

**THE IMPACT OF PERCEIVED SOCIAL SUPPORT ON PSYCHOLOGICAL  
DISTRESS AMONG PARENTS OF CHILDREN WITH DEVELOPMENTAL  
DELAY**

Submitted to

**THE TAMILNADU Dr. M.G.R. MEDICAL UNIVERSITY**



Submitted in partial fulfilment of the requirements for the degree of

**M.Phil. in Clinical Psychology**

September 2023



Submitted by

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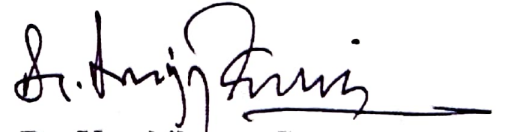
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## CERTIFICATE

This is to certify that **KUMARASWAMY H.** has been a research scholar for M.Phil. Degree in Clinical Psychology, National Institute for Empowerment of Persons with Multiple Disabilities (Divyangjan), Chennai during the academic year of 2021-2023. Hereby, it is certified that the dissertation titled "**THE IMPACT OF PERCEIVED SOCIAL SUPPORT ON PSYCHOLOGICAL DISTRESS AMONG PARENTS OF CHILDREN WITH DEVELOPMENTAL DELAY**" is the original research work done by **KUMARASWAMY H. (Register No: 154221104506)** submitted in partial fulfillment of requirements for the Degree of Master of Philosophy in Clinical Psychology and has not previously formed the basis of award for any other degree or diploma to the candidate.

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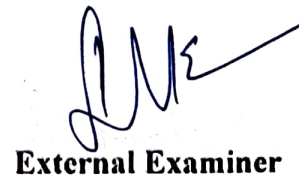
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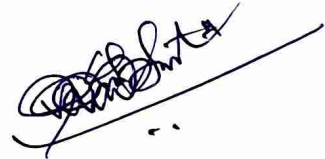
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## DECLARATION

I, **KUMARASWAMY H.**, hereby declare that the thesis titled “**THE IMPACT OF PERCEIVED SOCIAL SUPPORT ON PSYCHOLOGICAL DISTRESS AMONG PARENTS OF CHILDREN WITH DEVELOPMENTAL DELAY**”, was carried out by me at the National Institute for Empowerment of Persons with Multiple Disabilities (NIEPMD), Chennai, during the year 2021-2023, is an original research work carried out under the guidance and supervision of Dr. S. Karthikeyan, Associate Professor & Head, Department of Clinical Psychology, NIEPMD, Chennai. This work has not formed the basis of award for any other degree.

Signature of the candidate

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This institute is a central body funded by Department of Empowerment of Persons with Disabilities (Divyangjan), Ministry of Social Justice & Empowerment, and Government of India. The MPhil programme offered at NIEPMD is recognized by Rehabilitation Council of India (RCI), New Delhi, and affiliated with the Tamil Nadu Dr M.G.R. Medical University

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## ACKNOWLEDGEMENT

It gives me immense pleasure to thank all those who guided and helped me for the completion of this dissertation. I am grateful to God almighty who bestowed upon his grace and wisdom to complete this work.

I expressed my sincere gratitude to **Dr. Karthikeyan. S**, Associate Professor and Head of the Department, Department of Clinical Psychology, NIEPMD, Chennai for his kind help to make my endeavor successful.

I am deeply indebted to **Ms. Srigothri Rajesh**, Lecturer, Department of Clinical Psychology, NIEPMD, Chennai for giving me the freedom and timely essential guidance to make this work successful without whom, this research wouldn't have been possible.

I thank **Ms. P. Kalaivani**, Assistant Professor, **Mr. Johny E.V.**, **Mr. Kumaran Rajan** and **Ms. S.K. Anandhalakshmi**, Lecturers, Department of Clinical Psychology, NIEPMD, Chennai for their constant guidance, suggestions, and support. I would like to extend my thanks to Mr. Amrudeen and Mrs. Merlin, Department of Clinical Psychology for their constant support.

I also thank all the participants from NIEPMD (Early Intervention Unit) for giving me the time and permission to collect my data.

I expressed my heartfelt thanks to my friend **Mr. Samuel George**, Research Scholar, for being extremely patient with my doubts and helping me with SPSS and writing my dissertation.

As a mark of gratefulness, I express my heart bound thanks to my parents for their moral support, their timely help and motivation, and my classmates for their continuous encouragement

I owe my heartfelt gratitude to everyone who helped directly and indirectly for the successful completion of the study. And PGDEI students Sugandhi, Malini.

**KUMARASWAMY H.**



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## **ABSTRACT**

The present study was conducted to find the impact of perceived social support on psychological distress among parents of children with developmental and also find the relationship. Also find the relationship between the study variable and socio demographic correlates. Correlational Research Design was used to collect and analyse the data for the present study. The sample of the study was selected from target population in the clients of National Institute for Empowerment of Persons with Multiple Disabilities (NIEPMD), Chennai. Parents of children with developmental delay whose age of their child ranges from 1-6 years. The method of sampling was purposive sampling (non- random sampling) participants included 50 parents of children with developmental delay. Tools used for the study are consent form, Multidimensional Scale of Perceived Social Support (MSPSS) assess the how they get perceived social support. Consists of 13 items with 7-point Likert type and Kessler Psychological Distress Scale (K10) is a self- report screening instrument that assess the level of psychological distress. It consists of 10 items with 5 step Likert type. Found there is significant correlation with perceived social support and psychological support. Also, mothers had significant high score on psychological distress. The study limitations are the availability of the parents is limited due to their daily busy schedules and time constrains, limited only one institute in the state.

**Keywords:** *Perceived Social Support, Psychological Distress, Developmental Delay*

# **INTRODUCTION**

## **1. The context of the study**

Neurodevelopmental disorders are a group of disorders occurring early in development, characterized by the behaviour needed for functioning and social interaction in formal or informal settings being affected. The circumscribed or global impairment of personal, social, academic, or occupational skills, thereby resulting in behavioural problems, communication difficulties, poor self-care, and poor educational attainment. Examples of disorders with neurodevelopmental challenges in children include Autistic Spectrum Disorders (ASDs), Cerebral Palsy, and Epilepsy, among others. Children with neurodevelopmental disorders (CNDs) and their management are complex public health issues deserving improved policy, service, and research attention. Such attention should be focused on diagnosis improvement, burden estimation, social perception, and the well-being of caregivers (who are often the parents or family) to ensure better care for the affected children. The well-being of caregivers of CNDs is important because if impaired, it could impact negatively on the quality of care and the outcome of intervention programs for these children. For example, the decision to seek treatment, the choice, type, and administration of treatment are significantly influenced by caregivers. Again, the increasing emphasis on community-based and family-centred care for CNDs further underscores the centrality of the roles of the family or caregivers.

