, and lead to poor behaviour. In addition, parents of children with ASD and sleep problems tend to report greater family stress and poorer overall health among themselves. Fortunately, sleep problems can often be treated with changes in behaviour, such as following a sleep schedule or creating a bedtime routine. Some children may sleep better using medications such as melatonin, which is a hormone that helps regulate the body’s sleep-wake cycle. Like any medication, melatonin can have unwanted side effects. Talk to your child’s doctor about possible risks and benefits before giving your child melatonin. Treating sleep problems in children with ASD may improve the child’s overall behaviour and functioning, as well as relieve family stress.

1.2.1.6. Intellectual disability

Many children with ASD have some degree of intellectual disability. When tested, some areas of ability may be normal, while others—especially cognitive (thinking) and language abilities—may be relatively weak. For example, a child with ASD may do well on tasks related to sight (such as putting a puzzle together) but may not do as well on language-based problem-solving tasks.

Children with a form of ASD like Asperger syndrome often have average or above-average language skills and do not show delays in cognitive ability or speech.

1.2.1.7. Seizures

One in four children with ASD has seizures, often starting either in early childhood or during the teen years. Seizures, caused by abnormal electrical activity in the brain, can result in a short-term loss of consciousness, or a blackout convulsions, which are uncontrollable, shaking of the whole body, or unusual movements staring spells. Sometimes lack of sleep or a high fever can trigger a seizure. An electroencephalogram (EEG), a nonsurgical test that records electrical activity in the brain, can help confirm whether a child is having seizures

1.2.1.8. Co-occurring mental disorders

Children with ASD can also develop mental disorders such as anxiety disorders, attention deficit hyperactivity disorder (ADHD), or depression. Research shows that people with ASD are at higher risk for some mental disorders than people without ASD. Managing these co-occurring conditions with medications or behavioural therapy, which teaches children how to control their behaviour, can reduce symptoms that appear to worsen a child’s ASD symptoms. Controlling these conditions will allow children with ASD to focus more on managing the ASD.

1.2.2. CAUSES OF AUTISM

Experts are still uncertain about all the causes of autism. In all likelihood, there are multiple causes – rather than just one. It appears to be that a number of different circumstances — including environmental, biological, and genetic factors – set the stage for autism and make a child more likely to have the disorder.

In a few cases, autistic behaviour is caused by:

●Rubella (German measles) in the pregnant mother

●Tuberous sclerosis (a rare genetic disorder that causes benign tumours to grow in the brain as well as in other vital organs)

●Fragile X syndrome (the most common inherited form of intellectual disability)

●Encephalitis (brain inflammation)

●Untreated phenylketonuria (PKU) – when the body lacks an enzyme needed for normal metabolism

●In the past several years, there has been interest in a theory that suggested a link between autism and the use of thimerosal, a mercury-based preservative used in the measles-mumps-rubella (MMR) vaccine, although this has been disproved and discredited at present.

Other potential causes of autism are environmental toxins, including pesticides and heavy metals such as mercury. Heavy metals are certainly more commonly encountered in the environment now than they were in the past. It may be that people with autism or those at higher risk for developing it are more sensitive than others to these toxins. (http://www.mychildwithoutlimits.org/understand/autism/what-causes-autism/)

1.2.3. DIAGNOSTIC CRITERIA

The current specific criteria for ASD diagnoses are drawn from three domains: i) Impaired social interaction, as shown by: a) marked impairment in the use of non-verbal communicative behaviours (such as eye-to-eye gaze, facial expression, body postures); b) failure to develop age-appropriate peer relationships; c) a lack of spontaneous sharing of affect and interests with others; and d) lack of social or emotional reciprocity (limited interest in or awareness of others' reactions, interests, or feelings). ii) Qualitative impairments in communication skills, as shown by: a) delays in, or lack of, language acquisition (absence or reduced frequency of early language development as babbling and playing with sounds, and later, absence of phrase speech); b) inability to initiate or maintain a conversation; c) stereotyped and repetitive use of language or idiosyncratic language (echolalia, oddly formal speech, neologisms); and d) lack of development of age appropriate pretend play or social imitative play. iii) Presence of restricted and repetitive patterns of behaviour, interests and activities, as shown by: a) pronounced preoccupation with one or more unusual and restricted interests; b) inflexible adherence to specific routines or rituals; c) motor stereotypies (hand flapping, finger flicking, pacing, and jumping); and d) preoccupations with parts of objects.

(http://www.mychildwithoutlimits.org/understand/autism/what-causes-autism/)

1.2.4. TREATMENT APPROACHES

1.2.4.1. Parent Training

Parental and family involvement is considered an essential element of intervention programs for children with autism. The basic assumption of behavioural parent training is that child behaviour is learned and maintained through contingencies within the family context and that parents can be taught to change these contingencies in order to promote and reinforce appropriate behaviour. Evidence involving young children supports the recommendation of parent training as an effective method for increasing social skills. However, the manner in which parents are incorporated into the intervention process is important, as well as individualizing the parent education program to consider different family needs and circumstances; not every parent benefits from traditional behavioural parent education programs. Parent education appears to work best with highly motivated and well-functioning adults who are not coping with additional psychological or life stressors, which interferes with their acquisition and implementation of positive parenting strategies. The literature documents the effectiveness of parent education programs and the lack of maintenance of behavioural gains when parents do not participate in their children's interventions programs.

1.2.4.2. Treatment and Education of Autistic and Related Communication-Handicapped

Children (TEACCH)

TEACCH is a classroom based, clinical service and professional training program, developed at the University of North Carolina, at Chapel Hill, and started in 1972 by Eric Schopler. This program has been incorporated widely into North American educational settings and has contributed significantly to the evidence base of autism interventions. The TEACCH approach is called structured teaching because it is based on evidence and observation that individuals with autism share a pattern of behaviours, such as the ways individuals think, eat, dress, understand their world, and communicate. The essential mechanisms of structured teaching consist of organizing the environment and activities in ways that can be understood by the individuals; using individuals' relative strengths in visual skills and interest in visual details to supplement relatively weaker skills; using individuals' special interests to engage them in learning; and supporting self-initiated use of meaningful communication.

1.2.4.3. Cognitive-Behavioural Therapy (CBT)

A growing number of reports have begun to provide moderate evidence for the efficacy of CBT approaches for school-age and young adolescents with ASD. Improvements in anxiety, self-help, and daily living skills have been reported, with 78% of 7-11 year-olds in the CBT-treated group rated as positive responders in one trial. Such findings encourage the consideration of modified CBT approaches to address anxiety in high functioning children with ASD, which is important given that as many as 30-40% of children with ASD report high levels of anxiety-related symptoms.

(http://www.mychildwithoutlimits.org/understand/autism/what-causes-autism/)

1.3. CEREBRAL PALSY

Cerebral Palsy is a neurological disorder caused by a non-progressive brain injury or malformation that occurs while the child's brain is under development-before, during or immediately after birth. Cerebral Palsy primarily affects body movement and muscle coordination, muscle control, muscle tone, reflex, posture and balance. It can also impact fine motor skills, gross motor skills and oral motor functioning. However, it does not necessarily affect intelligence or cognitive ability, and since it is not progressive, it does not get worse with age. (https://www.medicalnewstoday.com/articles/152712.php)

1.3.1. SYMPTOMS

An infant with cerebral palsy may have muscular and movement problems, including poor muscle tone. Muscle tone refers to a person's automatic ability to tighten and relax muscle when required. Some of the features may be as follows:

- Over-developed or underdeveloped muscles, leading to stiff or floppy movement.
- Poor coordination and balance, known as *ataxia*.
- Lying down in awkward positions.
- Favouring one side of the body over the other.
- Late achievement of developmental milestones such as crawling, walking, or speaking.

- Hearing and eyesight problems.

- Problems controlling bladder and bowel movements.

- Drooling, and problems with feeding, sucking, and swallowing.

https://www.healthline.com/health/cerebral-palsy

1.3.2. CLINICAL FEATURES

70 to 80 percent of patients with cerebral palsy have spastic clinical features. Affected limbs may demonstrate increased deep tendon reflexes, tremors, muscular hypertonicity, weakness, and a characteristic scissors gait with toe-walking. The athetoid or dyskinetic type of cerebral palsy, affecting 10 to 20 percent of patients, is characterized by abnormally slow, writhing movements of the hands, feet, arms, or legs that are exacerbated during periods of stress and absent during sleep. The rarest form, ataxic cerebral palsy, affects 5 to 10 percent of patients and predominately impairs balance and coordination. These patients walk with a wide-based gait and have intention tremors that complicate performance of daily activities requiring fine-motor function. Intellectual impairment occurs in about two thirds of patients with cerebral palsy. About one half of pediatric patients have seizures.

Growth problems are common, as well as neurologic abnormalities such as impaired vision or hearing and abnormal touch and pain perceptions. By definition, cerebral palsy is non-progressive; therefore, children who experience loss of previously acquired skills, or who show slowing of development, disappearance of reflexes, or unusual body odours should be evaluated for genetic, metabolic, muscular, or neuronal tumor disorders that precipitate neurodegenerative conditions.

https://www.aafp.org/afp/2006/0101/p91.html

1.3.3. TYPES

There are four types of Cerebral Palsy: Spastic, Athetoid (or Dyskinetic), Ataxic, and Hypotonic.

1. Spastic Cerebral Palsy – Spastic cerebral palsy is the most common type of cerebral palsy. The muscles of people with spastic cerebral palsy feel stiff and their movements may look stiff and jerky. Spasticity is a form of hypertonia, or increased muscle tone. This results in stiff muscles which can make movement difficult or even impossible. There are three different types of spastic cerebral palsy- Spastic hemiplegia, Spastic diplegia and Spastic quadriplegia. (https://cerebralpalsy.org.au/our-research/about-cerebral-palsy/what-is-cerebral-palsy/types-of-cerebral-palsy/spastic-cerebral-palsy/)

2. Athetoid or Dyskinetic Cerebral Palsy – This is the second most common type. Intelligence is usually normal, but muscle problems affect the whole body. Weak or tight muscle tone causes random and uncontrolled body movements. The child will have problems walking, sitting, maintaining posture, and speaking clearly because the tongue and vocal cords are hard to control. Some children drool if they have problems controlling facial muscles.

3. Ataxic Cerebral Palsy – Ataxic cerebral palsy is the least common type of the disorder, affecting around 5% to 10% of all people with Cerebral Palsy. Ataxic cerebral palsy is derived from the word “ataxia,” meaning lack of coordination and order. Along with tremors, children with ataxic cerebral palsy may also have speech and oral problems. Tasks that need fine motor skills are most affected. (https://www.birthinjuryguide.org/cerebral-palsy/types/ataxic/)

4. Hypotonic Cerebral Palsy – Hypotonic cerebral palsy results from an injury to the cerebellum. Muscle problems appear earlier. The infant's head and body will be floppy. There is only moderate resistance when an adult tries to move the infant's limbs. The infant may rest with their elbows and knees loosely extended, instead of flexed and may have breathing difficulties.

1.3.4. CAUSES

Muscle coordination is controlled by the upper part of the brain, called the cerebrum. Damage to the cerebrum before, during, or within 5 years of birth can cause cerebral palsy. The cerebrum is also responsible for memory, ability to learn, and communication skills. This is why some people with cerebral palsy have problems with communication and learning. Cerebrum damage can sometimes affect vision and hearing. Most often, the damage occurs before birth, probably during the first 6 months of pregnancy. Some causes of cerebral palsy are as follows:

- **Periventricular Leukomalacia (PVL)** – A kind of damage that affects the brain's white matter because of a lack of oxygen in the womb. It may occur if the mother has an infection during pregnancy, such as rubella or German measles, low blood pressure, preterm delivery, or if she uses an illegal drug.

- **Abnormal Development of the Brain** – Disruption of brain development can affect the way the brain communicates with the body's muscles and other functions. During the first 6 months of pregnancy, the brain of the embryo or fetus is particularly vulnerable. Damage can stem from mutations in the genes responsible for brain development, certain infections such as toxoplasmosis, a parasite infection, herpes and herpes-like viruses, and head trauma.

- **Intracranial Hemorrhage** – Sometimes, bleeding inside the brain happens when a fetus experiences a stroke. Bleeding in the brain can stop the supply of blood to vital brain tissue, and this tissue can become damaged or die. The escaped blood can clot and damage surrounding tissue.

- **Brain damage after birth** – A small proportion of cases happen because of damage after birth. This can happen because of an infection such as meningitis, a head injury, a drowning accident, or poisoning.

- **Multiple births** – For example, in the case of twins or triplets being born, there is a higher chance of the children being diagnosed with Cerebral Palsy.

- **Factors that may contribute to a higher risk of cerebral palsy include:**

  i. Multiple births, for example, twins

  ii. Damaged placenta

  iii. Sexually transmitted infections (STIs)

  iv. Consumption of alcohol, illegal drugs, or toxic substances during pregnancy

  v. Malnourishment during pregnancy

  vi. Breech delivery

https://www.medicalnewstoday.com/articles/152712

1.3.5. DIAGNOSIS

Observation of slow motor development, abnormal muscle tone, and unusual posture are common initial clues to the diagnosis of cerebral palsy. Assessment of persistent infantile reflexes is important. In infants who do not have cerebral palsy, the Moro reflex is rarely present after six months of age, and hand preference rarely develops earlier than 12 months of age. Hand preference may occur before 12 months of age if spastic hemiplegia is present. Progressive hereditary neurologic or metabolic disorders must be eliminated as the cause of observed abnormalities.

The testing strategy is based on the clinical picture, pattern of development of symptoms, family history, and other factors influencing the probability of specific diagnoses. Targeted laboratory tests and cerebral imaging using computed tomography, magnetic resonance imaging, and ultrasound are useful physical diagnostic tools. Surveillance for associated disabilities such as hearing and vision impairment, seizures, perception problems with touch or pain, and cognitive dysfunction can help complete the clinical assessment and determine the diagnosis.

(https://www.mayoclinic.org/diseases-conditions/cerebral-palsy/symptoms-causes/syc-20353999)

1.3.5.1. ASSESSMENT INSTRUMENTS

Several assessment instruments are available to quantify and monitor developmental milestones and skills and to assess the quality of life of patients and their caregivers. Readily available and useful assessment instruments include the Child Health Questionnaire, the Wong-Baker FACES Pain Rating Scale, and the Gross Motor Function Classification System for Cerebral Palsy. Functional scales such as the Gross Motor Function Classification System for Cerebral Palsy standardize self-initiated movements and measure change in gross motor function over time, and this particular scale is widely accepted and easy to administer in the primary care office. Other functional scales include: the Pediatric Evaluation of Disability Inventory, a judgment-based, standardized instrument using parent report through a structured interview measuring both fine- and gross-motor movements related to self-care and mobility; the Functional Independence Measure (FIM) for adults and the WeeFIM for children, which measure the amount of assistance a person would require to perform activities of daily living; and the Ashworth and Modified Ashworth scales, which grade muscle spasticity.

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1.3.5.2. TREATMENT

The types of treatment for patients with cerebral palsy depend on the patient's specific symptoms and range from physical therapy to medication use and surgery.

1.3.5.2.1 GLOBAL STRATEGIES

Neurodevelopmental treatment (i.e., the Bobath method) is a common cerebral palsy treatment strategy that aims to control sensorimotor components of muscle tone, reflexes, abnormal movement patterns, postural control, sensation, perception, and memory by utilizing specific handling techniques. A 2001 American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) evidence report stated that, although patients with neurodevelopmental treatment did show some immediate improvement in dynamic range of motion, there was no consistent evidence that neurodevelopmental treatment changed abnormal motoric responses, slowed or prevented contractures, or facilitated more normal motor development of functional motor activities. It was concluded that the current literature base does not offer enough conclusive evidence for an opinion for or against conductive education as an intervention strategy.