Society views parenthood positively, but it views the birth of a disabled child negatively. Awareness of society's ambivalence, adds to the stress the family feels within themselves. The care of CNDs is more often than not very stressful for caregivers. For instance, caregivers who are largely parents to cope with behavioural challenges, difficulty in communication, functional impairment, along with disability and associated stigma. All these are additional to bearing economic costs of the prescribed treatments for any related problem. A review of the literature,



though preponderantly from the West, suggests the experience of a significant burden by caregivers of CNDs. In particular, elevated degrees of psychological distress and higher rates of mental and physical health problems have been reported. Some of the propounded factors for these disparate findings on the distressful experience of caregivers of CNDs include level of impairment in the child, study design and contextual issues. Unfortunately, little is known about the experience of caregivers in relation to their roles among CNDs. This dearth of information poses a major challenge for the provision of qualitative care for these children, especially because caregivers in resource-restricted countries do not only play a central role in ensuring the well-being of these children but are sometimes solely saddled with significant treatment responsibilities due to inequitable distribution of treatment resources, exorbitant cost of care, and poor health insurance coverage. (Olagunju A.T. et.al 2017)

As it is, there is a need for research efforts among caregivers of CNDs based on the earlier mentioned gaps and because findings among caregivers in the developed countries cannot be representative of the experience of caregivers in developing countries where the interplay of socioeconomic and cultural factors are important. In view of the constraint that poor data can have on evidence-directed planning of intervention programs and treatment services.

The child brings along with him a major change in social, emotional, interpersonal, economical and physical change in the life of the parent. Every parent has their expectations and dreams for their new creation. Brain injury, genetics, hereditary and other neurological factors could affect the child's normal development. This leads to the presence of special traits, peculiar behaviour-physical patterns and socio-emotional problems, which could be incapacitating and have a lifelong effect on the development of the child.

## **1.1 PERCEIVED SOCIAL SUPPORT**

Perceived social support refers the perception of financial, moral and psychological support from friends, family members or others as appropriate when needed. (Encyclopaedia of Psychology)

Social support is the perception of being cared for by others and having a reliable network to turn to when needed, in everyday situations or specific moments of crisis (Taylor, 2011). It can be perceived from three sources: family, friends, and significant others (Zimet et al., 1988).

Received social support is the objective support coming from others near to individuals, which focuses on the quantity and quality of the given support, whereas perceived social support reflects the perceived availability and adequacy of social connections, referring to the subjective perception and assessment.

Research and experts in the field of rehabilitation opined that every form of benefits from social and emotional support, this will enable the autonomy.

Perceived availability of support refers to the subjective perception of support being available from one's friends, family, team-mates and coaches who may provide assistance, if needed (Rees and Freeman, 2010).

Perceived family refers to support makes a person feel cared for, loved, and dependent on family numbers when needed

Social support theory emerged from publications by Don Drennon-Gala and Francis Cullen, both of whom drew on insights from several theoretical traditions. The theory is centered on the proposition that instrumental, informational, and emotional supports.

Two elements of social relationship structure are distinguished: (a) social integration, which refers to the existence or quantity of social relationships, and (b) social network structure, referring to the structural proper- ties that characterize a set of relationships.

Researchers have also said that having a strong support system has many positive benefits. Some of the best benefits include higher levels of well-being, better coping skills, and a longer healthier life. Having a support system has also been proven to reduce depression and anxiety and reduce stress.

Emotional support means give the other their undivided attention, allow them to say what they feel without judgement, ask questions to clarify or better understand their experiences, verbally summarize or reflect on what they have said. Lack of social support indicates the share of people who report having no friends or relatives whom they can count on in times of trouble.

### **Benefit of supportive family**

It is important to surround ourselves with family and friends for support and comfort in both times of joy and distress. Studies have shown that having supportive relationships is a strong protective factor against mental illnesses and helps to increase our mental well-being. The benefits of having and using personal support systems include reduced stress, decreased

physical health problems, and improved emotional well-being. Taking stock of social support system is an excellent way to assess help actually comes from and who provides it.

First, the Main Effect theory (Cohen and Wills, 1985) states that individuals with strong social support groups will have fewer physical and mental health problems than those with weaker social support. Thus, it is the quality of the social support group which is important (Cohen and Wills, 1985).

Getting support needs met through many of the people in the life can provide social support. These can include parents, spouse or partner, children, siblings, other family members, friends, co-workers, neighbour, health professionals, support groups, and sometimes even strangers. While social support is usually conceptualized and perceived as a positive resource in chronic disease, it sometimes turns into a negative experience and may end in social isolation and deteriorate health.

Social support fosters self-esteem and inhibits feeling incompetent or helpless in coping with stress. There is a preponderance of evidence that suggests social support is linked with lower depression, lower anxiety, and lower hopelessness levels among patient with depression.

### **The Importance of Social Support in Mental Health**

The importance of Social Support in Mental Health has been observed repeatedly in psychological research. Mental health is defined as a state of well-being, in which someone knows their capabilities and uses them effectively and productively in a way that is useful for their communities. Health is a concept influenced by a set of complex factors which includes social support. Social factors can play a critical role in fostering positive mental health.

Social support (or the perception of support) provides physical and psychological advantages for people faced with stressful physical and psychosocial events and is considered as a factor reducing (and protecting against) psychological distress.

## **1.2 PSYCHOLOGICAL DISTRESS**

Psychological distress refers to the unpleasant emotions or feelings a person experiences when overwhelmed, which can severely affect daily life activities. (Encyclopaedia of Psychology)

Stress responses are normal reactions to environmental or internal perturbations and can be considered adaptive in nature. Distress occurs when stress is severe, prolonged, or both. Emotional distress refers to mental suffering as an emotional response to an experience that arises from the effect or memory of a particular event, occurrence, pattern of events or condition.

### **Psychological distress can come out as:**

- Fatigue.
- Sadness.
- Anxiety.
- Avoidance of social situations.
- Fear.
- Anger.
- Moodiness.

### **Symptoms of emotional distress:**

- Feeling overwhelmed, helpless, or hopeless.
- Feeling guilty without a clear cause.
- Spending a lot of time worrying.
- Having difficulty thinking or remembering.
- Sleeping too much or too little.
- Having changes in appetite.
- Relying more heavily on mood-altering substances, such as alcohol.

Disability in children might result in an emotional and social burden to the parents. They often experienced plenty of negative feelings, such as stress, anxiety, depression as they were much more fearful of their future and the future of their children, which could impact their health (Parameswari & Eljo, 2009).

Some of the top sources of stress, according to the Child Mind Institute, include: Feeling isolated from other parents and friends. Feeling overwhelmed by the number of therapies and other obligations that come with having a child with special needs. Feeling guilty or sad about a child's disability. This syndrome is divided into the alarm reaction stage, resistance stage, and exhaustion stage. The alarm reaction stage refers to the initial symptoms of the body under acute stress and the "fight or flight" response. Personality traits explained 5% variance in symptoms when controlling for age, gender, solitary living, negative economic impact, and mental distress at baseline. Higher neuroticism predicted higher mental distress, whereas higher conscientiousness and extraversion predicted less mental distress. Type D personality is



a vulnerability factor for general psychological distress that affects mental and physical health status and is associated with disease-promoting mechanisms and work-related problems in apparently healthy individuals.

**Among the many challenges are:**

- Learning about the disability.
- Researching, locating and accessing effective treatments and resources.
- Coping with the emotional and physical demands of caring for an individual with a disability.

Parent may experience uncontrollable tears, sadness, and feelings of hopelessness. Parent may feel he or she is somehow to blame for the disability or the situation. Parent may act out his or her anger or direct it toward another person.

The negative stress response, often involving negative affect and physiological reactivity: a type of stress that results from being overwhelmed by demands, losses, or perceived threats. It has a detrimental effect by generating physical and psychological maladaptation and posing serious health risks for individuals.