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1.3.5.2.2. PHYSICAL THERAPY

Muscle strengthening and fitness programs are popular interventions for cerebral palsy; however, advocates of neurodevelopmental treatment advise against the use of resistive exercise, because it is believed to increase spasticity. Several recent studies have examined the effectiveness of resistive exercise. A study using the stretch reflex as measured by the pendulum test found that children with cerebral palsy did not demonstrate increased spasticity of the quadriceps femoris muscle immediately following strengthening exercises as compared with children without cerebral palsy.

Transporting a child with cerebral palsy to regularly scheduled physical therapy sessions can cause significant family stress. One study compared attendees of an intermittent program (two to four treatments per week over a four-week period with rest periods of eight-week duration) with patients completing four visits a week without rest periods. Greater improvement was evident in the higher intensity phases; however, in both scenarios it was shown that the children did not regress during the rest period. Superior clinical results have been observed in children participating in functional physical therapy activities when compared with those emphasizing normalization of movement.

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1.3.5.2.3. MEDICATIONS

● **Botulinum toxin**: Upper motor neuron syndrome often leads to common patterns of motor dysfunction and characteristic spasticity and contractures. Botulinum toxin (Botox) is a formulation of botulinum toxin type A, derived from the bacterium.

● **Clostridium Botulinum**: This bacterium produces a protein that blocks the release of acetylcholine and relaxes muscles. Several studies have supported the use of botulinum toxin type A in the treatment of equine spasticity during walking, but a literature review did not find strong evidence to support or refute its use for the treatment of leg spasticity in patients with cerebral palsy.

● **Baclofen (Lioresal):** The AACPDM Treatment Outcomes Committee Review Panel's systematic literature review in 2000 evaluated the use of intrathecal baclofen for spastic and dystonic cerebral palsy. Summary results reported limited evidence for reduced spasticity in the lower extremities, with unclear effects for upper extremities.

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1.3.5.2.4. SURGICAL TREATMENTS

Selective dorsal rhizotomy is a procedure intended to minimize or eliminate spasticity by selectively cutting dorsal rootlets from spinal cord segments L1 to S2. Postoperatively, it can create proprioceptive loss, bladder or bowel dysfunction, prolonged marked hypotonia, persistent back pain, or spinal deformities. Muscle imbalance caused by spasticity can lead to complete dislocation of hips. The incidence of hip dislocation in children with cerebral palsy has been reported to be as high as 59 percent. After surgery, patients were immobilized in a hip spica cast for a minimum of six weeks. Adverse events reported included decubitus ulcers, lower extremity fracture at cast removal, and technical complications related to the use of the hardware.

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1.3.5.2.5. EXTERNAL AIDS

Orthoses are commonly used in conjunction with physical therapy, botulinum toxin type A, baclofen, and neurosurgery or orthopedic surgery to prevent inappropriate joint movements. A literature review reported poor evidence-based support for the use of lower limb orthoses to prevent deformities or improve activities in children.

One study found it a useful adjunctive therapy for pediatric upper limb dysfunction; however, two other studies did not find a significant clinical effect when it was applied to lower limb dysfunction. Cerebral stimulation to the superior-medial cerebellar cortex by an implantable, controlled-current pulse generator apparently can reduce seizure activity and spasticity of primitive reflexes, increase muscle tone and co-contraction, and reduce athetoid movements in patients with cerebral palsy.

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1.3. SELECTED VARIABLES OF THE STUDY

Some of the variables of the present study are daily living, mobility, communication, caregivers, peer groups, comfort and emotion, and health.

1. Daily Living

Daily living can be impaired due to impaired motor function. Upper limb impairment can especially affect the ability to perform and participate in activities of daily living and in leisure activities. There is a degree of limitation in the home environment, as well as the social environment **(Van Zelst, Miller, Russo & Murchland, 2006).** Studies also revealed significant disruptions in recreation, community, personal care, education, housing, nutrition, etc., and as the disruption progressed, the severity increased. Therefore, life habits are greatly disturbed. **(Lepage, Noreau, Bernard & Fougeyrollas, 1998).**

Studies also showed that there is a high level of dependence on caregivers. Children with disabilities have varying degrees of difficulty in doing tasks of daily living, which most often persist into adulthood **(Andren & Grimby, 2000).**

2. Mobility

In cases of Cerebral Palsy, mobility is a huge factor; limbs are affected, and there is a significant loss of mobility. These children experience various motor impairments, and many health care interventions are aimed at reducing these activity limitations. But to do so, it is important to have reliable and valid instruments to measure activity limitations in children with Cerebral Palsy **(Van Ravesteyn, Scholtes, Becher, Roorda, Verschuren & Dallmeijer, 2010**).

In cases of rehabilitation of children with Cerebral Palsy, mobility is the primary goal. Studies have been examined to see the effectiveness of task-oriented training in bettering mobility for these children. Studies support the efficacy of task-oriented strength training for improving mobility function in children with cerebral palsy. The results suggest that children with cerebral palsy may benefit from a task-oriented strength training program **(Salem & Godwin, 2009).**

In the case of Autism Spectrum Disorders (ASD), research shows that there is mobility dysfunction and catatonia in adolescents and adults with ASD. Catatonia is a later complication of ASD, and further research would help identify causes, neuropathology, and early signs of vulnerability. **(Wing & Shah, 2000).**

3. Communication

Very often, children with disabilities have development and/or sensorimotor issues. This is what causes a large proportion of restrictions in their daily life, mobility, and communication. There have been studies to create and validate the Communication Function Classification System (CFCS) for children with Cerebral Palsy. Research has proved that the CFCS is both reliable and valid, and helps children with Cerebral Palsy communicate and contributes highly to their daily life **(Hidecker, Paneth, Rosenbaum, Kent, Lillie, Eulenberg, Chester, Jr., Johnson, Michalsen, Evatt & Taylor, 2011).**

In the case of adolescents with Autism Spectrum Disorders (ASD), studies show that most have more difficulties with participation than with the engagement of activities. Individual domain analyses indicate no difficulties with mobility and mild difficulties with self-care. It was seen that participation in a community or group setting caused more difficulty than the actual motor movements **(Poon, 2011).**

4. Caregivers

Studies on disabled children often focus only on the child; very rarely is there emphasis on the family and the caregiver. Contemporary research shows that the disease not only affects the child, but also the caregiver. The caregiver is the most important person in the child's life, because of their motor, speech, and other impairment. Caregivers of these children have a higher stress level, and are affected psychologically. Caregivers of children with severe disabilities show signs of depression, and emotional and social isolation. Therefore, health professionals must take into account the caregiver's state, as well as the child's while opting for **treatment (Ones, Yilmaz, Cetinkaya& Caglar, 2005).**

Also, it is not only the parents who are considered caregivers. While they are the primary caregivers who care for the disabled child, teachers too play a very important role in creating inclusiveness, and it is not only the parent who suffers extreme stress, but also the teachers and caregivers in the school setting **(Lecavalier, Leone & Wiltz, 2006).**

5. Peer Groups

While it is understood that children with disabilities depend heavily on parents and caregivers for their daily tasks, studies have been performed to see whether the same accounts for socialization with and dependence on peers. Studies have shown that children with certain types of disabilities viewed friendships as important, but negligible participation in organized social activities, and a primary orientation toward sedentary activities was present **(Tessier, Hefner & Newmeyer, 2014).**

In cases of children with Autism Spectrum Disorders (ASD), the prevalence of having friendships, peer relationships, and participating in social and recreational activities were all low, according to research, due to both; individual and environmental factors **(Orsmond, Krauss& Seltzer, 2004)**.

Findings for children with Cerebral Palsy indicates that these children (especially females) had fewer reciprocated friendships, exhibited fewer sociable/leadership behaviours, and were more isolated and victimized by their peers than their classmates without a disability. This seems to suggest that females and males with CP are perceived differently from their peers in a mainstreaming context **(Nadeau & Tessier, 2006).**

6. Comfort and Emotion

There is a prevalence of behavioural and emotional problems among children with Cerebral Palsy. It ranges between 25% and 60%, and reflects differences in age of childhood populations, psychometric measures, and the severity of cerebral palsy. In one study, it was found that 40 to 50% of preschool children with cerebral palsy had substantial behavioural and/or emotional difficulties when judged by parents, whereas this applied to 60 to 65% when assessed by preschool teachers. **(Sigurdardottir, Indredavik, Eiriksdottir, Einarsdottir, Gudmundsson & Vik, 2010)**.

Subsequent research shows that severe disability in the child was associated with high mental distress in the parent and linked to low support from friends. Therefore, there was a growth of emotional distress for not only the caregiver, but for the child himself. **(Al-Gamal & Long, 2013).**

7. Health

Disorders such as cerebral palsy, autism, and/or other developmental disorders tend to have adverse effects on children's health and functioning. They can lead to chronic physical, cognitive, speech, or psychological conditions. According to one study, among children with 1 or more developmental disorder, prevalence estimates for limitations in movement (6.1%), needed help with personal care (3.2%), needed special equipment (3.5%), received home health care (1.4%), and regularly took prescription medication(s) (37.5%) were 4 to 32 times higher than for children without these disabilities. Cerebral palsy, autism, mental retardation, blindness, and deafness were associated with the highest levels of health and functional impact indicators **(Boulet, Boyle & Schieve, 2009).**

Meanwhile, another study concluded that for children with moderate to severe Cerebral Palsy, feeding dysfunction is a common problem, and is associated with poor health and quality of living. Children with a feeding dysfunction require their food to be mashed or cut up for the nutrients to reach them even mildly **(Fung, Samson-Fang, Stallings, Conaway, Liptak, Henderson, Worley, O'Donnell, Calvert, Rosenbaum, Chumlea & Stevenson, 2002).**

1.5. OBJECTIVES OF THE STUDY:

The major objectives that were the focus of this study are as follows:

1. To determine the difference between two groups of disability- Cerebral Palsy and Autism with respect to correlates of mental health, that is, personal care/ activities of daily living, positioning, transferring and mobility, comfort and emotions, communication and social interaction, health, child’s overall quality of life and importance of items to child’s quality of life

2. The magnitude and direction of relationship will be found amongst the variables personal care/ activities of daily living, positioning, transferring and mobility, comfort and emotions, communication and social interaction, health, child’s overall quality of life and importance of items to child’s quality of life - for the two groups of disability - Cerebral Palsy and Autism.

3. To conduct a case study for each group, with a set of predetermined questions covering many aspects of disability in addition to those mentioned in the first objective.

The Survey of Relevant Literature was done thoroughly, so as to serve as a theoretical base, as seen in the next chapter.

SURVEY OF RELEVANT LITERATURE

2.0. A Literature Survey is a very important step in any research project. It provides findings from similar research areas, like the present area of interest. It helps determine the nature and direction of the present study.

2.1. Review of Literature: Autism

Bal, Harden, Lamb, Hecke, Denver & Porges (2010), concluded with their study that children with Autism Spectrum Disorder (ASD) were slower in emotion recognition, and selectively made more errors in detecting anger. ASD children had lower amplitude Respiratory Sinus Arrhythmia (RSA) and faster heart rate. Within the ASD group, children with higher amplitude RSA recognized emotions faster. Less severe ASD symptoms and increased gaze to the eye region in children with ASD were related to more accurate emotion recognition.

Bauminger, Shulman & Agam (2003), conducted a study on Social interaction with peers and the understanding and feelings of loneliness. This was examined in high-functioning children with autism and their ‘normal’ peers, matched for IQ, chronological age, gender, and maternal education. Overall, children with autism revealed a good understanding of both social interaction and loneliness, and they demonstrated a high level of social initiation. However, they spent only half the time in social interactions with peers compared with their matched counterparts, and they interacted more often with a typically developing child than with another special education child.

Children with autism reported higher degrees of loneliness than their typical age-mates, as well as a lower association between social interaction and loneliness, suggesting their poorer understanding of the relations between loneliness and social interaction.

DaSilva & Fernandes (2016), explored how children with autism interact with their neurotypical peers in a school setting, what features might make this more difficult and how the experience can be improved. They found that in group settings, children with autism sometimes have difficulties with conversation, maintaining social relationships and participating in symbolic play. The authors showed that if their neurotypical peers were accepting and encouraging, the children with autism were more likely to be included in activities. This led to children on the autism spectrum becoming more comfortable in these settings and spending more time in these groups later on.

Factor, Perry & Freeman (1990), hypothesized that autistic children represent a source of stress for their parents, but the most appropriate way to measure this stress is not clear. The present study therefore sought to replicate past research, and to extend it by validating this method of measuring parental stress compared to more traditional measures. Results indicated that mothers, fathers, and professionals agreed on the severity of child behaviours. Mothers found these behaviours significantly more stressful than fathers. The stress related to specific child behaviours was significantly correlated with more general measures of parental stress.

Falkmer, Anund, Sörensen & Falkmer (2004), investigated the transport mobility situation for children with autism spectrum disorders, using questionnaires from 1,631 parents. The results showed that almost 3 out of 4 parents were worried when their child was transported by school transport or by the Special Transport System. Transports in the family vehicle caused worry among almost half of the parents. The parents' worries were justified by the fact that the children were not transported according to general safety recommendations.

Golan, Ashwin, Granader, McClintock, Day, Leggett & Baron-Cohen (2010), evaluated 'The Transporters', an animated series designed to enhance emotion comprehension in children with Autism Spectrum Conditions (ASC). 20 children with ASC watched The Transporters every day for 4 weeks. Participants were tested before and after intervention on emotional vocabulary and emotion recognition at three levels of generalization. The intervention group improved significantly more than the clinical control group on all task levels, thus concluding that using The Transporters significantly improves emotion recognition in children with ASC.

Goldstein (2002), reviewed speech and language intervention procedures applied to children with autism. In particular, interventions incorporating sign language, discrete-trial training, and milieu teaching procedures have been used successfully to expand the communication repertoires of children with autism. Other important developments in the field stem from interventions designed to replace challenging behaviors and to promote social and scripted interactions. The few studies of the parent and classroom training studies that included language measures also are analyzed. The main aim of this study was to seek to outline the extent to which previous research has helped identify a compendium of effective instructional practices that can guide clinical practice.

Hale & Flusberg (2005), in their longitudinal study, investigated the developmental trajectory of discourse skills and theory of mind in children with autism. Children were tested at two time points spaced one year apart. Each year they provided a natural language sample while interacting with one parent, and were given standardized vocabulary measures and a developmentally sequenced battery of theory of mind tasks. Hierarchical regression analyses demonstrated that theory of mind skills contributed unique variance to individual differences in contingent discourse ability and vice versa, when measured concurrently; however, they did not predict longitudinal changes. The findings offer some empirical support for the hypothesis that theory of mind is linked to communicative competence in children with autism.

Jasmin, Couture, McKinley, Reid, Fombonne & Gisel (2009), explored the impact of sensori-motor skills on the performance of Daily Living Skills in preschool children with Autism Spectrum Disorders. The authors found that the children showed atypical sensory responses, and very poor motor skills and daily living skills. They observed that sensory avoiding – an excessive reaction to sensory stimuli – and fine motor skills were highly correlated with daily living skills, even when cognitive performance was taken into account. They concluded that sensori-motor deficits have an impact on the autonomy of children with Autism Spectrum Disorders, and interventions should aim at improving and supporting the development of sensori-motor skills.

Kamps, Royer, Dugan, Kravits, Gonzalez-Lopez, Garcia, Carnazzo, Morrison& Kane (2000), conducted a study on the increasing evidence of peer-mediated interventions for students with autism and whether they are effective in increasing participation in natural settings. Still unknown are the contributions peers make to the generalization of social behaviours. Results from two investigations of this issue are reported. In Study 1, social interaction with peers increased during interventions compared to controls; however, students in cooperative learning control groups showed higher levels of generalization than those in social groups. In Study 2, videotaped probes of 34 students indicated greater generalization of skills from groups with trained peers, and less from groups with untrained and stranger peers.

Lee, Harrington, Louie & Newschaffer (2007), examined Quality of Life and Parental concerns in children with autism during childhood, early childhood, adolescence compared to children with Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder (ADD/ADHD). Families with children diagnosed with autism reported more profound Quality of Life effects than families of children with ADD/ADHD or unaffected controls. Children with autism were significantly less likely to attend religious services, more likely to miss school, and less likely to participate in organized activities. Parental concerns over learning difficulty, being bullied, stress-coping, and achievement were overwhelming in the autism group relative to the comparison groups.