**Causes of Distress**

- Interpersonal relations problems such as conflicts, illness/death of a loved one, divorce, abuse, romantic partner, etc.
- Financial difficulties
- Anxiety

- Depression
- Traumatic event

### **1.3. DEVELOPMENTAL DELAY**

A developmental delay refers to a child who has not gained the developmental skills expected of him or her, compared to others of the same age. Delays may occur in the areas of motor function, speech and language, cognitive, play, and social skills (DSM-V).

#### **Developmental Delay Causes and Risk Factors**

- Being born prematurely.
- Genetic conditions like Down syndrome or muscular dystrophy.
- Poor eyesight or hearing.
- Malnutrition.
- Alcohol or drug use during pregnancy.
- Physical abuse or neglect.
- Lack of oxygen during delivery.

#### **Potential Warning Signs of Developmental Delays**

- Child doesn't play games involving back and forth play.
- Child doesn't respond to his or her own name.
- Child doesn't seem to recognize familiar people.

Developmental and behavioural screening tests look at how a child is developing. The screenings are made up of checklists and questionnaires for parents. They include questions about their child's language, movement, thinking, behaviour, and emotions. Many of the questions are based on developmental milestones.

### **Prevalence of disabilities in India**

The study revealed a prevalence of developmental delay 6.6% (95%CI 3.6-9.8) among children of slums aged below two years. Various studies reported prevalence of delay ranging between 1.5% 7.9%, among marginalized population in India using the same screening tool. (Sukhanya Gupta & Prbha Srivasthava, 2021)

Overall, India has a prevalence of 10.5/1000 in ID. Urban population has slightly higher rate (11/1000) than rural (10.08/1000;  $P = 0.044$ ). (Ram Lakhen et.al 2015)

The percentage of disabled to the total population increased from 2.13% in 2001 to 2.21% in 2011. In rural areas, the increase was from 2.21% in 2001 to 2.24% in 2011 whereas, in urban areas, it increased from 1.93% to 2.17% during this period. The same trend was observed among males and females during this period.

### **Common Developmental Disabilities**

Among the most common are intellectual disability, autism spectrum disorder, Down syndrome, and cerebral palsy. Language and speech problems are the most common type of developmental delays. Approximately 7% of the population is expected to have developmental language difficulties.

## **Characteristics of developmental delay**

- Difficulty bathing, dressing, grooming, and feeding one's self.
- May have difficulty performing age-appropriate skills independently.
- Social skills may be poor (relationships with family and friends)
- Cannot choose own activities.
- Problems using early literacy, writing, and math skills.

The studies reviewed lead us to conclude that the prevalence rate of NDDs fluctuates globally between 4.70 and 88.50%; these variations depend on methodological aspects such as estimation procedures, as well as on socio-contextual phenomena.

Developmental delays might be short term, or the first sign of a long-term concern. A developmental disability is a chronic problem resulting from a mental or physical impairment, or both.

The diagnosis of developmental delay is made by any number of professionals, including developmental pediatricians, neurologists, and psychologists. This diagnosis is often made in early childhood when a child does not meet typically expected developmental milestones.

## **1.4 AUTISM SPECTRUM DISORDERS (ASD)**

Autism spectrum disorder (ASD) is the name for a group of developmental disorders. ASD includes a wide range, “a spectrum,” of symptoms, skills, and levels of disability. Autism spectrum disorders (ASD) represent a range of brain disorders that are characterized by restricted patterns of behaviour and impairments in social communication and interactions.

Symptoms/behaviours of ASDs can range from mild to severe, and may seem to appear gradually or suddenly. Atypical development may be observed from birth or more commonly, become noticeable during the 12- to 36-month period (DSM- V)

ASDs are usually evident by the age of 3, though diagnosis may be made as early as 12 to 18 months, and as late as 4 to 6 years (or later). According to the Centre for Disease Control (CDC), about 1 in 88 children have an autism spectrum disorder. ASDs are three to four times more common in boys than in girls. However, girls with these disorders tend to have more severe symptoms and lower intelligence. Some children will need ongoing supervision, while others, with the right support, may pursue higher education and fulfilling jobs. These disorders affect people of all racial, ethnic and socioeconomic groups. To date, no biological diagnostic tests exist that detect autism. But scientists are hopeful that advanced imaging techniques and differences in blood levels of proteins in autistic versus normal children may have implications for diagnosis. Already, improved diagnostic procedures have allowed clinicians to diagnose children at a younger age. Formal diagnosis involves parental input and structured and systematic screening instruments, such as the Modified Checklist for Autism in Toddlers (M-CHAT) and the Autism Behavioural Checklist (ABC) for older children. The Childhood Autism Rating Scale (CARS) and the Autism Diagnostic Inventory-Revised (ADI-R) are used, as well. These tools measure the prevalence of symptoms.

There is no one treatment for ASDs; however, it is widely accepted that the earliest interventions allow the best outcomes. Treatments generally address both cognitive and behavioural functioning. They may include a combination of medications (for challenging behaviours), behavioural therapy, psycho-education, family support groups, educational

interventions, speech and language therapy, occupational therapy and specialized training to develop and improve acquisition of necessary skills.

Researchers are exploring several genes which are believed to contribute to the development of these disorders as well as several brain regions that have been linked to the disorders. Abnormal brain development during the first months of life is being studied to determine if structural abnormalities, such as in the mirror neuron systems, may be caused by genetic and/or environmental factors. A cognitive perspective suggests that people's coping styles and appraisals of stressful life events are important in determining how strongly those events influence mental health; psychological distress will worsen if people cannot find adaptive ways to interpret their difficult circumstances (Beck & Haigh, 1962)

Researches has found that a newer class of atypical antipsychotic medications may better treat the serious behavioural disturbances in children with autism who are between 5 and 17 years old. Applied behavioural analysis may be an effective adjunctive treatment in reinforcing desirable and reducing undesirable behaviours. Other work focuses on improving social communication in children with autism. Some have found that structured multidisciplinary behavioural programs are more successful. Parental involvement, a predictable schedule, regular behaviour reinforcement and active engagement of attention in highly structured activities to enhance a strength or ability may all contribute to creating an effective treatment program. Psychoanalytic understanding of what causes autism is overviewed with lot of scepticism.

Dr. Kanner was the first to establish a relationship between the personality type of the parents and the presence of autistic child. Various eminent psychoanalytic theorists have their own



opinion based on their theories and present treatment strategies to deal with this problem. Research work done by S. Bhattacharya discusses theories about development of autism and quotes Bettelheim, who theorizes that autism is caused by the deficits in affective communication in infancy between the mother and the child (for e.g. feeding difficulties could lead to increased anxiety and rejection from the child, which if not handled or understood by mother can increase the anxiety and lead the child to fall into the vicious cycle of paranoid rejection).

Margarete Mahler (1952) proposed the concept of symbiotic psychosis for children who seemed to fail in the task of separating their psychological selves from the hypothesized early fusion with their mother. This concept was coined by her as "Normal Autistic Phase", which was just a phase of development that all new born grows out of with the loving support of the mother or care giver. Autism could be seen as fixation at this stage of development and child's inability to grow out of it successfully.