McStay, Dissanayake, Scheeren, Koot &Begeer (2013), examined differences in 'parenting stress' reported by parents of children with autism and typically developing children. The results revealed that child hyperactivity was the only factor significantly related to parenting stress in parents of children with autism, overruling measures of autism severity and child quality of life. This finding indicates the significant influence of problematic behaviours on parenting demands and perceptions of parenting skills in parents of children with autism, over other child characteristics conceived as within the parent's control. Study implications for future research are discussed.

Memari, Panahi, Ranjbar, Moshayedi, Shafiei, Kordi & Ziaee (2015), investigated the pattern of participation of children with Autism Spectrum Disorder (ASD) in daily physical and play activities. It was seen that only 12% of children with ASD were active and 88% were inactive. Addressing the frequency of activity participation, results showed that only 6% of children with ASD "often" participated in physical activities, whereas 85.5% of them had "never/rarely" participated, and 8.5% were "sometimes" involved in physical activities. It was also seen that boys with ASD participated in physical activities more than girls with ASD.

Ming, Brimacombe & Wagner (2007), state that Autism Spectrum Disorders (ASD) manifest as impairments in social interaction, language and speech development, and the appearance of repetitive behaviours with restricted interests. The objective of their study was to describe the prevalence of motor deficits in ASD. The results suggest that fine motor control and programming deficits are common co-occurrence of children with ASD. The reduced prevalence of these motor deficits in older children suggests improvement over time, whether through natural progression, results of interventional therapy, or the combination of the two. However, ASD children with the motor deficits were not more likely to receive service than those without the motor deficits.

Pierce & Schreibman (1994), studied the potency of pictorial self-management to teach Daily Living Skills to autistic children. Stimulus and response generalization, stimulus control of self-management materials, and maintenance of behaviour change were also assessed. Their results showed that children with autism could successfully use pictures to manage their behaviour in the absence of a caregiver, generalize their behaviour across settings and tasks, and maintain behaviours at follow-up. In addition, when compared to the baseline, all children showed a significant decrease in stereotypic behaviours.

Siller & Sigman (2002), observed the behaviours of caregivers of children with autism show during play interactions, and studied how far the caregiver's behaviour was in sync with the child. The study had two findings by the authors. First, caregivers of children with autism synchronized their behaviours to their children's activities. Second, caregivers of children with autism who showed higher levels of synchronization during initial play interactions had children who developed superior joint attention and language over a period of 1, 10, and 16 years than did children of caregivers who showed lower levels of synchronization. These findings suggest a developmental link between parental sensitivity and the child's subsequent development of communication skills in children with autism. Implications for parent training interventions are also discussed.

Zhen-Huan, Qiao-Ling, Yong & Xiao-Zhen (2016), studied the Quality of Life of children with Autism Spectrum Disorder (ASD). In comparison with other conditions, there has been a lack of focus on their quality of life. This study examined Paediatric Quality of Life of autistic children, from a multidimensional perspective. Results suggest greater impairment in adaptive functioning and emotional disorders.

2.2. Review of Literature: Cerebral Palsy

Arnaud, White-Koning, Michelsen, Parkes, Parkinson, Thyen, Beckung, Dickinson, Fauconnier, Marcelli, McManus & Colver (2007), studied the psychological symptoms of children with cerebral palsy, and its impact on the child and family. Results showed that a significant proportion of children with cerebral palsy have psychological symptoms or social impairment sufficiently severe to warrant referral to specialist services. Care must be taken in the assessment and management of children with cerebral palsy to ensure psychological problems are not overlooked and potentially preventable risk factors like pain are treated effectively.

Dababneh (2013), aimed at identifying the behavioural difficulties facing the children with cerebral palsy in Jordan. In addition, it attempted to determine the differences between those children according to certain variables such as gender, age, level of family income, and level of disability. The results revealed that children with cerebral palsy on average – according to their parents' reports – had a moderate degree of overall behavioural problems across internalised problems that were composed of subscales such as shyness, depression, anxiety, and social isolation; and across externalised problems composed of the aggressiveness scale. There were significant differences due to the gender variable on the overall scale and on the anxiety dimension in favour of male children. Moreover, there were significant differences on the shyness and isolation dimensions due to the level of disability in favour of children with cerebral palsy and mental retardation.

Davis, Shelly, Waters, Boyd, Cook, Davern & Reddihough (2010), in their study, explored the quality of life of mothers and fathers of children with cerebral palsy, aged 3-18 years and examined whether the impact of caring for a child with Cerebral Palsy changes from childhood to adolescence. The findings showed that there were no differences in parental quality of life among subgroups (i.e. mothers and fathers, age groups). Caring for a child with cerebral palsy, therefore, affects a parent's physical well-being, social well-being, family well-being and financial stability.

Dickinson, Parkinson, Sieberer, Schirripa, Thyen, Arnaud, Beckung, Fauconnier, McManus, Michelsen, Parkes & Colver (2007), based this study on the quality of life of children with cerebral palsy, factors that influence it, and how it compares with quality of the general population. It was concluded that children with cerebral palsy had similar quality of life to children in the general population in all domains except schooling and physical wellbeing. This finding should guide social and educational policy to ensure that disabled children participate fully in society. Because of its association with quality of life, children's pain should be carefully assessed.

Donnell, Rosenbaum, Brehaut, Walter, Russell, Swinton, Zhu & Wood (2005), stated that one of the main challenges for parents is to manage their child's chronic health problems effectively and juggle this role with the requirements of everyday living. Thus, data on demographic variables and caregivers' physical and psychological health were assessed using standardized, self-completed parent questionnaires as well as a face-to-face home interview. Findings suggest that a higher level of behaviour problems was associated with lower levels of both psychological and physical health of the caregivers, whereas fewer child behaviour problems were associated with higher self-perception and a greater ability to manage stress. Child behaviour problems were an important predictor of caregiver psychological well-being. In families of children with cerebral palsy, strategies for optimizing caregiver physical and psycho-logical health include support for behavioural management and daily functional activities as well as stress management and self-efficacy techniques.

Engel-Yeger, Jarus, Anaby &Law (2009), investigated the effects of cerebral palsy and gender on youth participation in activities outside of formal school. It was seen that typically developing youths engaged in a broader range of activities and did so more frequently than did youths with cerebral palsy. Similar levels of enjoyment in activity were found in both groups. Thus, it was concluded that physical limitations associated with cerebral palsy may affect the frequency of a child's participation in activity outside of school; however, youths with cerebral palsy may express levels of enjoyment similar to those of typically developing peers while participating in activity.

Imms, Reilly, Carlin & Dodd (2008), investigated the participation of children with cerebral palsy in activities outside school and to compare their participation with a large representative sample of children. It was seen that children participated in a wide range of activities. Participation levels were lower in formal than informal activities, with diversity being lowest in active-physical and skill-based activities. Intensity of participation was low; children tended to participate with family close to home, rather than with friends in the broader community, except when they were participating in activities within the formal domain or skill-based activities.

Lawlor, Mihaylov, Welsh, Jarvis & Colver (2005), studied aims to ascertain from families of children with cerebral palsy, the features of such environments which facilitate or restrict participation. The main themes to be studied were the importance of mobility, transport, support by and to parents and attitudes of individuals and institutions towards children. This study concludes with the importance of the environment for the participation of children with cerebral palsy, and also contributes to the development of a tool to quantify the environment to allow the development of models to determine the environments which maximize children's participation.

Logar (2012), aimed to recognize psychological problems in children with cerebral palsy, and their families, as well as the necessities to provide psychological help without disturbing them. According to the author, it "highlights the importance of acknowledging disability as a manifestation of a person's ongoing adaptation to respective special needs, i.e. diverse consequences of disability that are affecting every individual child regarding education, self-dependent life, establishing social roles and adaptation to the characteristics of the environment in which affected people are living".

Majnemar, Shevall, Law, Poulin & Rosenbaum (2010), aimed to describe and identify factors associated with motivation in children with cerebral palsy. School-aged children (6-12 years) were recruited for this cross-sectional study, on quality of life. The results showed that high motivation was associated with fewer activity limitations and behavioural problems and reduced family burden. Low motivation may adversely influence a child's functional potential and the effectiveness of interventions. It was concluded with strategies focusing on the child, peers, adults, or activities are proposed to enhance the children’s motivation to engage in more challenging activities.

Manuel, Naughton, Balkrishnan, Smith & Koman (2003), assessed the importance of disability severity and child functional status as predictors of maternal depressive symptoms and the moderating effects of maternal appraisal, social support, and family. Mothers of 270 children with cerebral palsy were surveyed on their appraisal of the child's disability, social support, and family demographics. It was found that thirty percent of the mothers had depressive symptoms above the cut-off on a depression screening instrument. Their study concluded that mothers of children with cerebral palsy may be at risk for depression. Interventions that take into account the moderating effects of social support may increase maternal adaptation.

Mehraban, Hasani & Amini (2016), have observed the participation of children with cerebral palsy aged 8 to 14 years, and their normal peers, in a cross-sectional method. Results showed that there were significant differences between both the groups, and the authors concluded that physical disability could influence children’s daily activities and socialization. Understanding the participation of physically disabled children could then help health care professionals in designing and introducing appropriate treatment according to the children’s needs.

Nadeau & Tessier (2006), aimed to describe the social experience of children with cerebral palsy in mainstream classes in Canada and compare it with that of their classmates without disability. Disabled children and children with no impairment/disability were compared on the basis of sex, age, parents' education level, and family income by the authors. Social adjustment measures (social status, reciprocated friendships, social isolation, aggression, sociability/leadership, and victimization) were also obtained, by conducting a class-wide sociometric interview in the classes of the children with cerebral palsy. Their findings showed that children with cerebral palsy– specifically females – had fewer reciprocated friendships, exhibited fewer sociable/leadership behaviours, and were more isolated and victimized by their peers than their classmates without a disability. This suggests that children with cerebral palsy are perceived differently from their peers in a mainstreaming context.

Palisano, Tieman, Walter, Bartlett, Rosenbaum, Russell & Hanna (2003), analyzed the usual mobility methods of children with cerebral palsy at home, school, and outdoors, or in the community, and examined whether children with cerebral palsy were more dependent on adult assistance for mobility in certain settings. The results of the authors’ study indicated that compared with the school setting, children were more dependent on adult assistance for mobility when outdoors, or in the community, and less dependent at home. The findings suggest that environmental setting is an important consideration for assessment and intervention to improve mobility of children with cerebral palsy.

Parkes, Hill, Platt & Donnelly (2010), studied the prevalence, clinical associations, and trends over time of oromotor dysfunction and communication impairments in children with cerebral palsy. Of the authors' sample, 36% had motor speech problems, 21% had swallowing/chewing difficulties, 22% had excessive drooling, and 42% had communication impairments (excluding articulation defects). All impairments were significantly related to intellectual impairment. Therefore, these impairments were seen to be common in children with CP and are associated with poorer gross motor function and intellectual impairment.

Ribeiro, Vandenberghe, Prudente, Vila & Porto (2016), conducted a study with an aim to comprehend how the age group and the severity of the motor impairment of children with cerebral palsy modify the mothers' experiences of stress and to understand the coping strategies they use. It was seen that mothers of children with mild impairment suffer more from the challenge of dealing with their children's emotional problems, aggression and learning difficulties. For mothers whose children have severe impairment, the major difficulties relate to coping with health complications and functional limitations. Mothers of younger children report diverse sources of stress and scarcity of resources; while mothers of adolescents have greater experience and are able to take up their life projects again. Experience, knowledge and support received are critical for adaptation.

Santos, Massi, Willig, Carnevale, Berberian, Freire, Tonocchi & DeCarvalho (2017), analyzed the perceptions of the family caregivers on the care delivered to children and adolescents presented with cerebral palsy. It was found that the family members' accounts on care delivered to children and adolescents with cerebral palsy are mostly connected with positive feelings, such as love, happiness, privilege and overcoming. However, for a significant share of these family members, their own quality of life depends on the cared subject's health condition, blurring the distinction between their own needs and those of the cared subjects.

Vasconcelos, Moura, Campos, Lindquist & Guerra (2009), have aimed to identify functional differences among children with cerebral palsy at different levels of motor dysfunction, and to investigate the relationship between these differences and the domains of mobility, self-care and social function in functional skills and caregiver assistance. The results of the authors' work showed a strong correlation between mobility and self-care and between mobility and social function.

Weber, Bolli, Heimgartner, Merlo, Zehnder & Katterer (2016), studied patients with cerebral palsy, and assessed how psychological problems influence their participation in society. 121 adults and 88 children were studied by their caregivers in a two-centre cross-sectional study, and the authors interpreted that both groups found the same frequency of abnormalities in attention problems, social interaction, and peer problems. They conclude that the persistence of psychological and social problems from childhood into adulthood underlines the importance of focusing on early intervention.

While the Introduction and the Literature Review are important, in-depth study of the methodological details is discussed in the next chapter.

METHODOLOGY

3.1. METHODOLOGY

After stating the objectives of the present study, along with the related literature survey in earlier chapters 1 and 2, it is necessary to study in-depth, the methodological details of the study which aims to study the Correlates of Mental Health in Children with Cerebral Palsy and Autism.

According to the World Health Organization's **World Report on Disability (2011)**, 15% of the global population has some form of disability due to different causes. Population-based studies from around the world report that the prevalence estimates of CP range from 1.5 to more than 4 per 1,000 live births or children of a defined age range (10–14). The overall birth prevalence of CP is approximately 2 per 1,000 live births (15–17). In India, approximately 3.8% of the population has a form of disability. Of these, nearly 15-20% of the physically handicapped children suffer from

Cerebral Palsy (CP). The estimated incidence of CP in India is around 3 every 1000 live births; however, being a developing country, the expected actual figure may be much higher.

Autism spectrum disorder (ASD) on the other hand, is another universal disability. Its estimated prevalence is 1% in the United Kingdom and 1.5% in the United States. According to the WHO, it is estimated that worldwide, 1 in 160 children has an ASD. Some well-controlled studies have, however, reported figures that are substantially higher. The prevalence of ASD in many low- and middle-income countries is so far unknown. Based on epidemiological studies conducted over the past 50 years, the prevalence of ASD appears to be increasing globally.

The prevalence was estimated to be 61.9/10,000 globally in 2012. In India – which is a populous country of nearly 1.3 billion people with children ≤15 years constitute nearly one-third of the population – it has been estimated that more than 2 million people might be affected with ASD in India. Most of the reported studies on ASD are based upon hospital-based data and thus lack information on the prevalence estimates of this disorder in India. There is also under-recognition of the disorder due to a delay in the diagnosis of ASD at a young age.

3.1.1. Sample

- 30 children with Cerebral Palsy- 15 male, 15 female approximately (Cerebral Palsy with Mental Retardation may also be included.)
- 30 children with Autism- 15 male, 15 female approximately (Autism with Mental Retardation may also be included.)

Inclusion Criteria:

- Age: 7-18 years
- Socio-Economic Status: Low and Lower Middle.
- Nationality: Indian
- Education- Basic elementary education (basic English and mathematical skills).

Exclusion Criteria:

- Children not falling within the age range of 7-18 years of age.
- Children not belonging to low and lower middle socio-economic status.
- Non- Indian.
- Children with any other disability other than Cerebral Palsy and Autism. (If needed, then the sample, may include Cerebral Palsy with Mental Retardation and Autism with Mental Retardation.)

3.1.2. Hypothesis:

3.1.2.1 There will be a difference between the above-mentioned two groups of disability; that is; Cerebral Palsy and Autism with respect to the correlates of mental health, that is, personal care, positioning and transfer, communication and social interaction, comfort and emotions, health, child's overall quality of life and importance of items to child's quality of life.

3.1.2.2. There will be a significant relationship amongst the variables of personal care, positioning and transfer, communication and social interaction, comfort and emotions, health, child's overall quality of life and importance of items to child's quality of life for the two groups of disability - Cerebral Palsy and Autism.

3.1.2.3. A case study with a set of predetermined questions, covering the above-mentioned aspects of disability will reveal different aspects of each of the two groups, through qualitative understanding.

3.1.2. Tools Used

The tools used in this project are an Information Schedule to find out the preliminary details of the subjects and whether they met the selection criteria mentioned above for qualitative and quantitative analysis, as well as the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD©) Questionnaire (Narayanan, Weir & Fehlings; 2007)

3.1.2.1. Information Schedule

With regard to the Information Schedule, considering that most of the children were not in a condition to respond to questions, details about the caregiver was taken, such as age of the caregiver, sex of the caregiver, educational qualification of the caregiver, relation of the caregiver to the child, and date of birth of the caregiver.

3.1.2.2. The Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD©) Questionnaire (Narayanan, Weir & Fehlings; 2007)

3.1.2.2.1. History

Created by Narayanan, Weir, and Fehlings in 2007, this questionnaire was developed, because till then, no validated instruments had measured the impact of disability on a child's overall health, comfort, their functional capacity and quality of life, therefore, consequently, the evidence remains unclear as to how to how to improve quality of life for these children. The Caregiver Priorities project was initiated to address this problem and led to the development and validation of the Caregiver Priorities & Child Health Index of Life with Disabilities (CPCHILD™) questionnaire.

3.1.2.2.2. Description

The CPCHILD© Questionnaire measures the caregiver's perspective about the child's

health status, comfort, wellbeing, functional abilities and ease of caregiving. It is a useful proxy measure of health-related quality of life of children with severe disabilities, such as Cerebral Palsy or Autism. The items for the pilot questionnaire were derived from recommendations of caregivers of children with severe disabilities, and healthcare professionals across multiple disciplines involved in the care of these children.

The CPCHILD™ currently consists of 37 items distributed among six sections representing the following domains:

1. Activities of daily living/personal care (nine items)
2. Positioning, transferring and mobility (eight items)
3. Comfort and emotions (nine items)
4. Communication and social interaction (seven items)
5. Health (three items)
6. Overall quality of life (one item)

In Section 7, caregivers rate the importance of each of these items' contribution to their child's quality of life.

3.1.2.2.3. Scoring

In the first 6 sections, the questions are structured in such a way, that there are 7 possible responses, ranging from 0 (No possible) to 6 (No problem at all). Here, the children must state whether they can or cannot perform particular tasks, as stated by the question, and then, on a 4-point scale – from 0 being 'Total Dependence', to 3 being 'Independent', how dependent they are on their caregivers. For the 7th section, caregivers rated the importance of each item's contribution to their child's quality of life (QOL) on that 6-point ordinal scale from 0 (least important) to 5 (most important).

3.1.2.2.4. Reliability

The initial questionnaire was tested in cross- sectional iterative survey of caregivers of children with cerebral palsy and traumatic brain injury. With their recommendations on different domains of it, the CPCHILD™ questionnaire underwent a number of studies to evaluate its reliability and validity.

3.1.3. Procedure

The present study was Kolkata-based, and was kept in accordance with the inclusion and exclusion criteria. Institutions were approached with the specific topic and the precise description for the research. On specified dates, the children were observed, with consent of the institution and the caregivers. The researcher introduced herself to the caregiver and explained the study, as well as assured confidentiality; that the questionnaire was to be filled then and there, and would not be disclosed; that the data collected was for research purposes only.

3.1.4. Precautions

1) The caregivers were assured that this was not a test. There were no right or wrong answers to the questions.

2) Caregivers were assured confidentiality

3) The caregivers were to participate in the research only if they wished to; they were not forced. They were assured that they were free to do it only if they wanted to, on their free will.

4) There was no time limit to fill the questionnaire.

5) In case of difficulties, the caregiver was asked to approach the researcher.

3.1.5. Sampling

Descriptive, Correlational Research Design with Purposive Random Sampling.

3.1.6. Analyses

3.1.6.1. Analyses of Data

The data collected was subjected to both, quantitative as well as qualitative analysis. After data collection, the responses were scored, and mean, standard deviation (SD) and t-test was computed. Correlation was computed as another statistical technique for the above data. In addition to the quantitative analysis, a case study for each group was also conducted to derive a holistic view about the two groups of disability.

3.1.6.2. Method of Analyses

Data was analysed using the methods described below:

●Descriptive Statistics (Mean, S.D., and Correlation)

●Inferential Statistics (t-Test)

3.1.6.3. Plan of Analyses

Level of Variables	Purpose	Mode of Analyses
Univariate Bivariate (Only for correlation)	Descriptive	Mean, S.D., and Correlation
	Testing inter-group difference in the selected variables	t-Test

The Results of the Study are detailed in the following chapter.

RESULTS

RESULTS

4.0. The data obtained from the respondents were systematically arranged and properly tabulated with respect to each of the variables considered in the present study. The presentation of the data has reflected the measures of the obtained selected project variables and their statistical distributions on the basis of which suitable statistical techniques were applied to analyze and find out the necessary information to serve the objectives of the study.

To understand the nature of differences between the respondents with Autism and Cerebral Palsy, in the probe of a study of correlates of mental health, descriptive and inferential statistics in the form of Mean, SD and 't' test respectively were calculated. With the help of these statistics, attempts were taken to study the different variables of personal care/ activities of daily living, positioning, transferring and mobility, comfort and emotions, communication and social interaction, health, child's overall quality of life and importance of items to child's quality of life. Another descriptive statistics of correlation was used to determine the contribution and relationship of the different variables of personal care/ activities of daily living, positioning, transferring and mobility, comfort and emotions, communication and social interaction, health, child's overall quality of life and importance of items to child's quality of life.

The difference between the two groups was highlighted by the 't' test. The findings are as follows:

TABLE 4.1.1: MEANS, STANDARD DEVIATIONS, AND t VALUES OBTAINED BY RESPONDENTS WITH AUTISM (N=30) AND CEREBRAL PALSY (N=30) ON THE SELECTED VARIABLES.

VARIABLES	AUTISM		CEREBRAL PALSY		t-VALUE
	Mean	Standard Deviation	Mean	Standard Deviation	
Personal Care/ Activities of Daily Living	571.40	189.822	419.13	213.934	2.916
Positioning, Transferring and Mobility	593.23	162.355	395.20	265.372	3.487**
Comfort and Emotions	721.43	73.141	636.90	112.985	3.440*
Communication and Social Interaction	541.93	125.642	441.67	153.068	2.773

Health	258.67	42.323	221.33	53.546	2.996*
Child's Overall Quality of Life	77.90	16.312	68.00	20.069	2.097
Importance of Items to the Child's Quality of Life	2404.67	461.532	2710.00	454.123	-2.583

$*p<0.05$ and $**p<0.01$

➢Table 4.1.1 reveals significant differences between respondents of Autism and Cerebral Palsy with respect to the variables of Positioning, Transferring and Mobility, Comfort and Emotions and Health.

➢The t-test measure indicate that the Comfort and Emotions variable (t= 3.440, $p<0.05$) and Health variable (t=2.996, $p<0.05$) was found to play an important role and thus produced significant influence in the lives of children with Autism and Cerebral Palsy.

➢The Positioning, Transferring and Mobility (t=3.487, $p<0.01$) variable was also found to have produced significant influence between the two groups.

➢The mean score for the children with Autism were found to be higher than the children with Cerebral Palsy for all three significant variables, that is, Comfort and Emotions, Health and Positioning, Transferring and Mobility. The mean difference was found to be significant for all three variables.

➢Overall, respondents of Autism scored higher in all dimensions, except the variable "Importance of items to Child's Quality of Life". The respondents of Cerebral Palsy showed more heterogeneity in responses for all variables except the variable "Importance of items to Child's Quality of Life".

The above-mentioned data is graphically represented below:


MEAN
3000
2500
2000
1500
1000
500
0
Personal Care/ Activities of Daily Living
Positioning, Transferring & Mobility
Comfort & Emotions
Communication & Social Interaction
Health
Overall Quality of Life
Importance of Items to Child's Quality of Life
Autism
Cerebral Palsy

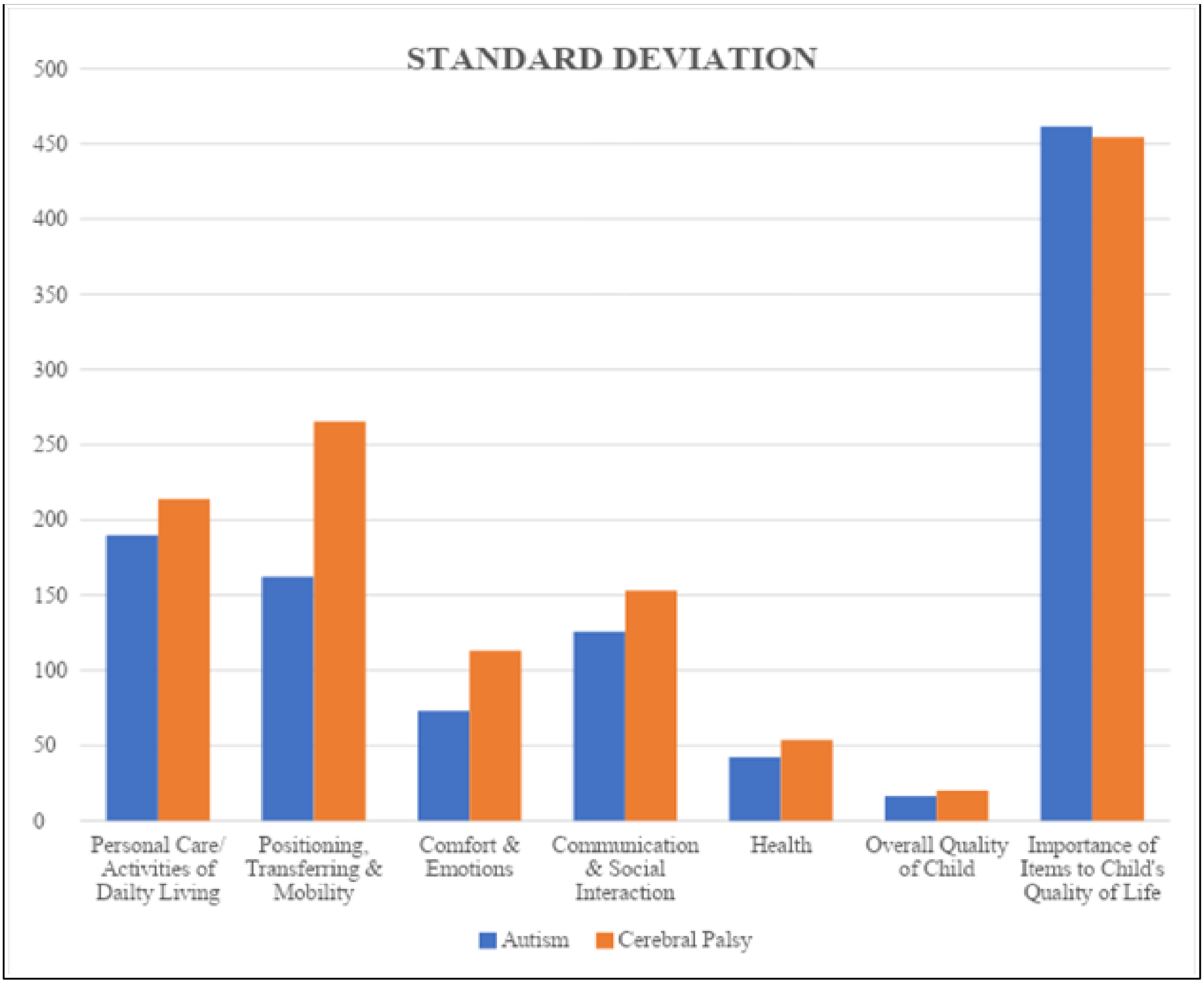
STANDARD DEVIATION
500
450
400
350
300
250
200
150
100
50
0
Personal Care/ Activities of Dailty Living
Positioning, Transferring & Mobility
Comfort & Emotions
Communication & Social Interaction
Health
Overall Quality of Child
Importance of Items to Child's Quality of Life
Autism
Cerebral Palsy

TABLE 4.1.2: INTER CORRELATION MATRIX FOR THE CORRELATES OF MENTAL HEALTH IN CHILDREN WITH AUTISM (N=30)

VARIABLES	PC	PTM	CE	CSI	H	OQOL	IIQOL
Personal Care/ Activities of Daily Living (PC)	1.00						
Positioning, Transferring and Mobility (PTM)	.364*	1.00					
Comfort and Emotions (CE)	.510**	.491**	1.00				
Communication and Social Interaction (CSI)	.363*	.489**	.507**	1.00			
Health (H)	.529**	.649**	.563**	.479**	1.00		

Child’s Overall Quality of Life (OQOL)	-.193	-.177	-.065	.195	-.007	1.00	
Importance of items to the Child’s Quality of Life (IIQOL)	-.110	.208	.071	.361	.199	.025	1.00

*p< .05 **p< .01

Significant and positive correlations were found between Positioning, Transferring and Mobility (PTM) and Personal Care/ Activities of Daily Living (PC) (r= .364, p< .05), Comfort and Emotions (CE) and Personal Care/ Activities of Daily Living (PC) (r= .510, p< .01). The inter-correlations also indicate a positive correlation between Comfort and Emotions (CE) and Positioning, Transferring and Mobility (PTM) (r= .491, p< .01). A positive correlation was also found between Communication and Social Interaction (CSI) and Personal Care/ Activities of Daily Living (PC) (r= .363, p< .05), Communication and Social Interaction (CSI) and Positioning, Transferring and Mobility (PTM) (r= .489, p< .01), Communication and Social Interaction (CSI) and Comfort and Emotions (CE) (r= .507, p< .01). A positive correlation was also indicated between Health (H) and Personal Care/ Activities of Daily Living (PC) (r= .529, p< .01, Health (H) and Positioning, Transferring and Mobility (PTM) (r= .649, p< .01), Health (H) and Comfort and Emotions (CE) (r= .563, p< .01), Health (H) and Communication and Social Interaction (CSI) (r= .479, p< .01).

TABLE 4.1.3: INTER CORRELATION MATRIX FOR THE CORRELATES OF MENTAL HEALTH IN CHILDREN WITH CEREBRAL PALSY (N=30)

VARIABLES	PC	PTM	CE	CSI	H	OQOL	IIQOL
Personal Care/ Activities of Daily Living (PC)	1.00						
Positioning, Transferring and Mobility (PTM)	.773**	1.00					
Comfort and Emotions (CE)	.664**	.573**	1.00				
Communication and Social Interaction (CSI)	.691**	.614**	.629**	1.00			
Health (H)	.184	.063	.433*	.322	1.00		
Child’s Overall Quality of Life (OQOL)	-.438*	-.446*	-.151	-.441*	-.113	1.00	

Importance of items to the Child's Quality of Life (IIQOL)	.466**	.511**	.270	.552**	-.099	-.171	1.00

*p< .05 **p< .01

Significant and positive correlations were found between Positioning, Transferring and Mobility (PTM) and Personal Care/ Activities of Daily Living (PC) (r= .773, p< .01), Comfort and Emotions (CE) and Personal Care/ Activities of Daily Living (PC) (r= .664, p< .01), Comfort and Emotions (CE) and Positioning, Transferring and Mobility (PTM) (r= .573, p< .01). The inter-correlations also indicate a positive correlation between Communication and Social Interaction (CSI) and Personal Care/ Activities of Daily Living (PC) (r= .691, p< .01), Communication and Social Interaction (CSI) and Positioning, Transferring and Mobility (PTM) (r= .614, p< .01), Communication and Social Interaction (CSI) and Comfort and Emotions (CE) (r= .629, p< .01). Significant and positive correlations were found between Health (H) and Comfort and Emotions (CE) (r= .433, p< .05). A negative and significant correlation was found between Child's Overall Quality of Life (OQOL) and Personal Care/ Activities of Daily Living (PC) (r= -.438, p< .05), Child's Overall Quality of Life (OQOL) and Positioning, Transferring and Mobility (PTM) (r= -.446, p< .05), Child's Overall Quality of Life (OQOL) and Communication and Social Interaction (CSI) (r= -.441, p< .05). A positive correlation was also found between Importance of items to the Child's Quality of Life (IIQOL) and Personal Care/ Activities of Daily Living (PC) (r= .466, p< .01), Importance of items to the Child's Quality of Life (IIQOL) and Positioning, Transferring and Mobility (PTM) (r= .511, p< .01), Importance of items to the Child's Quality of Life (IIQOL) and Child's Overall Quality of Life (OQOL) (r= .552, p< .01).