## **1.5 CEREBRAL PALSY (CP)**

Cerebral palsy is a term used to describe a broad spectrum of motor disability, which is non progressive and is caused by damage to the brain, at or around birth (DSM-V). Signs and symptoms vary between people. Often, symptoms include poor coordination, stiff muscles, weak muscles, and tremors. There may be problems with sensation, vision and hearing, swallowing and speaking. Often babies with cerebral palsy do not roll over, sit, crawl, or walk as early as other children their age. Difficulty with the ability to think or reason and seizures each occurs in about one third of people with CP. While the symptoms may get more noticeable over the first few years of life, the underlying problems do not worsen over time.

Most often the problems occur during pregnancy; however, they may also occur during childbirth, or shortly after birth. Often the cause is unknown. Risk factors include preterm birth, being a twin, certain infections during pregnancy such as toxoplasmosis or rubella, exposure to methylmercury during pregnancy, a difficult delivery, and head trauma during the first few years of life, among others. About 2% of cases are believed to be due to an inherited genetic cause. A number of sub-types are classified based on the specific problems present. For example, those with stiff muscles have spastic cerebral palsy, those with poor coordination have ataxic cerebral palsy, and those with writhing movements have athetoid cerebral palsy.

Diagnosis is based on the child's development over time. Blood tests and medical imaging may be used to rule out other possible causes. CP is partly preventable through immunization of the mother and efforts to prevent head injuries in children such as through improved safety. There is no cure for CP; however, supportive treatments, medications, and surgery may help many individuals. This may include physical therapy, occupational therapy, and speech therapy. Medications such as diazepam, baclofen, and botulinum toxin may help relax stiff muscles.

Surgery may include lengthening muscles and cutting overly active nerves. Often external braces and other assistive technology are helpful. Some children have near normal adult lives with appropriate treatment. While alternative medicines are frequently used there is no evidence to support their use. CP is the most common movement disorder in children. It occurs in about 2.1 per 1,000 live births.

## **1.6 ATTENTION DEFICIT HYPER ACTIVITY DISORDER (ADHD)**

ADHD is one of the most common neurodevelopmental disorders of childhood. It is usually first diagnosed in childhood and often lasts into adulthood. Children with ADHD may have

trouble paying attention, controlling impulsive behaviors (may act without thinking about what the result will be), or be overly active (DSM-V)

### **Symptoms in children and teenagers**

- Having a short attention span and being easily distracted.
- Making careless mistakes – for example, in schoolwork.
- Appearing forgetful or losing things.
- Being unable to stick to tasks that are tedious or time-consuming.
- Appearing to be unable to listen to or carry out instructions.

Perhaps the strongest link between the environment and ADHD occurs before a child is born. Prenatal exposure to smoking is associated with the behaviors of children with ADHD according to the CDC. Children who were exposed to alcohol and drugs while in the womb are more likely to have ADHD according to a 2012 study.

## **1.7 COMMUNICATION DISORDER**

A child's communication is considered delayed when the child is noticeably behind his or her peers in the acquisition of speech and/or language skills.

A communication disorder is an impairment in the ability to receive, send, process, and comprehend concepts or verbal, nonverbal and graphic symbol systems. A communication disorder may be evident in the processes of hearing, language, and or speech. A communication disorder may range in severity from mild to profound. (DSM-V)

Communication disorders are grouped into four main categories: speech disorders, language disorders, hearing disorders, and central auditory processing disorders.

**There are five communication disorders in the DSM-5:**

- Language Disorder
- Speech Sound Disorder (previously Phonological Disorder)
- Childhood-Onset Fluency Disorder (Stuttering)
- Social (Pragmatic) Communication Disorder
- Unspecified Communication Disorder.
- Developmental language disorder, language delay, or developmental dysphasia.

The cause of a communication disorder is not always known. However, common causes include abnormal structures (oral, pharyngeal, or laryngeal), oral-motor dysfunction, neurological problems or brain injury, learning problems, and hearing loss. Language disorders are a type of communication disorder. Those who aren't familiar with the term may think a language disorder is related to speech production, but it is actually related to the ability to understand and employ the use of language.

## **REVIEW OF LITERATURE**

## **2.1 RELATED STUDIES ON PERCEIVED SOCIAL SUPPORT**

Lauren E. Tobing & David S. Glenwick (2007) studied to explore potential predictors of psychological distress and moderators of the relation between parenting stress and psychological distress in mothers of children with pervasive developmental disorders (PDDs). Ninety-seven mothers of children diagnosed with autism spectrum disorders completed measures assessing children's functional impairment, parenting stress, number of social supports, satisfaction with social support, parenting sense of competence, number of coping strategies, and maternal psychological distress. Consistent with hypotheses, parenting competence and satisfaction with social support were negatively related to maternal distress. However, number of coping strategies and number of social supports were not significantly related to distress. Regression analyses revealed that number of social supports augmented, rather than moderated, the relation between a composite of children's functional impairment/parenting stress and maternal distress.

Rajesh Kumar Mourya & R N Singh (2016) examine the role of family environment, social support and coping style in quality of life among the parents of children with neuro-developmental disabilities. Fifty such parents (N = 50) participated in this study and were divided into two groups: parents of children with intellectual disability (N = 29) and parents of children with cerebral palsy (N = 21). Besides, thirty parents having normal children (N = 30) also participated. Their age ranged from 26-55 years. The participants in case of affected children were selected from some rehabilitation centres and special school at Varanasi. They were administered Family Environment Scale, Multi-dimensional Scale of Perceived Social Support, Coping Checklist, and Quality of Life scale. Correlational analysis revealed that perceived social support, good family environment and positive coping style were positively

associated with quality of life. The results of stepwise regression analysis indicate that perceived social support, family environment and coping style emerged as significant predictors of quality of life among the parents of children with neuro-developmental disabilities.

Olagunju O et.al (2017) studied children with neurodevelopmental disorders (CNDs) are a group requiring more attention as their care is often challenging, particularly for parents with primary caregiving roles in resource-restricted settings. This study had set out to investigate the burden and psychological distress among caregivers of children with neurodevelopmental delays. A total of 60 respondents (caregivers and children) were included in the study. The Zarit Caregivers Burden Scale (ZCBS) and General Health Questionnaire version 12 (GHQ-12) were administered to elicit caregivers' experience with respect to burden and psychological distress, respectively. The results found the common presenting complaints by caregivers were inability to walk (32.7%), repetitive behaviour (25.5%), difficulty with verbal communication (10.9%), non-socialization (9.1%), seizures (9.1%), and hyperactivity (3.6%). Problems were noticed at  $\leq 1$  year in 46.7% while they were noticed after 2 years in more than half the children, and a little above one-eighth (14%) had siblings with similar problems. On the ZCBS, nine (15.0%) caregivers reported a significant burden. In addition, 23 (38.3%) caregivers had psychological distress. Caregivers' burden was significantly related to the report of psychological distress in caregivers ( $P < 0.001$ ) and there was a trend toward the presence of psychological distress in almost all caregivers with children experiencing seizures. The findings in this study underscore the need for counselling and psychosocial support for caregivers of children with neuro developmental disabilities.

Regina Bushin et.al (2017) research on Gender and race differences in treatment rates for attention-deficit/hyperactivity disorder (ADHD) are well documented but poorly understood.