4.2. Case Studies

4.2.1. Autism

Two case studies were conducted on 2 of the 30 children with Autism. The former scored the lowest on the assessment questionnaire, and the latter scored the highest, and are given below:

4.2.1.1. This case study is an assessment of a child with Autism based on the response given by the caregiver in an interview. The present subject is a nineteen-year-old male with severe Autism Spectrum Disorder. He was detected with this disorder at a young age and hence was admitted to Autism Society of West Bengal. This institution is a government aided institution who takes in Autistic children and helps them to be as less dependent as possible. This child goes to this institution daily and is accompanied by his mother. In this institution, through the lessons taught and the activities arranged for the children, he is taught to use his limbs properly and is helped learn means of communication. The mother explained that the institute he is in has helped him communicate better and helped in developing his understanding skills.

Since the child is faced with many difficulties throughout the day, the assistance of his mother is of utmost importance. His mother is a graduate in Hindi and has completed her M.A. in Hindi. She is 47 years of age and has dedicated almost 20 years of her life in taking care of her child's needs. She had to leave her previous job to do so. Presently, she is a parent volunteer in Autism Society of West Bengal. She has a strong bond with her child and she believes that however severe the case might be, she will never fail to understand the needs of her child.

During the responses provided by the caregiver, it was clear that the child faced issues in daily life situations. He was fully dependent on his mother's assistance. Since communication was not an issue for the mother and the child, the mother gave instructions to the child or prompted the child on how he must go about when there is work in hand. The subject is quite obedient as in the absence of his mother, he is able to conduct himself in the best way possible. He is able to walk and does not require assistance but mere supervision. Apart from that, the child requires help in wearing his clothes and shoes and is unable to comb his hair. However, with verbal and gestural prompting, he somehow manages to brush his teeth, but his mother has to do the final cleaning.

At home, when the subject is asleep, he experiences sleep disturbance which could sometimes become severe. Hence, he is prescribed medicines to calm his nerves, for sleep disturbances, restlessness and for seizures as he has an epileptic history. He is also prescribed Vitamin tablets. Recent from the time of interview, the subject was suffering from fever and cough and cold and therefore was advised medication. The caregiver further mentioned that her son is to visit the doctor for check-up once in every three months.

Overall, the subject is a happy child. He loves to listen to music in Hindi and Bengali, and likes to walk around in parks, visit malls and restaurants. He is restless and gets excited in overwhelming situations. Besides his cheery nature, he also throws tantrums and behaves peculiarly when he meets strangers.

4.2.1.2. The present subject is a part of the Aarohaan, Pre-vocational Unit at the Autism Society West Bengal for young adults. This child and her monozygotic twin are 21 years old. Soon after their birth, the twin sisters had been diagnosed with Autism Spectrum Disorder (ASD).

The subject is very intelligent and grasps concepts quickly. She is extremely talented and her hobbies include painting, stitching and art and craft. She loves making cards and accessories such as bracelets, earrings, necklaces etc. She always tries to wear accessories that are in accordance with her attire. The present subject enjoys drawing and making cards for all occasions.

The subject has a very sharp memory. She can remember the name and the date of birth of individuals by simply asking them about it once. The next time she meets them; she greets and acknowledges them with their name, followed by their date of birth. Every time someone asks the subject a question, she repeats the question out loud, before answering it. Not only is she fond of inquiring individuals of their date of birth, but she also informs them about her date of birth and expects them to remember the date so that they are able to answer her correctly when she asks them about it in the future. If she wakes up in the morning and recalls someone's birthday, she immediately informs her mother about it.

The present subject is quite self-reliant and manages her day-to-day activities independently, without much of a hassle. With regard to 'personal care and activities of daily living', she does not encounter any problem and does not need any kind of assistance. However, for activities such as bathing, changing her clothes, putting on footwear etc., minimal supervision is required. On most days, the subject and her identical twin, can be seen dressed in the same outfit.

With regard to 'positioning, transferring and mobility', the subject independently performs activities such as getting in and out of bed, transferring from one place to the other, etc. However, in order to move about outdoors, getting in and out of a motor vehicle, visiting public places etc., she faces a little difficulty and requires a certain degree of assistance.

Over the last two weeks from the time the subject was observed, she expressed emotional agitation once or twice. However, on the whole, the child has a calm and composed demeanor. She has a positive attitude towards everything that she participates in. The present subject can 'very easily' understand those around her such as her caregiver, her parents, teachers, friends, etc. Without much difficulty, she interacts with others and mixes well with individuals even if she does not know them from before. As much as she enjoys spending time by herself by engaging in art and craft related activities and playing by herself, she also likes participating in group activities. The subject's 'overall health' and 'overall quality of life' and is 'excellent'. She visits the doctor scarcely for her routine checkups.

The subject sells her things at Art Exhibition organized by the society and also participates as a dancer in programs. She is an independent and self-reliant individual.

4.2.2. Cerebral Palsy

As done above with Autism, two case studies were also conducted on 2 of the children with Cerebral Palsy. The first case study is based on the lowest-scorer on the assessment questionnaire, and the second case study is based on the highest score and is given below:

4.2.2.1. This case study describes the quality of life of a 10-year-old female child with severe Spastic Cerebral Palsy along with Global Developmental Delay with the aim to improve the overall quality of life. She was classified as a level 5 on the Gross Motor Function Classification System (GMFCS). The child is fully dependent and she is transported in manual wheelchair.

During the assessment, the teacher and the child's caregiver were present to answer the questions. The present subject is a 10-year-old female with severe Cerebral Palsy with GDD. She belongs to a middle socio-economic status household and lives with two working parents. The child has several conditions associated with cerebral palsy, such as epilepsy, behaviour disorder. She has regular follow-up care with medical staff to monitor her CP and epilepsy. The child faces difficulties in positioning and transfer as it is fully dependent. The child is kept under constant supervision. It is difficult for the caregiver to understand the child's needs as she only uses rejection and crying as the mediums of communication. The child is made to understand simple concepts of food, water, toilet through picture indication. The child is presently being given toilet training and she is also given verbal prompts of two words at a time to make common words familiar. The child understands when her name is being called she makes eye movements but cannot react to it. The child cooperates with the caregiver when she is being fed or transferred from one position to another. The child listens to the caregiver and the teacher when she is giving some kind of instruction. Overall, the quality of life is highly affected due to the lack of communication and other physical difficulties. The special educators provide training to the child to simplify the daily life difficulties and for giving the child a better quality of life.

4.2.2.2. This case study describes the impact of physiotherapy intervention on a 14-year-old male child with mild Diplegic Cerebral Palsy with the aim to improve his participation in activities. The child was referred to physiotherapy due to the decline in walking abilities and functional ability. He was classified as a level 3 on the Gross Motor Function Classification System (GMFCS). The child walks using a handheld mobility device (crutches).

The present subject is a 14-year-old male with mild Diplegic Cerebral Palsy. He started experiencing decline in walking abilities when he was 10 years old. He belongs to a high socio-economic status household and lives with his parents and a younger brother. The child was referred for physiotherapy to help his inability in walking, function and with a goal to be able to perform activities of daily life more independently. The child only has motor function difficulty associated with Cerebral Palsy but does not show any other behavioural or learning difficulties.

During the assessment, along with the child, his teacher was present to assist him in answering questions. The child was extremely good in social communication and he loves to interact with new people. The child uses underarm crutches to ambulate and walk. It has been noted that with the help of physiotherapy, there has been a lot of improvement in his transitional activities, daily living activities. The child is able to complete the majority of his personal care activities. However, assistance is needed in other complex activities. He loves to attend school every day. The child loves recreational activities such as painting, football, watching movies etc. The child maintains a good relationship with his parents and younger brother. The child goes for his physiotherapy session enthusiastically for four days in a week. The therapy includes strength and flexibility improvement, muscle tone improvement, etc. It helps to make daily movement easier for the child. The child receives cooperation from all his family members and teachers and does not complain about any such difficulty in cooperation and adjustment.

With the results obtained, the difference in the profile of correlates of mental health of children with cerebral palsy and autism are discussed in the following chapter. The magnitude and direction of relationship amongst the variables constituting correlates of mental health have also been highlighted.

DISCUSSION

The result presented in the earlier chapter has been discussed in the following manner:

5.1. DIFFERENCE IN THE PROFILE OF CORRELATES OF MENTAL HEALTH IN CHILDREN WITH CEREBRAL PALSY AND AUTISM

Table 4.0 shows the mean, standard deviation, t values for the selected variables in Autistic children (N=30) and children with Cerebral Palsy (N=30). Significant difference was obtained between the children with autism and cerebral palsy with respect to Personal Care/Activities of Daily Living (t=2.916), Positioning, Transferring and Mobility (t=3.487), Comfort and Emotions (t=3.440), Communication and Social Interaction (t=2.773), Health (t=2.996), Child's Overall Quality of Life (t=2.097) and Importance of Items to Child's Quality of Life (t=-2.583).

5.1.1. PROFILE OF PERSONAL CARE/ ACTIVITIES OF DAILY LIVING

Personal Care Activities include food habits, maintaining oral hygiene, bathing and washing, changing clothes, haircare and toilet activities.

With respect to the profile of this domain, the sample of children with Autism (M= 571.40) show better independence in the domain of personal care and daily living, than the sample of children with Cerebral Palsy (M= 419.13). This means that children with Autism were less dependent on their caregivers and required less assistance in conducting daily life activities. On the other hand, children with Cerebral Palsy faced greater difficulty in carrying out their daily activities.

The Standard Deviation for Autism was 189.822 and for Cerebral Palsy was 213.934. This implies that the deviation from the mean was lesser in the case of Autistic children than that of children with Cerebral Palsy. It was observed that with the given sample groups, only 3 out of the 30 Autistic children were completely dependent on their caregivers for activities such as drinking, eating, brushing their teeth, bathing, etc. But in the care of Cerebral Palsy, 10 out of the 30 were almost entirely dependent on their caregiver with the remaining 20 also needing assistance in varying degrees, because they did not have proper fine motor skills; only gross motor skills.

Jasmin, Couture, McKinley, Reid, Fombonne & Gisel (2009), explored the impact of sensorimotor skills on the performance of Daily Living Skills in preschool children with Autism Spectrum Disorders. The authors found that the children showed atypical sensory responses, and very poor motor skills and daily living skills. They observed that sensory avoiding – an excessive reaction to sensory stimuli – and fine motor skills were highly correlated with daily living skills, even when cognitive performance was taken into account. They concluded that sensorimotor deficits have an impact on the autonomy of children with Autism Spectrum Disorders, and interventions should aim at improving and supporting the development of sensori-motor skills.

According to the study provided by Jasmin, Couture, McKinley, Reid, Fombonne & Gisel (2009), children with Autism showed difficulty in performing their daily life activities due to problems in their sensory motor skills. This research therefore, is not in support of the present findings. In the research findings provided by the present study, it was seen that children with Autism were comparatively independent except for three (M= 571.40).

Memari, Panahi, Ranjbar, Moshayedi, Shafiei, Kordi & Ziaee (2015), investigated the pattern of participation of children with Autism Spectrum Disorder (ASD) in daily physical and play activities. It was seen that only 12% of children with ASD were active and 88% were inactive. Addressing the frequency of activity participation, results showed that only 6% of children with ASD "often" participated in physical activities, whereas 85.5% of them had "never/rarely" participated, and 8.5% were "sometimes" involved in physical activities. It was also seen that boys with ASD participated in physical activities more than girls with ASD.

The above-mentioned study states the inactivity of children with Autism with regard to daily physical and play activities. In contrast to these findings, the results of the present study show that children with Autism are generally active and involve themselves in daily living and play activities (SD=189.822). According to the findings of this study, only three out thirty children would have similar responses to such activities.

5.1.2. PROFILE OF POSITIONING, TRANSFERRING AND MOBILITY

This domain includes the capability of the child to change positions in sitting, standing and lying down on the bed. The degree of difficulty in transferring from the wheelchair or chair is also taken into consideration. The mobility of the child is determined with respect to walking, moving of limb, moving about at home or outdoors, getting in and out of motor vehicles and visiting public places.

Therefore, with respect to the profile of this domain, it was seen that the sample group with Autism had more mobility as compared to the sample group with Cerebral Palsy. Of the 30 children in the Autism sample group, only 2 were completely dependent and on a wheelchair, and few of the children in this group also had a crutch or another implement to help them move. In the case of the sample group with Cerebral Palsy though, 14 of the 30 were confined to a wheelchair and hence were completely dependent, and the ones who did not need wheelchairs required crutches and/or a caregiver at all times. Therefore, it was observed that the sample of children with Autism (M= 593.23) shows a higher value of mean than the sample of children with Cerebral Palsy (M=395.20).

The Standard Deviation for Autism was 162.355 and for Cerebral Palsy was 265.372. This implies that the deviation from the mean was lesser in the case of Autistic children than that of children with Cerebral Palsy.

Ming, Brimacombe & Wagner (2007), state that Autism Spectrum Disorders (ASD) manifest as impairments in social interaction, language and speech development, and the appearance of repetitive behaviours with restricted interests. The objective of their study was to describe the prevalence of motor deficits in ASD. The results suggest that fine motor control and programming deficits are common co-occurrence of children with ASD. The reduced prevalence of these motor deficits in older children suggests improvement over time, whether through natural progression, results of interventional therapy, or the combination of the two. However, ASD children with the motor deficits were not more likely to receive service than those without the motor deficits.

The study by Ming, Brimacombe & Wagner (2007) does support the present study. Only two of the children with Autism were fully dependent, and others, while they did have varying levels of dependence, they had a deficiency in fine motor skills, but could generally move on their own.

Palisano, Tieman, Walter, Bartlett, Rosenbaum, Russell & Hanna (2003), analyzed the usual mobility methods of children with cerebral palsy at home, school, and outdoors, or in the community, and examined whether children with cerebral palsy were more dependent on adult assistance for mobility in certain settings. The results of the authors' study indicated that compared with the school setting, children were more dependent on adult assistance for mobility when outdoors, or in the community, and less dependent at home. The findings suggest that environmental setting is an important consideration for assessment and intervention to improve mobility of children with cerebral palsy.

The study by Palisano, Tieman, Walter, Barlett, Rosenbaum, Russell & Hanna (2003) is in support of the present study. In the present sample, it was seen that 14 of the 30 children were entirely dependent on their caregivers when in a school setting, though they had slightly less dependence at home, which was a familiar space. But in a school setting, or the outdoors, they were heavily dependent, as this study states.

5.1.3. PROFILE OF COMFORT AND EMOTIONS

Comfort and Emotions include the ability of the child to carry out their activities of daily life with comfort. Their emotional response to their surroundings with respect to their feelings and temperament in the past two weeks from the time of interview was noted. Their disturbance in sleep was also recorded.

The recorded Mean and Standard Deviation for the sample group with Autism was recorded to be 721.43 and 73.141 respectively, while the Mean and Standard Deviation for the sample group with Cerebral Palsy was found to be 636.90 and 112.985 respectively.

With regard to the sample group with Autism, their comfort levels were relatively high, because many children in the sample had a level of independence and could perform tasks and move on their own, with minimal assistance. However, their emotional satisfaction was rather low. Most children in the group were recorded as having been sad, agitated, or angry almost every alternate day in a period of two weeks. This indicates that though they have physical comfort, they are often not understood emotionally by their caregivers, parents, and teachers.

In the case of the sample group with Cerebral Palsy, almost the opposite was observed. Most of the children with Cerebral Palsy had occasional emotional outbursts, but on a whole, they were relatively cheerful and happy in the two-week period; they were not overly angry or agitated. But their comfort was very low, with most reporting varying levels of pain in the past two weeks.

This stems from the fact that – although the symptoms look similar to a layman – Autism is a developmental disorder that impairs the ability to interact and communicate, and Cerebral Palsy is primarily a congenital disorder of movement and muscle tone.

Bal, Harden, Lamb, Hecke, Denver & Porges (2010), concluded with their study that children with Autism Spectrum Disorder (ASD) were slower in emotion recognition, and selectively made more errors in detecting anger. ASD children had lower amplitude Respiratory Sinus Arrhythmia (RSA) and faster heart rate. Within the ASD group, children with higher amplitude RSA recognized emotions faster. Less severe ASD symptoms and increased gaze to the eye region in children with ASD were related to more accurate emotion recognition.

This study supports the present research, as it has been shown that while physical comfort is alright for children with Autism, their overall emotional state was not satisfied, and they were agitated and angry.

Dababneh (2013), aimed at identifying the behavioural difficulties facing the children with cerebral palsy in Jordan. In addition, it attempted to determine the differences between those children according to certain variables such as gender, age, level of family income, and level of disability. The results revealed that children with cerebral palsy on average – according to their parents' reports – had a moderate degree of overall behavioural problems across internalized problems that were composed of subscales such as shyness, depression, anxiety, and social isolation; and across externalized problems composed of the aggressiveness scale. There were significant differences due to the gender variable on the overall scale and on the anxiety dimension in favor of male children. Moreover, there were significant differences on the shyness and isolation dimensions due to the level of disability in favor of children with cerebral palsy and mental retardation.

This study by Dababneh (2013) does in part support the present research, as it was noted that there were emotional outbursts from children suffering from cerebral palsy in the two week period. However, it differs, because in this case, the children did not have internalized problems of shyness or depression; their mental state was relatively cheerful.

5.1.4. PROFILE OF COMMUNICATION AND SOCIAL INTERACTION

This domain involves the ability of the child to interact, communicate and respond to the caregivers, as well as respond to unfamiliar individuals. This domain includes; the ability to include oneself with others during an activity, comprehending the instructions given by the caregiver and conducting oneself in the absence of the caregiver in a social environment is taken into consideration. Participating in recreational activities with family and friends is also recorded.

With respect to the profile of this domain, the sample of children with Autism (M= 541.93) shows a higher value of mean than the sample of children with Cerebral Palsy (M= 441.67). This means that children with Autism communicate easily with their caregivers compared to children with Cerebral Palsy. This is seen despite the fact that it is Autism which is a developmental disorder characterized by the inability to communicate. This is due to the fact that in Cerebral Palsy, oftentimes, the muscles and movement affects is not limited only to the limbs, but also the ability to use the muscles of the face to speak. In the cases of children who were confined to wheelchairs in the sample group of children with Cerebral Palsy, they were unable to move not only their hands and feet, but were also unable to speak. In cases such as these, communication – even with caregivers – is highly difficult. This is why the children with Cerebral Palsy scored lower in this domain than the children with Autism did.

The Standard Deviation for Autism was 125.642 and for Cerebral Palsy it was 153.068. This indicated that there were more deviations and no clear pattern of communication and interaction in the sample group of children with Cerebral Palsy than in the sample group of children with Autism.

Bauminger, Shulman & Agam (2003), conducted a study on Social interaction with peers and the understanding and feelings of loneliness. This was examined in high-functioning children with autism and their ‘normal’ peers, matched for IQ, chronological age, gender, and maternal education. Overall, children with autism revealed a good understanding of both social interaction and loneliness, and they demonstrated a high level of social initiation. However, they spent only half the time in social interactions with peers compared with their matched counterparts, and they interacted more often with a typically developing child than with another special education child. Children with autism reported higher degrees of loneliness than their typical age-mates, as well as a lower association between social interaction and loneliness, suggesting their poorer understanding of the relations between loneliness and social interaction.

This study partly supports the present research because, with respect to Autistic children, it was observed that these children socially interacted with their peers, teachers and family members well and were also found to have good communications skills due to the fact that the majority of Autistic children were not physically impaired.

Parkes, Hill, Platt & Donnelly (2010), studied the prevalence, clinical associations, and trends over time of oromotor dysfunction and communication impairments in children with cerebral palsy. Of the authors' sample, 36% had motor speech problems, 21% had swallowing/chewing difficulties, 22% had excessive drooling, and 42% had communication impairments (excluding articulation defects). All impairments were significantly related to intellectual impairment. Therefore, these impairments were seen to be common in children with CP and are associated with poorer gross motor function and intellectual impairment.

This study is consistent with the present research, as it was observed that in the case of children with Cerebral Palsy, majority of the children were physically impaired and thus, associated with poorer gross motor functions. It was also observed that children with Cerebral Palsy were intellectually impaired due to the fact that there is essentially damage caused to the brain, with respect to this condition.

Weber, Bolli, Heimgartner, Merlo, Zehnder & Katterer (2016), studied patients with cerebral palsy, and assessed how psychological problems influence their participation in society. 121 adults and 88 children were studied by their caregivers in a two-centre cross-sectional study, and the authors interpreted that both groups found the same frequency of abnormalities in attention problems, social interaction, and peer problems. They conclude that the persistence of psychological and social problems from childhood into adulthood underlines the importance of focusing on early intervention.

This study supports the present research as it was observed that, with respect to Cerebral Palsy, the children did not actively participate in recreational activities with friends and family. This was because these children are faced with mobility issues as, majority of them are restricted to wheelchairs.

The studies mentioned above are therefore consistent with the present study as children with Cerebral Palsy display a lower score (M= 441.67) under the domain of Communication and Social Interaction.

5.1.5. PROFILE OF HEALTH

The domain of Health includes the list and number of medications taken by the child, as well as the frequency of visits to the doctor. It also includes the overall health of the child, particularly in the last two weeks, during the time of the interview.

In regard to this domain, the Standard Deviation for Autism was 42.323 and the Standard Deviation for Cerebral Palsy was 53.546. The Mean for Autism was 258.67, while the Mean for Cerebral Palsy was 221.33. This indicates that children with Autism had better overall health than the children with Cerebral Palsy. It was also seen that between both sample groups, the children with Autism had less frequent visits to the doctor.

Another factor seen was that the sample group with Autism had less medication than the sample group with Cerebral Palsy. In the case of Cerebral Palsy, it was seen that many of those children were also epileptic. Therefore, they had medications for epileptic seizures, joint and muscle pains and spasms, and a few also had antipsychotic medications. In the case of Autism, medications varied depending on the degree of Autism the child had, but the most common medications were for anxiety, sleeplessness, as well as antipsychotic drugs, mainly for aggression. 8 of the 30 in the sample group of children with Autism frequently took Risperidone, which is an atypical antipsychotic used to treat disorders, such as schizophrenia, bipolar disorder, and irritability and aggression associated with Autism. This medication can work by helping to restore the balance of certain natural substances in the brain.

Gurney, McPheeters & Davis (2006), compared parent-reported prevalence of health conditions and health care use between children with and without autism using a cross-sectional analysis. It was found that children with autism had a significantly higher prevalence of depression or anxiety problems and behavioral or conduct problems than children without autism. Respiratory, food, and skin allergies were reported by parents more often for children with autism. Children with autism had significantly higher mean physician visits over 12 months for preventive care, non-emergency care, and hospital emergency care, and were far more likely than children without autism to receive physical, occupational, or speech therapy to need treatment or counseling for an emotional, developmental, or behavioral problem, and, among those taking a prescribed medication, the use of the medication was long-term.

The study by Gurney, McPheeters & Davis (2006) states that children with Autism have frequent doctor visits and comparatively have poor health conditions as reported by the caregivers. However, according to the present research findings, the results retrieved says otherwise. Therefore, this research study is not in line/ supports the present study.

Donnell, Rosenbaum, Brehaut, Walter, Russell, Swinton, Zhu & Wood (2005), stated that one of the main challenges for parents is to manage their child's chronic health problems effectively and juggle this role with the requirements of everyday living. Thus, data on demographic variables and caregivers' physical and psychological health were assessed using standardized, self-completed parent questionnaires as well as a face-to-face home interview. Findings suggest that a higher level of behaviour problems was associated with lower levels of both psychological and physical health of the caregivers, whereas fewer child behaviour problems were associated with higher self-perception and a greater ability to manage stress. Child behaviour problems were an important predictor of caregiver psychological well-being. In families of children with cerebral palsy, strategies for optimizing caregiver physical and psycho-logical health include support for behavioural management and daily functional activities as well as stress management and self-efficacy techniques.

The above study proves that children with Cerebral Palsy suffer from chronic health problems and this becomes a difficulty for their caregivers. This finding is in support of the present research study. However, Donnell, Rosenbaum, Brehaut, Walter, Russell, Swinton, Zhu & Wood (2005) have also compared caregiver's psychological and physical health which adversely affected the well-being of the child with Cerebral Palsy. Since the current study did not include a separate questionnaire for the caregivers specifically, it was not possible to assess the psychological and physical well-being of the caregivers and show how it affected the child's health, but rather, only the child's health.

5.1.6. PROFILE OF CHILD'S OVERALL QUALITY OF LIFE

This domain was only concerned with one detail; the child's overall quality of life, in the past two weeks, from the time of the interview. Therefore, it was seen that, in regard to the child's overall quality of life, the sample of children with Autism (M=77.90) have scored higher than the sample of children with Cerebral Palsy (M=68.00). Therefore, it is observed that Autistic children had a better quality of life than the children with Cerebral Palsy. The Standard Deviation for Autism was 16.312 and the Standard Deviation for Cerebral Palsy was 20.069. This implies that there was heterogeneity of scores from the mean in the sample of children with Cerebral Palsy as compared to the children with Autism.

This was because of many different factors as observed in the previous domains. It was observed that from both sample groups in this research, the group with Cerebral Palsy has lower scores in activities of Personal Care, Mobility, Comfort and Emotions, Communication, and Health. This group was found to be far more dependent on caregivers than the group with Autism, was found to have limited mobility as compared to the group with Autism, was seen to have less comfort than the other group, as well as has problems communicating as compared to the Autistic children. All this obviously lowers the sample group with Cerebral Palsy's overall quality of life, in comparison to the sample group with Autism.

Zhen-Huan, Qiao-Ling, Yong & Xiao-Zhen (2016), studied the Quality of Life of children with Autism Spectrum Disorder (ASD). In comparison with other conditions, there has been a lack of focus on their quality of life. This study examined Pediatric Quality of Life of autistic children, from a multidimensional perspective. Results suggest greater impairment in adaptive functioning and emotional disorders.

The study by Zhen-Huan, Qiao-Ling, Yong & Xiao-Zhen (2016) does not support the current research findings. In the present study, it was seen that children with autism had a better overall quality of life when compared with other conditions – in this case, cerebral palsy. There was a higher level of independence from this group, and hence, their quality of life was fair.

Dickinson, Parkinson, Sieberer, Schirripa, Thyen, Arnaud, Beckung, Fauconnier, McManus, Michelsen, Parkes & Colver (2007), based this study on the quality of life of children with cerebral palsy, factors that influence it, and how it compares with quality of the general population. It was concluded that children with cerebral palsy had similar quality of life to children in the general population in all domains except schooling and physical wellbeing. This finding should guide social and educational policy to ensure that disabled children participate fully in society. Because of its association with quality of life, children's pain should be carefully assessed.

The study by Dickinson, Parkinson, Sieberer, Schirripa, Thyen, Arnaud, Beckung, Fauconnier, McManus, Michelsen, Parkes &Colver (2007) does in part support the present study. It is true that children with cerebral palsy did considerably better in other sections, and had more trouble in schooling and physical well-being. However, they also had considerable emotional distress as compared to the other group, so their quality of life is not similar to the general population, as of this sample group.

5.1.7. PROFILE OF IMPORTANCE OF ITEMS TO CHILD’S QUALITY OF LIFE

In this domain, the caregiver of the child answered questions as to how important an item was to their child. Examples of a few items include; eating/drinking independently, standing for transfer/exercise, emotional state or behaviour, attending school, able to play with others, and overall health, among other items. This time, unlike the previous domains, it was seen that the sample of children with Autism (M=2404.67) scored lower than the sample of children with Cerebral Palsy (M=2710.00). This difference was observed and validated by the caregivers of the children in both sample groups. There can be two reasons for these results. Firstly, the sample group of children with Cerebral Palsy is far more restricted in all domains as compared to the sample group of children with Autism. Things that most of the children with Autism can do rather easily – such as standing up independently, or sleeping without disturbance or pain – is difficult for the children with Cerebral Palsy, and hence, they ascribe more value to it.

Another reason could simply be because of subjectivity. These questions were not answered by all the children themselves; rather, it was answered by their caregivers, since most children were unable to communicate, or were not able to communicate with unfamiliar people at all; very few children were able to answer for themselves. For the vast majority, data was collected through interviews by the caregivers – parents and teachers – as well as through observation. Therefore, subjectivity on the caregivers’ part may have played a part in these results, since they may have stated the importance of the items on the questionnaire to them rather than its importance to their child/student.

Another factor could be the motivational factor in the children of both the groups. There is a direct relationship between the rate of motivation provided to the child and his performance in various kinds of activities. Children who received encouragement from their caregivers and teachers were seen to perform in a better way than of those who did not receive enough motivation from their parents or caregivers and teachers.

However, the Standard Deviation for Autism (SD=461.532) was still seen to be higher than the Standard Deviation for Cerebral Palsy (SD=454.123). This shows that the sample of children with Autism ascribe importance to different items in the questionnaire than the sample of children with Cerebral Palsy, who ascribed importance to more or less the same items on the questionnaire.

McStay, Dissanayake, Scheeren, Koot & Begeer (2013), examined differences in ‘parenting stress’ reported by parents of children with autism and typically developing children. The results revealed that child hyperactivity was the only factor significantly related to parenting stress in parents of children with autism, overruling measures of autism severity and child quality of life. This finding indicates the significant influence of problematic behaviours on parenting demands and perceptions of parenting skills in parents of children with autism, over other child characteristics conceived as within the parent’s control.

The above study by McStay, Dissanayake, Scheeren, Koot & Begeer (2013) is in support of the present research findings, as it was seen that parents who had children with elevated anger or hyperactivity, were in constant distress. Children who had better temperament and were relatively calmer could carry out the daily living activities, routine activities in school with ease than the children who were easily agitated and hyperactive. This factor enhanced the parental stress of the children in a learning environment as these children showed problematic behavior in many situations.

Siller & Sigman (2002), observed the behaviours of caregivers of children with autism shown during play interactions, and studied how far the caregiver’s behaviour was in sync with the child. The study had two findings by the authors. First, caregivers of children with autism synchronized their behaviours to their children's activities. Second, caregivers of children with autism who showed higher levels of synchronization during initial play interactions had children who developed superior joint attention and language over a period of 1, 10, and 16 years than did children of caregivers who showed lower levels of synchronization. These findings suggest a developmental link between parental sensitivity and the child's subsequent development of communication skills in children with autism. Implications for parent training interventions are also discussed.

The above study by Siller & Sigman (2002), relate mutually with the findings of the present study. In this study, it was found out, caregivers of the children with Autism who showed greater synchronization during the initial stages facilitated the language development in their children than who showed lesser sync; caregivers of children coordinated their behavior according to the needs of their children.

Imms, Reilly, Carlin & Dodd (2008), investigated the participation of children with cerebral palsy in activities outside school and to compare their participation with a large representative sample of children. It was seen that children participated in a wide range of activities. Participation levels were lower in formal than informal activities, with diversity being lowest in active-physical and skill-based activities. Intensity of participation was low; children tended to participate with family close to home, rather than with friends in the broader community, except when they were participating in activities within the formal domain or skill-based activities.