Using a mixed-methods approach, this study examines parental help-seeking steps for elementary school students at high risk for ADHD. Parents of 259 students (male/female, African American/Caucasian) identified as being at high risk for ADHD completed diagnostic interviews and provided detailed accounts of help-seeking activities since they first became concerned about their child. Help-seeking steps ( $n=1,590$ ) the inductive analysis revealed unique parental perceptions of their children's sick role and of the agents of identification and intervention for each of the four groups. Deductive analysis showed significant variations by race and gender in consultation experiences, in the person or entity being consulted and, in the transactions, occurring in the consultation, and in illness careers. ADHD symptoms are interpreted as having different implications for the sick role and the intervention, dependent on a child's gender and race. Educational interventions need to address cultural stereotypes contributing to inequitable access to treatment.

Kuru, N., & Piyal, B. (2018) examined to identify the perceived social support and quality of life of the parents of children with autism and to investigate the related factors. The sample of the study consists of 90 parents who accepted to join the research studies. The participants enrolled in the study included 90 biological parents (31 mothers; 59 fathers). Eighteen children had both mother and father participate (all participants subsequently will be referred to as 'parents'). This was a descriptive cross-sectional study. A socio-demographic form, the EUROHIS Quality of Life Scale (EUROHIS QOL-8) and the Multi-Dimensional Scale of Perceived Social Support (MSPSS) were used for data collection. Results found mean score on the EUROHIS QOL-8 was  $26.17 \pm 4.91$  and that on the MSPSS was  $51.06 \pm 20.6$ . A statistically significant relationship was found between the EUROHIS QOL-8 and MSPSS scores ( $r = 0.524$ ,  $P = 0.000$ ). There were significant differences on the average score on the EUROHIS QOL-8 and MSPSS based on fathers' job status. Results provide important insights



into the family experiences of parents of children with autism, and may aid the development of appropriate interventions to further support them. Providing support and understanding families of children with autism and their experiences, nurses, doctors and health professionals can positively affect their health outcomes. Healthcare professionals should focus on determining the needs of families to accordingly plan and implement appropriate programs.

Jones, J. B. (2019) studied Parents of children with autism report higher levels of stress than other parents. Another purpose of this study was to determine the extent to which unsupportive social interactions and online social support may also affect parents of children with autism. Unsatisfactory social interactions refer to responses from others that are perceived as being unhelpful, and may be detrimental to the well-being of parents of children with autism. A sample of 194 parents (103 mothers and 91 fathers) of children with autism aged 4 to 11 years completed an online survey, and 24 participants (12 mothers and 12 fathers) completed follow-up phone interviews. They found to be a good fit for understanding what contributes to family quality of life for both mothers and fathers of children with autism. Higher adequacy of social support and greater use of the reframing coping style were the most closely related to higher family quality of life for fathers. For mothers, greater adequacy of social support, higher psychological acceptance, and greater use of the reframing and acquiring social support coping styles and less use of passive coping styles were the most closely related to higher family quality of life. Online social support was not significantly related to family quality of life.

Cetinbakis, G., Bastug, G., & Ozel-Kizil, E. T. (2020) studied the aim of this study was to explore the caregiver burden and related factors such as expressed emotion (EE), social support, life satisfaction, dyadic adjustment, post-traumatic growth, and socio-demographic characteristics of mothers with autism spectrum disorder (ASD) children. Sixty-two mothers

of children with autism spectrum disorder and 60 mothers of typically developing children participated in the study. Higher maternal caregiving burden was associated with lower life satisfaction and higher level of disability in Turkish children with ASD. Also, higher life satisfaction of mothers with ASD children was related to higher social support and dyadic adjustment, and lower EE. These mothers need professional guidance and psychosocial support during the parenting process.

Kausar, N., Bibi, B., & Raza, S. B. (2021) examined the perceived social support (PSS) as a moderator between parental perceived stress (PPS) and quality of life (QOL) among parents having children with special needs. A sample of 300 parents was selected through purposive sampling from special education schools. The results shows that PPS, QOL and PSS had statistically significant relationships ( $p < .001$ ) with each other. Further, PPS is a significant moderator between PPS and QOL among targeted parents. On the basis of findings, it is concluded that there is an intense need of providing awareness and social support to empower parents for coping with stresses.

Çattik M & Aksoy V (2021) studied to demonstrate the relationship among social support, self-efficacy, and life satisfaction perceived by parents of children who have developmental disabilities in early childhood (0-6 years) and present the variables of this relationship that may be predictors. The study group consisted of 225 parents of children diagnosed with developmental disabilities during the early years. A total of 225 participants were included in the study, 139 mothers and 86 fathers. The Revised Parental Social Support Scale/RPSSS was used to assess the levels of social support received by the parents. The Parenting Self-Efficacy Scale-Turkish Version/PSES-TV was used to evaluate parents' perceptions of self-efficacy.

Finally, the Life Satisfaction Scale (LSS) was used to assess parents' levels of life satisfaction. Results revealed a weak but significant relation between parents' perceptions of levels of social support and levels of income. It was concluded that there was a strong and significant relation between parenting self-efficacy and social support variables, and parents' life satisfaction levels. Both variables appeared to explain a significant part of the total variance in life satisfaction. The result of the analyses suggested that both variables were significant predictors of life satisfaction.

## **2.2 RELATED STUDIES ON PSYCHOLOGICAL DISTRESS**

Davis, N. O., & Carter, A. S. (2008) studied elevated parenting stress is observed among mothers of older children with autism spectrum disorders (ASD), but little is known about parents of young newly-diagnosed children. Associations between child behaviour and parenting stress were examined in mothers and fathers of 54 toddlers with ASD (mean age = 26.9 months). Parents reported elevated parenting stress. Deficits/delays in children's social relatedness were associated with overall parenting stress, parent-child relationship problems, and distress for mothers and fathers. Regulatory problems were associated with maternal stress, whereas externalizing behaviours were associated with paternal stress. Cognitive functioning, communication deficits, and atypical behaviours were not uniquely associated with parenting stress.

Annette Estes et.al (2013) examined parenting-related stress and psychological distress in mothers of toddlers with ASD, developmental delay without ASD (DD), and typical development. The impact of child problem behaviour and daily living skills on parenting-stress and psychological distress were further investigated. Participants were part of a larger research

study on early ASD intervention. Parent self-report of parenting-related stress and psychological distress was utilized. Parents of toddlers with ASD demonstrated increased parenting-related stress compared with parents of toddlers with DD and typical development. Psychological distress did not differ significantly between the groups. Child behaviour problems, but not daily living skills emerged as a significant predictor of parenting-related stress and psychological distress. This was true for both mothers of children with ASD and DD. These findings suggest that parents' abilities to manage and reduce behaviour problems is a critical target for interventions for young children with ASD and DD in order to improve child functioning and decrease parenting-related stress.

Ali Dardas & Muayyad M. Ahmad (2014) examined the relationship between two sets of variables in a sample of parents of children with autistic disorder. The first set was composed of the parents' characteristics and the coping strategies used. The second set was composed of three stress sub scales V parental distress (PD), parent child dysfunctional interaction (PCDI), and difficult child (DC) the parental quality of life (QOL) tools were used. Results revealed that the parents who have higher incomes, use diverse problem-solving strategies, exhibit less escape avoidance, and exhibit less responsibility acceptance behaviour tended to report lower PD, PCDI, and DC scores and a higher QOL score. Also revealed that being an older parent, having more time since the child's autistic diagnosis, and using more distancing coping strategies were associated with lower PD scores, higher PCDI and DC scores, and better QOL. The results indicate that health professionals working with parents of children with autistic disorder need to consider holistically the factors that can potentially affect the parents' health and well-being and provide care that focuses on the parents as both clients and caregivers.

Keenan, B. M., Newman, L. K., Gray, K. M., & Rinehart, N. J. (2016) researched on there has been limited study of the relationship between child attachment and caregiver wellbeing amongst children with autism spectrum disorder (ASD). This study examined self-reported child attachment quality alongside caregivers' report of their own psychological distress, parenting stress and attachment style, amongst 24 children with high-functioning autism or Asperger's disorder (ASD; aged 7–14 years) and 24 typically developing children (aged 7–12 years), and their primary caregiver. Children with ASD were no less secure, but their caregivers were more stressed and reported more attachment-related anxiety, compared to typically developing dyads. Child attachment security was related to caregiver psychological distress and attachment style, but only amongst typically developing children. Impacts of emotion processing impairments on caregiver-child relationships in ASD are discussed.

VivianKhami (2018) studied to identify predictors of parental stress and psychological distress among parents of children with mental retardation in the United Arab Emirates. It examined the relative contributions of child characteristics, parents' socio-demographics, and family environment to parental stress and psychological distress. Participants were parents of 225 mentally retarded children, of whom 113 were fathers and 112 were mothers. Measures of parental stress (QRS-F), psychiatric symptom index (PSI) and family environment scale (FES) were administered in an interview format. Hierarchical multiple regression was used to predict parental stress and psychological distress. The results indicate that the model containing all three predictor blocks, child characteristics, parents' socio-demographics, and family environment, accounted for 36.3% and 22.5% of parental stress and parents' psychiatric symptomatology variance, respectively. The age of the child was significantly associated with parents' feelings of distress and psychiatric symptom status, and parental stress

was less when the child was older. Parents reported more psychiatric symptomatology when the child showed a high level of dysfunction. Fathers' work appeared to be a significant predictor of parental stress, indicating that for fathers who were not working the level of stress was higher than fathers who were working. Lower socioeconomic level was associated with greater symptom rates of cognitive disturbance, depression, anxiety, and despair among parents. Among the family environment variables, only the personal growth dimension stood out as a predictor of parental stress. An orientation toward recreational and religious pursuits, high independence, and intellectual and recreational orientations were associated with lower levels of parental stress. On the other hand, parents in achievement-oriented families showed elevated levels of parental stress.

Francesco (2018) compared the parenting stress experienced by parents of 239 children with Specific Learning Disorders (SpLD), Language Disorders (LD), Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), and typical development (TD). The clinical sample consisted of 186 children/adolescents, aged from 3 to 12 years old, results found There is considerable understanding that parents of children with developmental disabilities experience increased levels of stress, often related to the severity of their child's behaviour the experience of stress is dependent on how individuals perceive their situation and what are the coping strategies.

Jones, J. B. (2019) examined family quality of life refers to the extent to which families are satisfied with different domains in their lives. The concept of family quality of life was originally developed by a group of international researchers as a way to evaluate how having a family member with a disability, such as autism, affects the entire family unit. Parents of

children with autism report higher levels of stress than other parents. A sample of 194 parents (103 mothers and 91 fathers) of children with autism aged 4 to 11 years completed an online survey, and 24 participants (12 mothers and 12 fathers) completed follow-up phone interviews. Higher adequacy of social support and greater use of the reframing coping style were the most closely related to higher family quality of life for fathers. For mothers, greater adequacy of social support, higher psychological acceptance, and greater use of the reframing and acquiring social support coping styles and less use of passive coping styles were the most closely related to higher family quality of life. The findings of this study are hopeful, in that most parents of children with autism in this study reported good family quality of life, especially the parents who had relatively more supports and resources.

Olson, L et.al (2022) studied Parents of children diagnosed with autism spectrum disorder (ASD) report higher levels of stress than parents of typically developing children. Few studies have examined factors associated with parental stress in early childhood. Even fewer have investigated the simultaneous influence of sociodemographic, clinical, and developmental variables on parental stress. Examined factors associated with stress in parents of young children with ASD. Multiple regression models were used to test for associations between socioeconomic indices, developmental measures, and parental stress. Externalizing behaviours, communication, and socialization skills accounted for variance in parental stress, controlling for ASD diagnosis. Results highlight the importance of interventions aimed at reducing externalizing behaviours in young children as well as addressing stress in caregivers of children with ASD.

### **2.3 Need & significance of the study**

- Perceived social support can improve the treatment and intervention outcome.
- It was found a research gap, as limited research studies in the Indian context, among parents/ care givers of developmental delay.
- The present study identifies importance of perceived social support and psychological distress among parents of children with developmental delay.
- To suggest social support options for parents of children with developmental delay.
- To educate/provide awareness among parents on importance of mental health by seeking social support.
- This study was attempted to determine the severity of the perceived social support and psychological distress among the caregivers of children with developmental delay.



## **METHOD**

The current study was conducted to understand the impact of perceived social support on psychological distress among parents of children with developmental delay.

### **3.1 AIM**

The aim of the present study is to understand the impact of perceived social support on psychological distress among parents of children with developmental delay.

### **3.2 OBJECTIVES OF STUDY**

- To assess the impact of perceived social support on psychological distress among parents of children with developmental delay.
- To find out the relationship between perceived social support, and psychological distress among parents of children with developmental delay.
- To identify the significance of socio-demographic variables on perceived social support and psychological distress among parents of children with developmental delay.

### **3.3 HYPOTHESES**

1. There will be a significant relationship between perceived social support and psychological distress among parents of children with developmental delay.
2. Perceived social support will predict a unique variance in psychological distress among parents of children with developmental delay.

3. There will be a significant difference in perceived social support and psychological distress among parents of children with developmental delay based on income.
4. There will be a significant difference in perceived social support and psychological distress among parents of children with developmental delay based on type of developmental disorder.
5. There will be a significant difference in perceived social support and psychological distress among parents of children with developmental delay based on the gender of the parents.
6. There will be a significant difference in perceived social support and psychological distress among parents of children with developmental delay based on the gender of the child.
7. There will be a significant difference in perceived social support and psychological distress among parents of children with developmental delay based on their residence.
8. There will be a significant difference in perceived social support and psychological distress on type of family among parents of children with developmental delay.

### **3.4 RESEARCH DESIGN**

Correlational Research Design was used to collect and analyse the data for the present study.

### **3.5 STUDY VARIABLES**

Independent Variable - Perceived Social Support

Dependent Variable - Psychological Distress (Parents of children with developmental delay)

## **3.6 METHOD**

A quantitative method of study has been adapted for this study.

## **3.7 SAMPLING PROCEDURE**

The sample of the study was selected from target population within in the clients of National Institute for Empowerment of Persons with Multiple Disabilities (NIEPMD), Chennai, Tamil Nadu. Parents of children with developmental delay whose age of their child ranges from 1-6 years. The method of sampling was purposive sampling (non- random sampling) participants included 50 parents of children with developmental delay.

### **3.7.1 Inclusion Criteria**

1. Parent of children with Developmental Delay, ASD, ADHD, Communication Disorders & Locomotor Disorder diagnosed by multidisciplinary team.
2. Child's age ranges from 1-6 years.
3. Parent should be the primary caregiver of the child, should be mother or father.

### **3.7.2 Exclusion Criteria**

1. Presence of psychiatric/neurological morbidities in parents of children with developmental disorders,
2. Grandparents and any other family members.