The above-mentioned study by Imms, Reilly, Carlin & Dodd (2008), supports the findings of the present study, where it was revealed the intensity of the participation of the children with Cerebral Palsy was low. It was observed that most of the children of this sample interacted or responded more comfortably with their caregivers and teachers than people who were less known to them. For this group, skill-based activities are given more importance than the physical activities. However, in the present study, few exceptions were noted where, some children interacted comfortably with unknown persons and also performed physical activities such as outdoor games very well along with the skill-based activities (M=2710.00).

Majnemar, Shevall, Law, Poulin & Rosenbaum (2010), aimed to describe and identify factors associated with motivation in children with cerebral palsy. School-aged children (6-12 years) were recruited for this cross-sectional study, on quality of life. The results showed that high motivation was associated with fewer activity limitations and behavioural problems and reduced family burden. Low motivation may adversely influence a child's functional potential and the effectiveness of interventions. It was concluded with strategies focusing on the child, peers, adults, or activities are proposed to enhance the children's motivation to engage in more challenging activities.

In the study conducted by Majnemar, Shevall, Law, Poulin & Rosenbaum (2010), motivation in the children with Cerebral Palsy was identified. The study shows higher motivational factors resulted in fewer physical limitations; and lesser behavioural problems and lower motivational factors reflected on a child's functional potential. This study supports the present research finding as here, it was seen that children who received greater motivation from their teachers and caregivers performed better in their daily activities and skill-based tasks as compared to the children who did not receive enough motivation and encouragement.

The correlational findings of the present study were found to be in congruence with those of other research studies.

In the case of children with Autism, the present study shows that while physical comfort is alright for children with Autism, their overall emotional state was not satisfied, and they were agitated and angry. These findings show that the health conditions of a child drastically affect the comfort and emotions of the child. In the present study, significant and positive correlation was found between Health (H) and Comfort and Emotions (CE) (r= .563, p< .01). Similarly, **Bal, Harden, Lamb, Hecke, Denver & Porges (2010),** in their study, concluded that children with Autism Spectrum Disorder (ASD) were slower in emotion recognition, and selectively made more errors in detecting anger. ASD children had lower amplitude Respiratory Sinus Arrhythmia (RSA) and faster heart rate. Within the ASD group, children with higher amplitude RSA recognized emotions faster. Less severe ASD symptoms and increased gaze to the eye region in children with ASD were related to more accurate emotion recognition.

The study by **DaSilva & Fernandes (2016)**, which intended to explore how children with autism interact with their neurotypical peers in a school setting, found that in group settings, children with autism sometimes have difficulties with conversation, maintaining social relationships and participating in symbolic play. The researchers showed that if their neurotypical peers were accepting and encouraging, the children with autism were more likely to be included in activities. This led to children on the autism spectrum becoming more comfortable in these settings and spending more time in these groups later on. In the present study as well, significant and positive correlations were found between the different variables such as Communication and Social Interaction (CSI) and Personal Care/ Activities of Daily Living (PC) (r= .363, p< .05), Health (H) and Communication and Social Interaction (CSI) (r= .479, p< .01) and Communication and Social Interaction (CSI) and Comfort and Emotions (CE) (r= .507, p< .01)

In a study by **Jasmin, Couture, McKinley, Reid, Fombonne& Gisel (2009)**, exploring the impact of sensori-motor skills on the performance of Daily Living Skills in preschool children with Autism Spectrum Disorders, found that the children showed atypical sensory responses, and very poor motor skills and daily living skills. They observed that sensory avoiding – an excessive reaction to sensory stimuli – and fine motor skills were highly correlated with daily living skills, even when cognitive performance was taken into account. They concluded that sensori-motor deficits have an impact on the autonomy of children with Autism Spectrum Disorders, and interventions should aim at improving and supporting the development of sensori-motor skills. In the present study as well, significant and positive correlations were found between Positioning, Transferring and Mobility (PTM) and Personal Care/ Activities of Daily Living (PC) (r= .364, p< .05).

The findings of the study conducted by **Ming, Brimacombe & Wagner (2007)**, states that Autism Spectrum Disorders (ASD) manifest impairments in social interaction, language and speech development, and the appearance of repetitive behaviours with restricted interests. They concluded that fine motor control and programming deficits are common co-occurrence of children with ASD but those with the motor deficits were not more likely to receive service than those without the motor deficits. The present study also shows that significant and positive correlations were found between Communication and Social Interaction (CSI) and Positioning, Transferring and Mobility (PTM) (r= .489, p< .01).

In case of Cerebral Palsy also, a similarity was found between the correlational findings of the present study with that of studies conducted by other researchers.

While studying patients with Cerebral Palsy and assessing how psychological problems influence their participation in society **Weber, Bolli, Heimgartner, Merlo, Zehnder & Katterer (2016)**, reported that both the groups (adults and children) were found to show the same frequency of abnormality in attention problem, social interaction and peer problems. They concluded that the persistence of psychological and social problems from childhood into adulthood underlines the importance of focusing on early intervention. In the present study as well, it was found that the children with Cerebral Palsy did not actively participate in recreational activities with friends and family. This was because these children are faced with mobility issues as, majority of them are restricted to wheelchairs. A significant and positive correlation has been found between Communication and Social Interaction (CSI) and Positioning, Transferring and Mobility (PTM) (r= .614, p< .01).

Analyzing the usual mobility method of children with cerebral palsy at home, school, and outdoors, or in the community, **Palisano, Tieman, Walter, Bartlett, Rosenbaum, Russell & Hanna (2003),** concluded thatchildren with Cerebral Palsy were more dependent on adult assistance for mobility in certain settings. The results of the study indicated that compared with the school setting, children were more dependent on adult assistance for mobility when outdoors, or in the community, and less dependent at home. The findings suggest that environmental setting is an important consideration for assessment and intervention to improve mobility of children with cerebral palsy. Similarly in the present study, a significant and positive correlation was found between Positioning, Transferring and Mobility (PTM) and Personal Care/ Activities of Daily Living (PC) (r= .773, p< .01). Hence the findings reflect how children with Cerebral Palsy were dependent on their caregivers or parents for personal care and other activities of daily living with regard to their positioning, transferring and movement.

The study by **Mehraban, Hasani & Amini (2016)**, showed that although there were significant differences between both the groups (children with Cerebral Palsy and normal peers), physical disability could influence children's daily activities and socialization and an understanding of such can facilitate health care professionals in designing and introducing appropriate treatment for them. In the present study as well, it was seen that variables such as mobility and the level of independence or dependency of a child with Cerebral Palsy, affected the day-to-day activities as well as their pattern of interaction with those around them. Significant and positive correlations were found between Positioning, Transferring and Mobility (PTM) and Personal Care/ Activities of Daily Living (PC) (r= .773, p< .01), Communication and Social Interaction (CSI) and Personal Care/ Activities of Daily Living (PC) (r= .691, p< .01), Communication and Social Interaction (CSI) and Positioning, Transferring and Mobility (PTM) (r= .614, p< .01).

In the study by **Nadeau & Tessier (2006)**, it was evidently seen that children with Cerebral Palsy are perceived differently from their peers in a mainstreaming context thus indicating that the health condition, ability to perform activities of daily living, their level of dependency and mobility are what differentiated children with Cerebral Palsy from the children with no impairment/ disability. The present study also shows a significant and positive correlation between Communication and Social Interaction (CSI) and Personal Care/ Activities of Daily Living (PC) (r= .691, p< .01), Communication and Social Interaction (CSI) and Positioning, Transferring and Mobility (PTM) (r= .614, p< .01), Communication and Social Interaction (CSI) and Comfort and Emotions (CE) (r= .629, p<.01).

The study by **Vasconcelos, Moura, Campos, Lindquist & Guerra (2009)**, investigated the functional differences in children with Cerebral Palsy in the domains of mobility, self-care and social function in functional skills and caregiver assistance, also showed a strong correlation between mobility and self-care and mobility and social function. In the present study as well, significant and positive correlation has been found between Positioning, Transferring and Mobility (PTM) and Personal Care/ Activities of Daily Living (PC) (r= .773, p< .01) and Communication and Social Interaction (CSI) and Positioning, Transferring and Mobility (PTM) (r= .614, p< .01.

The results of the present study showed a comprehensive comparison of children with Autism and Cerebral Palsy. The findings as discussed above were related with other studies. The conclusion reached, implications of the study, as well as the limitations of the study are highlighted in the next chapter.

CONCLUSION

6.0 The discussion of the findings of the present study has led to the summary of the work and to draw the following conclusions.

The objectives of the present study was -

a)To determine the difference between two groups of disability- Cerebral Palsy and Autism with respect to correlates of mental health, that is, personal care/ activities of daily living, positioning, transferring and mobility, comfort and emotions, communication and social interaction, health, child's overall quality of life and importance of items to the child's quality of life.

b)The magnitude and direction of relationship will be found amongst the variables of personal care/ activities of daily living, positioning, transferring and mobility, comfort and emotions, communication and social interaction, health, child's overall quality of life and importance of items to the child's quality of life- for the two groups of disability- Cerebral Palsy and Autism.

c) To conduct a case study for each group, with a set of predetermined questions covering many aspects of disability in addition to those mentioned in the first objective.

Information Schedule was used to find out the preliminary details of the subjects and whether they met the selection criteria mentioned above for qualitative and quantitative analysis, as well as the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD©) Questionnaire (Narayanan, Weir & Fehlings; 2007).

The data was collected and scored using the appropriate scoring key. After scoring, the raw scores were statistically analyzed using different measures of descriptive and inferential statistics. Descriptive, Correlational Research Design along with Purposive Random Sampling was used as the sampling method. After data collection, the responses were scored, and mean, standard deviation (SD) and t-test was computed. Correlation was computed between all the variables for both the groups. In addition to the quantitative analysis, a case study for each group was also conducted to derive a holistic view about the two groups of disability.

The conclusion drawn from the present study may be summarized as follows:

1. Significant difference was obtained between the children with autism and cerebral palsy with respect to Personal Care/Activities of Daily Living, Positioning, Transferring and Mobility, Comfort and Emotions, Communication and Social Interaction, Health, Child's Overall Quality of Life and Importance of Items to Child's Quality of Life.
2. With respect to the profile of the domain of personal care and daily living, the sample of children with Autism show better independence than the sample of children with Cerebral Palsy and thus, Autistic children were less dependent on their caregivers than children with Cerebral Palsy.
3. With respect to the profile of the domain of positioning, transferring and mobility, it was seen that the sample group with Autism had more mobility as compared to the sample group with Cerebral Palsy.
4. With regards to the profile of the domain of comfort and emotions, similar results were seen in both groups- Autism and Cerebral Palsy. Comfort levels were relatively high and emotional satisfaction was low with respect to the sample group with Autism. In case of the sample group with Cerebral Palsy, emotional satisfaction was relatively higher with occasional outbursts and comfort levels were very low.
5. The children with Autism could communicate easily with their caregivers compared to children with Cerebral Palsy with respect to the domain of communication and social

interaction. This is due to the fact that in Cerebral Palsy, most often, the muscles and movement affects is not limited only to the limbs, but also the ability to use the muscles of the face to speak.

6. The scores of standard deviation and the scores of mean indicate that children with Autism had better overall health than the children with Cerebral Palsy.
7. With regards to the domain of the child's overall quality of life, it was found that Autistic children had a better quality of life than the children with Cerebral Palsy.
8. It was found that the sample children with Autism scored lower than the sample of children with Cerebral Palsy with regards to the domain of importance of items to child's quality of life.
9. With regard to the children with Autism, Positioning, Transferring and Mobility was seen to have a significant positive correlation with other variables such as Personal Care/ Activities of Daily Living (r =.364, p< .05), Comfort and Emotions r =.491, p< .01), Communication and Social Interaction (r= .489, p< .01) as well as Health (r= .649, p< .01). Positive correlation was also seen between Personal Care/Activities of Daily Living and Positioning, Transferring and Mobility (r =.364, p< .05), Personal Care/ Activities of Daily Living and Comfort and Emotions (r =.510, p< .01), Communication and Social Interaction and Personal Care/ Activities of Daily Living (r =.363, p< .05) and Health and Personal Care/ Activities of Daily Living (r = .529, p< .01). Comfort and Emotions and Communication and Social Interaction (r = .507, p< .01), Comfort and Emotions and Health (r= .563, p< .01) and Health and Communication and Social Interaction (r =.479, p< .01) were also seen to be positively correlated with one another.
10. With regard to children with Cerebral Palsy, significant and positive correlations were found between Positioning, Transferring and Mobility and Personal Care/ Activities of Daily Living (r= .773, p< .01), Comfort and Emotions and Personal Care/ Activities of Daily Living (r= .664, p< .01), Comfort and Emotions and Positioning, Transferring and Mobility (r= .573, p< .01). The inter-correlations also indicate a positive correlation between Communication and Social Interaction and Personal Care/ Activities of Daily Living (r= .691, p< .01), Communication and Social Interaction and Positioning, Transferring and Mobility(r= .614, p< .01), Communication and Social Interaction and Comfort and Emotions(r= .629, p< .01). Significant and positive correlations were found between Health and Comfort and Emotions (r= .433, p< .05). A negative and significant correlation was found between Child’s Overall Quality of Life and Personal Care/ Activities of Daily Living (r= -.438, p< .05), Child’s Overall Quality of Life and Positioning, Transferring and Mobility (r= -.446, p< .05), Child’s Overall Quality of Life and

Communication and Social Interaction (r= -.441, p< .05). A positive correlation was also found between Importance of items to the Child’s Quality of Life and Personal Care/ Activities of Daily Living (r= .466, p< .01), Importance of items to the Child’s Quality of Life and Positioning, Transferring and Mobility (r= .511, p< .01), Importance of items to the Child’s Quality of Life and Child’s Overall Quality of Life (r= .552, p< .01).

6.1 IMPLICATIONS OF THE STUDY

In the present study, the children with Cerebral Palsy had a lower Mean score than the children with Autism under the domain of personal care/daily living. This implies that children with Cerebral Palsy were more dependent on their caregivers for activities such as drinking, eating, brushing their teeth, bathing, etc. In the case of Cerebral Palsy, 14 out of 30 were confined to a wheelchair and hence were completely dependent on those around them, such as their parents or their caregivers, at all times. This implies that children with Cerebral Palsy were less mobile than children with Autism. Although, their physical comfort levels were very low, their emotional satisfaction was relatively higher which implies, Cerebral Palsy being a primarily congenital disorder of muscle tone and movement, impairs their physical abilities but they do not face a lot of difficulty being understand by their parents and caregivers with regard to their emotions. The present study also shows that children with Cerebral Palsy had more health issues than the children with Autism as the sample group of children with Cerebral Palsy had a lower mean than the sample group of children with Autism. With respect to a child's overall quality of health, the scores of children with Cerebral Palsy were also lower than that of children with Autism, implying that Autistic children had a better quality of life than the children with Cerebral Palsy.

In the present study, the children with Autism were less dependent on their caregivers as compared to the children with Cerebral Palsy for activities of daily living and personal care as they had a higher Mean value when compared to the other group of children. It was found that only 2 out of 30 children with Autism were completely dependent on a wheelchair, and few of the children in this group also had a crutch or another implement to help them move about which implies that the children of this group were more mobile as compared to the children with Cerebral Palsy. Their comfort levels were relatively high but their emotional satisfaction was rather low. This implies that though they have physical comfort, they are often not understood by their parents with regard to emotions which implies since Autism is a developmental disorder, it limits their ability to communicate and interact. With respect to the domain of communication and social interaction, children with Autism show a higher Mean than children with Cerebral Palsy. This indicates that children with Autism could communicate easily with their caregivers compared to the children with

Cerebral Palsy. The sample group of children with Autism had a higher Mean than the sample group of children with Cerebral Palsy, implying that children with Autism had a better overall health than the children with Cerebral Palsy. With respect to a child's overall quality of health, the scores of children with Autism were higher than that of children with Cerebral Palsy, implying that Autistic children had a better quality of life than the children with Cerebral Palsy.

The findings of the present study can be helpful for further research, for parents, practitioners and caregivers who are associated and working with children with Cerebral Palsy or Autism. The present findings may be useful in order to deal with the population of this nature.

6.2 LIMITATIONS OF THE STUDY

Any research cannot contribute completely without having certain limitations and providing scope for further research. Similarly, the present study also has its limitations which may be addressed and corrected in the future. Some of these limitations can be summarized as follows:

1) For the present study a sample of 60 children (30 children with Cerebral Palsy and 30 children with Autism) was used. So, it was not a very large sample.

2)The proposed sample of 15 male and 15 female children with Cerebral Palsy and 15 male and 15 female children with Autism was not achieved.

3) For the present study, it was difficult to obtain data from 7-18 years. As a result of which data collection took a long time.

4) The exclusion criteria of children not belonging to low and lower middle socio-economic status was also at times difficult to maintain.

The present study was time bound and therefore, it was not possible to overcome the limitations mentioned above. However, it provides scope for further research in this field.

6.3 ORIGINALITY OF THE PRESENT RESEARCH WORK:

The newness of the present research may be summarized as follows: -

1) The present study was solely carried out in an Indian sample. The focus and aim of the present research have also not been the focus of previous Indian studies.

2) The present research focuses on variables that are not only physical features but also mental features.

6.4 AREAS OF FURTHER RESEARCH

The researchers believe that the present study has opened different areas that are yet to be studied. The different studies which can be conducted in this area may consist of: -

1) More domains, like dexterity, life skills, learning ability.

2) More gender studies in this particular field, for comparative purposes.

3) More variables, other than the ones studied in the present research.

4) Other age groups of younger children and older people, for the purpose of comparison.

5) More emphasis on inclusive education and its importance.

The present research throws light upon the two groups of disability - Cerebral Palsy and Autism, in terms of mental health correlates. A link with various other studies has also highlighted the psychosocial relevance of the present research study. The comparison drawn for the data collected over a time period, have helped to identify the similarities or the differences between the two selected groups of disability. The present study focused on both, physical and psychological aspects of these children, which gives a more holistic approach to the study. Thus, the described scope of the present research study opens up a broader view about different groups of Disability and their very unique specifications. These findings will be useful for personnel who are very closely associated with this population and work with them regularly.

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APPENDICES

CPCHILD©

Caregiver Priorities &Child Health Index of Life with Disabilities

Instructions

1. This questionnaire is about your child’s health, comfort and well being, and about caring for his/her needs. 2. Please read the instructions carefully.

3. Please answer all questions by circling the number that fits best. You may write down any comments/clarifications in the space provided below each question.

For example:

LEVEL OF ASSISTANCE

Consider how each of the following activities is **usually** performed by/for your child. Rate how **difficult** each of these activities were in the past 2 weeks, **and** choose the **level of assistance** that was required to help your child perform these activities.		**TOTAL**	**MODERATE**	**SUPERVISED / MINIMAL**	**INDEPENDENT**
Very Easy **During the past 2 weeks, how difficult was the following:**	Impossible *Not Possible No (Almost Very Slightly Very problem Impossible) Difficult Difficult Difficult Easy Easy at all*				
1. putting on / wearing footwear? (socks, shoes, braces, etc.) _	**0 1 2 3 4 5 6** 5 _	**0**	**1**	**2** 2	**3**

In the above example, the task of putting on / wearing footwear was rated as *very easy*, and the child required a *minimal / supervised* level of assistance to put on footwear.

4. At the end of each section there is space for you to add any items that you think are missing from the questionnaire, which you believe are important to your child's health, comfort and well being.

Child's name: ____ _____

Name of parent or caregiver completing form: ____

Date: ____ _____________

SECTION 1: PERSONAL CARE / ACTIVITIES OF DAILY LIVING

LEVEL OF ASSISTANCE

Consider how each of the following activities is **usually** performed by/for your child. Rate how **difficult** each of these activities were in the past 2 weeks, **and** choose the **level of assistance** that was required to help your child perform these activities.		**TOTAL**	**MODERATE**	**S U M P I E N R I V M I A S L E D /**	**INDEPENDENT**
During the past 2 weeks, how difficult was the following:	*Not Possible No (Almost Very Slightly Very problem Impossible) Difficult Difficult Difficult Easy Easy at all*				
1. eating/drinking or being fed? (in the usual way that it is done i.e. orally or by tube or both) ________________________________ _	**0 1 2 3 4 5 6** ______________________________________	**0**	**1**	**2**	**3**

	____				
2. maintaining oral hygiene? (keeping mouth and teeth clean) ____________________________ ____	**0 1 2 3 4 5 6** ____ ____	**0**	**1**	**2**	**3**
3. bathing / washing? ________________________________ _	**0 1 2 3 4 5 6** ____ ____	**0**	**1**	**2**	**3**
4. toileting activities? (bladder & bowel function, hygiene etc.) ________________________________ _	**0 1 2 3 4 5 6** ____ ____	**0**	**1**	**2**	**3**
5. changing diapers/underwear? ____________________________ ____	**0 1 2 3 4 5 6** ____ ____	**0**	**1**	**2**	**3**
6. putting on/taking off upper body clothing ? (shirt, jacket, etc.) ________________________________ _	**0 1 2 3 4 5 6** ____ ____	**0**	**1**	**2**	**3**
7. putting on/taking off lower body clothing ? (pants, sweats, etc.) ____________________________ ____	**0 1 2 3 4 5 6** ____ ____	**0**	**1**	**2**	**3**

8. putting on/wearing footwear? (socks, shoes, braces, etc.) _________________________________	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
9. hair care (washing, drying, brushing/combing, braiding, etc.)	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
1A. other personal care activity? Specify:____________________	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**
1B. other personal care activity? Specify:____________________	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**

SECTION 2: POSITIONING, TRANSFERRING & MOBILITY

LEVEL OF ASSISTANCE

Consider how each of the following activities is **usually** performed by/for your child. Rate how **difficult** each of these activities were in the past 2 weeks, **and** choose the **level of assistance** that was required to help your child perform these activities.								**TOTAL**	**MODERATE**	**SUPERVISED/ MINIMAL**	**INDEPENDENT**
During the past 2 weeks, how difficult was:	*Not Possible No (Almost Very Slightly Very problem Impossible) Difficult Difficult Difficult Easy Easy at all*										
10. getting in and out of bed? ____________________________	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**0**	**1**	**2**	**3**

____					
11. transferring into/out of a wheelchair/chair? ______________________________ _	**0 1 2 3 4 5 6** ______________________________ ____	**0**	**1**	**2**	**3**
12. sitting in a wheelchair/chair? ______________________________ ____	**0 1 2 3 4 5 6** ______________________________ ____	**0**	**1**	**2**	**3**
13. standing for exercise/transfers? ______________________________ ____	**0 1 2 3 4 5 6** ______________________________ ____	**0**	**1**	**2**	**3**
14. moving about in the home? (in whatever way possible) ______________________________ _	**0 1 2 3 4 5 6** ______________________________ ____	**0**	**1**	**2**	**3**
15. moving about outdoors? (in whatever way possible) ______________________________ _	**0 1 2 3 4 5 6** ______________________________ ____	**0**	**1**	**2**	**3**
16. getting in and out of a motor vehicle? (car, van or bus) ______________________________ _	**0 1 2 3 4 5 6** ______________________________ ____	**0**	**1**	**2**	**3**

17. visiting public places? (park, theatre, sightseeing, etc) ______________________________	**0 1 2 3 4 5 6** ____ ____	**0**	**1**	**2**	**3**
2A. other activity? **Specify:**____________________ ______________________________	**0 1 2 3 4 5 6** ____ ____	**0**	**1**	**2**	**3**
2B. other activity? **Specify:**____________________ ______________________________	**0 1 2 3 4 5 6** ____ ____	**0**	**1**	**2**	**3**

SECTION 3: COMFORT & EMOTIONS

INTENSITY

During the past 2 weeks, how often did your child experience pain or discomfort	***Every Very Fairly A few Once None of day Often Often times or twice the time***	**SEVERE**	**MODERATE**	**MILD**	**NONE**
18. while eating/drinking or being fed? ______________________________	**0 1 2 3 4 5**	**0**	**1**	**2**	**3**

_	____ ____				
19. during toileting? (bladder & bowel function, hygiene, diapering, etc.) _______________________________ _	**0 1 2 3 4 5** ____ ____	**0**	**1**	**2**	**3**
20. while dressing/undressing? ____________________________ ____	**0 1 2 3 4 5** ____ ____	**0**	**1**	**2**	**3**
21. during transfers or position changes? ______________________________	**0 1 2 3 4 5** ____ ____	**0**	**1**	**2**	**3**
22. while seated? _______________________________ _	**0 1 2 3 4 5** ____ ____	**0**	**1**	**2**	**3**
23. while lying down in bed? _______________________________ _	**0 1 2 3 4 5** ____ ____	**0**	**1**	**2**	**3**
24. that disturbed your child's sleep? _____________________________ ___	**0 1 2 3 4 5** ____ ____	**0**	**1**	**2**	**3**
3A. during other activity? Specify:________________ ____	**0 1 2 3 4 5**	**0**	**1**	**2**	**3**

____________________________ ____	____ ____				
3B. during other activity? **Specify:________________** ____ ____________________________ ____	**0 1 2 3 4 5** ____ ____	**0**	**1**	**2**	**3**

During the <u>past 2 weeks</u>, how often was your child					
25. agitated, upset, or angry? _______________________________ _	**0 1 2 3 4 5** ____ ____	**0**	**1**	**2**	**3**
26. unhappy or sad? _______________________________ _	**0 1 2 3 4 5** ____ ____	**0**	**1**	**2**	**3**

SECTION 4: COMMUNICATION & SOCIAL INTERACTION

Consider how each of the following activities is **<u>usually</u>** performed by/for your child. Rate how **<u>difficult</u>** each of these activities were in the past 2 weeks.	
During the <u>past 2 weeks</u>, how much difficulty did your child have	*Not Possible No (Almost Very Slightly Very problem Impossible) Difficult Difficult Difficult Easy Easy at all*

27. understanding you? ________________________________	**0 1 2 3 4 5 6** ____
28. being understood by you? ________________________________	**0 1 2 3 4 5 6** ____
29. communicating with those who don’t know your child well? ________________________________	**0 1 2 3 4 5 6** ____
30. playing alone? ________________________________	**0 1 2 3 4 5 6** ____
31. playing with others? ________________________________	**0 1 2 3 4 5 6** ____
32. attending school/child care? ________________________________	**0 1 2 3 4 5 6** ____
33. participating in recreational activities (swimming, interacting with family and friends, etc.)? ________________________________	**0 1 2 3 4 5 6** ____
4A. other social activity? **Specify:** ________________________ ________________________________	**0 1 2 3 4 5 6** ____

	—
4B. other social activity? **Specify:** ____________________ _________________________ —	**0 1 2 3 4 5 6** ____ —

SECTION 5: HEALTH

In the past 2 weeks	***Please circle the option that fits best***
34. How many times has your child had to visit the doctor or the hospital? ____________________________	***Admitted Admitted 3 or more*** ***>7 days < 7 days times Twice Once None*** **0 1 2 3 4 5** ____ —

In the past 2 weeks	***Very Very Poor Poor Fair Good Good Excellent***
35. How would you rate your child's overall health? ____________________________	**0 1 2 3 4 5** ____ —

36. List the medications your child has been taking in the last 2 weeks

0. No medications

1. ____

2. ____

3. ____

4. ____

5. ____

6. ____

7. ____

8. ____

9. ____

SECTION 6: YOUR CHILD’S OVERALL QUALITY OF LIFE

In the past 2 weeks	***Very Very Poor Poor Fair Good Good Excellent***
37. How would you rate your child’s overall quality of life? ________________________________	**0 1 2 3 4 5** ____ —

SECTION 7: IMPORTANCE OF ITEMS TO YOUR CHILD’S QUALITY OF LIFE

How importantly do you think your child’s current status with each item contributes towards his/her quality of life?	**Least Not Very Slightly Fairly Very Most Important Important Important Important Important Important**

1. Eating / drinking or being fed	**0 1 2 3 4 5**
2. Maintaining oral hygiene	**0 1 2 3 4 5**
3. Bathing / washing	**0 1 2 3 4 5**
4. Toileting activities / hygiene	**0 1 2 3 4 5**
5. Changing diapers / underwear	**0 1 2 3 4 5**
6. Putting on/taking off upperclothing	**0 1 2 3 4 5**
7. Putting on/taking off lower clothing	**0 1 2 3 4 5**
8. Putting on / wearing footwear	**0 1 2 3 4 5**
9. Hair care / grooming	**0 1 2 3 4 5**
10. Getting in and out of bed	**0 1 2 3 4 5**
11. Transferring into / out of a wheelchair / chair	**0 1 2 3 4 5**
12. Sitting in a wheelchair / chair	**0 1 2 3 4 5**
13. Standing for exercise / transfers	**0 1 2 3 4 5**
14. Moving about indoors	**0 1 2 3 4 5**
15. Moving about outdoors	**0 1 2 3 4 5**
16. Getting in / out of a motor vehicle	**0 1 2 3 4 5**
17. Visiting public places	**0 1 2 3 4 5**
18. Comfort while feeding	**0 1 2 3 4 5**
19. Comfort during toileting activities	**0 1 2 3 4 5**
20. Comfort while dressing /undressing	**0 1 2 3 4 5**
21. Comfort during transfers or position changes	**0 1 2 3 4 5**
22. Comfort while sitting	**0 1 2 3 4 5**
23. Comfort while lying down	**0 1 2 3 4 5**

24. Comfort while sleeping	**0 1 2 3 4 5**
25. Emotional state or behavior	**0 1 2 3 4 5**
26. Happiness	**0 1 2 3 4 5**
27. Able to understand you	**0 1 2 3 4 5**
28. Able to be understood by you	**0 1 2 3 4 5**
29. Able to communicate with others	**0 1 2 3 4 5**
30. Able to play alone	**0 1 2 3 4 5**
31. Able to play with others	**0 1 2 3 4 5**
32. Able to attend school / child care	**0 1 2 3 4 5**
33. Able to participate in recreational activities	**0 1 2 3 4 5**
34. Minimizing doctor visits and hospitalization	**0 1 2 3 4 5**
35. Overall health	**0 1 2 3 4 5**
36. Minimizing number of medications	**0 1 2 3 4 5**

SECTION 8: FACTS ABOUT YOUR CHILD

1. My child is a:	**Male Female**
2. What is your child's date of birth?	_____ / _____ / _____ **Month Day Year**

3. What is the highest school grade your child has completed? (check only one grade)	**Preschool ___** **Kindergarten ___** **1st Grade ___** **2nd Grade ___** **3rd Grade ___** **4th Grade ___** **5th Grade ___** **6th Grade ___** **7th Grade ___** **8th Grade ___** **9th Grade ___** **10th Grade ___** **11th Grade ___** **12th Grade ___** **Ungraded ___** **If ungraded, how many years attended? _____**

SECTION 9: FACTS ABOUT YOU

1. Are you:	**Male Female**
2. What is your date of birth?	**_____ / _____ / _____** **Month Day Year**

3. Which of the following best describes your current work status? (check all that apply)	**Not working due to my child's health _____ Not working for other reasons _____** **Looking for work outside the home _____** **Working full or part time (either outside the home or at a home _____ based business)** **Full time homemaker _____**
4. Which of the following best describes your relationship to your child?	**Biological Parent _____** **Step Parent _____** **Foster Parent _____** **Adoptive Parent _____** **Guardian _____** **Professional caregiver _____** **Other (please explain)** **__________________________**
5. On average, how many days per week are you responsible for care giving activities for your child?	**_____ days per week**
6. What is the highest level of school you have completed?	**Some high school or less _____ High school diploma/GED _____ Vocational school or some college _____ College or University degree _____** **Professional or Graduate degree _____**

How long has it taken you to complete <u>this questionnaire only</u> (in units of time):________________

THANK YOU FOR YOUR PARTICIPATION!