### **3.8 Tools used in the study**

This study used the following tools for screening the participants to include into the study and to measure the perceived social support and psychological distress. Socio-demographic profile as well as consent forms were also included. (Appendix – 1)

#### **3.8.1 Consent Form**

A consent form explaining the research procedure was provided to the participants. It had information on purpose of the research, the participants role in the research process, ethics of confidentiality and rights of the subject as a participant during the data collection and anonymity in coding the data. (Appendix – 2)

#### **3.8.2 Socio-demographic details**

A profile prepared by the researcher to collect the demographic information of the participants were used. It includes age, gender, education, and marital status, etc. (Appendix- 2)

#### **3.8.3. Multidimensional Scale of Perceived Social Support (MSPSS)**

Multidimensional Scale of Perceived Social Support (MSPSS) assess the how they get perceived social support. It consists of 13 items with 7- point Likert type scale -very strongly disagree to very strongly agree. Social support level obtained by calculating the mean scores. It includes significant other subscale scores which is obtained by the sum across items 1, 2, 5, & 10 and divided by 4.

The internal consistency and temporal stability of each of the domains have been determined to be sufficient ( $\alpha = .68$  to  $.86$ , Costa & Mc Crae, 1992;  $r = .86$  to  $.90$ , Robins et al., 2001) (Appendix- 2)

### **3.8.4 Kessler Psychological Distress Scale (K10)**

Kessler Psychological Distress Scale (K10) is a self- report screening instrument that assess the level of psychological distress. It consists of 10 items with 5 step Likert type - All of the time (score 5) Most of the time (score 4) Some of the time (score 3) A little of the time (score 2) None of the time (score 1). Psychological distress level obtained by adding the scores and categorized based on the set of cut off scores. Scores of 10 - 19 indicates “Likely to be well”, scores of 20 - 24 Likely to have a mild disorder, 25 - 29 Likely to have a moderate disorder, 30 - 50 Likely to have a severe disorder. The numerous research has examined the K10’s reliability and validity in diverse clinical populations. Interrater and intra-rater reliability have both been demonstrated to be excellent (Cronbach’s alpha 0.9 – 0.95), and test-retest reliability has been reported to be high (0.78 to 0.9) (Robinson & Price, 1982, Failde et al., 2000). Additionally, high internal consistency has been noted (Failde et al., 2000).

This tool was used in the study to screen the participants for undiagnosed or unreported psychological distress. (Appendix-2)

## **3.9PROCESS OF DATA COLLECTION**

The individuals who met the inclusion criteria where approached, in person. They were clearly explained about the aim and purpose of the study. For the participants who were eligible for the study (parents of children with developmental delay). They were initially informed about the background of the study and how the study implication can be useful.

To all the participants tools of Perceived social support scale and psychological distress scale were given to complete. it took almost 10 – 15 minutes for each participant to respond to the questionnaire. The quality and integrity of research was ensured. Informed consent was obtained from the participants. The confidentiality and anonymity of the participants was ensured. Tools was used in the study are either open source or made publicly available for research under a commons license. The study results will be shared with the participants if intimated for their reference and understanding.

The proposal for the dissertation was presented to the Institute Ethical Committee was approved by them. The collected data was kept highly confidential and used only for research purposes. Anonymity of the participants were maintained throughout the research procedure.

### **3.10 ANALYSIS OF DATA**

The data was subjected to descriptive statistics of frequency, percentage, mean and standard deviation. The data obtained was run through normality testing, the results showed that the data obtained near normality in the distribution of the variable scores. Hence, parametric tests were used to obtain the study result. The data was subjected to Independent sample t-test using the software statistical package for social science version 25.0 (SPSS 25.0)

## **RESULTS & DISCUSSION**



**Table 4.1 Shows the Frequency and Percentage among Socio Demographic Variables**

Sample Description	Group	Number Participants (N)	Percent (%)
Gender of Parent	Male -Father	10	20.0
	Female – Mother	40	80.0
	Total	50	100.0
Gender of the child with DD	Male	40	80.0
	Female	10	20.0
	Total	50	100.0
Educational background of the parent	Illiterate	4	8.0
	Middle School	5	10.0
	High School	12	24.0
	Under Graduation	17	34.0
	Post-Graduation	12	24.0
	Total	50	100.0
Place of Residence	Urban	24	48.0
	Semi-urban	11	22.0
	Rural	15	30.0
	Total	50	100.0
Family Type	Nuclear Family	30	60.0
	Joint Family	20	40.0
	Total	50	100.0

Type of Developmental Disorder	ASD	20	40.0
	ADHD	8	16.0
	DD	13	26.0
	CD	5	10.0
	CP	4	8.0
	Total	50	100.0
Family Income per month	<5,000	7	14.0
	5,000 to 10,000	18	36.0
	>10,000	25	50.0
	Total	50	100.0

*\*ASD- Autism Spectrum Disorder, ADHD- Attention Deficit Hyper Activity Disorder, DD- Developmental Delay, CD- Communication Disorder, CP- Cerebral Palsy*

Table No. 4.1 shows the sociodemographic profile of the sample in terms of total number and the total percentage of the sociodemographic data of participants of the study. The analysis shows that fathers of children with developmental delay are 10 (20%) and mothers are 40 (80%). Based on the gender of the child male children are high in number is 40 (80%) and female children are 10 (20%). The educational background of the parents, predominantly Under Graduation 17 (34%), Post-Graduation 12 (24%), High School 12 (24%), Middle School 5 (10%) and Illiterate 4 (8%). Based on the place of residence majority of parents belong to Urban areas, 24 (48%) Rural areas 15 (30%) and Semi-urban areas 11 (22%). Based on family type most of the parents are belongs to Nuclear Family 30 (60%) and Joint Family is 20 (40%). Based on type of developmental disorder higher number of children belongs to Autism Spectrum Disorder 20 (40%), Developmental Delay 13 (26%), Attention Deficit Hyperactivity Disorder 8 (16%), Communication Disorder 5 (10%), Cerebral Palsy 4 (8%). Based on family

income most of the parents are categorised in (per month) >10,000 – 25 (50%) secondly 5,000 to 10,000 -18 (36%) lastly <5,000 - 7 (14%).

**Table 4.2**

***The mean and standard deviation of perceived social support and psychological distress among parents of children with developmental delay***

	M	SD	W
Perceived Social Support	5.01	1.42	.930
Psychological Distress	25.12	8.96	.954

\*  $p < 0.05$ , \*\* $p < 0.01$

The table results indicate Perceived Social Support ( $M = 5.01$ ) and ( $SD = 1.42$ ) and Psychological Distress ( $M = 25.12$ ) and ( $SD = 8.96$ ) corresponding  $W$  score is .930 & .954 respectively.

**Table 4.3**

***Relationship of perceived social support and psychological distress among parents of children with developmental delay.***

	PSS	PD
Perceived Social Support (PSS)		.480**
Psychological Distress (PD)	.480**	

\*Correlation is significant at the 0.05 level \*\*Correlation is significant at the 0.01 level

Pearson Correlation Coefficient was used to analyse the relationship between perceived social support and psychological distress among parents of children with developmental delay; A

significant relationship was found between perceived social support and psychological distress ( $r=.480, p < 0.01$ ).

**Table 4.4**

***Predicting perceived social support and psychological distress among parents of children with developmental delay.***

Predictors	Psychological Distress	
	B	T
Perceived Social Support	-.480	-3.788**
R <sup>2</sup>	.230	
F	14.350**	

\*  $p < 0.05$ , \*\*  $p < 0.01$

To understand the predictive role of perceived social support and psychological distress among parents of children with developmental delay, linear regression was carried out. As shown in Table 4.4, results indicated that perceived social support ( $\beta = - 0.480, t = -3.788, p < 0.01$ ) is a negative predictor of psychological distress, and they explained 4.1% of the variance in perceived social support and psychological distress among parents of children with developmental delay ( $R^2 = 0.230, F = 14.350, p < 0.01$ ).

**Table 4.5**

***Perceived social support and psychological distress among parents of children with developmental delay based on monthly income.***

	Monthly Income			
		M	SD	W
Perceived Social Support	<5K	4.28	2.05	.956
	5K to 10K	5.02	1.52	.894
	>10K	5.21	1.10	.921
Psychological Distress	<5K	27.29	11.65	.931
	5K to 10K	26.06	9.14	.957
	>10K	23.84	8.19	.929

The table results indicate perceived social support on parents of CWDD income group below <5,000 ( $M = 4.28$ ) and ( $SD = 2.05$ ), corresponding  $W$  score is .956, between 5,000 to 10,000 income group ( $M = 5.02$ ) and ( $SD = 1.52$ ), corresponding  $W$  score is .921, above 10,000 income group ( $M = 5.21$ ) and ( $SD = 1.10$ ), corresponding  $W$  score is .894. And the psychological distress on parents of CWDD, below 5,000 group ( $M = 27.29$ ) and ( $SD = 11.65$ ), corresponding  $W$  score is .931, between 5,000 to 10,000 ( $M = 26.06$ ) and ( $SD = 9.14$ ), corresponding  $W$  score is .957 and above 10,000 income group ( $M = 23.84$ ) and ( $SD = 8.19$ ), corresponding  $W$  score is .929

**Table 4.6**

***Results of one-way ANOVA showing differences in perceived social support and psychological distress among parents of children with developmental delay based on monthly income***

Variables	BMS	WMS	F	Sig.
Perceived Social Support	2.238	2.014	1.165	.321

Psychological Distress	44.77	81.908	0.547	.583
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The ANOVA results shows perceived social support and psychological on parents of CWDD ( $BMS = 2.238$  &  $44.7$ ) and ( $WMS = 2.014$  &  $81.908$ ) corresponding  $F$  ratio is  $1.165$  &  $0.547$ . respectively. Hence, no significant difference was observed between perceived social support and psychological distress among parents of children with developmental delay based on monthly income in the current sample (Tables 4.5 & 4.6).

**Table 4.7**

***Perceived social support and psychological distress among parents of children with developmental delay based on the type of developmental disorder.***

	Type of Developmental Disorder			
		M	SD	W
Perceived Social Support	ASD	4.75	1.50	.941
	ADHD	4.81	1.75	.943
	DD	5.33	1.39	.931
	CD	5.26	0.99	.740*
	CP	5.37	1.12	.852
Psychological Distress	ASD	24.35	8.92	.928
	ADHD	30.50	6.94	.915
	DD	22.85	11.10	.842*
	CD	25.60	6.30	.945
	CP	25.00	6.73	.990

\*  $p < 0.05$ , \*\* $p < 0.01$

The table results indicate perceived social support and psychological distress based on parents of CWDD in type of developmental disorder for ASD ( $M = 4.75$ ) & ( $SD = 1.50$ ), corresponding  $W$  score is .941. On ADHD ( $M = 30.50$ ) & ( $SD = 6.94$ ), corresponding  $W$  score is .915. On DD ( $M = 22.85$ ) & ( $SD = 11.10$ ), corresponding  $W$  score is .842\*, ( $* p < 0.05$ ) which is significant. On CD mean score is 25.60, standard deviation is 6.30, corresponding  $W$  score is .945. On CP mean score is 25.00, standard deviation is 6.73, corresponding  $W$  score is .990. The results of One-way ANOVA found between mean score is 0.958 & 77.959, within mean score is 2.123 & 80.610 and  $F$  ratio is .451 & .967 respectively.

**Table 4.8**

***Results of one-way ANOVA showing differences in perceived social support and psychological distress among parents of children with developmental delay based on the type of Developmental Disorder.***

Variables	BMS	WMS	F	Sig.
Perceived Social Support	0.958	2.123	.451	.771
Psychological Distress	77.959	80.610	.967	.435

Table 4.7 & 4.8 shows no significant difference was observed between perceived social support and psychological distress among parents of children with developmental delay based on the type of developmental disorder in the sample.

**Table 4.9**

***Perceived social support and psychological distress among parents of children with developmental delay based on the gender of the parents.***

Variables	Gender of the caregiver	M	SD	W	T	Sig.
Perceived Social Support	Male- Father	5.33	1.60	.901	0.778	.437
	Female-Mother	4.93	1.38	.931		
Psychological Distress	Male- Father	20.10	5.74	.891	-2.043	.023*
	Female-Mother	26.38	9.23	.965		

\*  $p < 0.05$ , \*\* $p < 0.01$

The table results indicate on perceived social support based on gender parents of CWDD fathers had higher ( $M = 5.33$ ) & ( $SD = 1.60$ )  $W$  score is .901. And mothers ( $M = 4.93$ ) & ( $SD = 1.38$ )  $W$  score is .931 and corresponding  $T$  score is 0.778. On psychological distress parents of CWDD mothers had higher mean score ( $M = 26.38$ ) & ( $SD = 9.23$ )  $W$  score is .891 and fathers ( $M = 20.10$ ) & ( $SD = 5.74$ ), corresponding  $t$  score is .023\*, which is significant.

A significant difference was observed in psychological distress among parents of children with developmental delay based on the gender of the caregiver in the current sample (Table 4.9).

**Table 4.10**

***Perceived social support and psychological distress among parents of children with developmental delay based on the gender of the child.***

Variables	Gender of the child	M	SD	W	't'	Sig.
Perceived Social Support	Male	5.11	1.21	.939	.953	.021*
	Female	4.63	2.10	.911		



Psychological Distress	Male	24.98	8.55	.957	1.293	.261
	Female	25.70	10.97	.929		

\*  $p < 0.05$ , \*\* $p < 0.01$

The table results indicate on perceived social support and psychological distress based on gender of the child, male children have ( $M = 5.11$ ) & ( $M = 24.98$ ), ( $SD = 1.21$  &  $8.55$ ), corresponding  $W$  score is .939 & .911 respectively. On the female children, ( $M = 4.63$  & ( $M = 25.70$ ), ( $SD = 2.10$  &  $10.97$ ), corresponding  $W$  score is .911 & .929 respectively. Based on the results the male children have significant  $T$  value .953 on .021\* (\*  $p < 0.05$  level).

A significant difference was observed in perceived social support among parents of children with developmental delay based on the gender of the child in the current sample (Table 4.10).

**Table 4.11**

***Based on their residence, perceived social support, and psychological distress among parents of children with developmental delay.***

	Residence			
		M	SD	W
Perceived Social Support	Urban	5.03	1.32	.946
	Semi-urban	5.51	0.86	.856
	Rural	4.61	1.81	.928
Psychological Distress	Urban	25.54	9.00	.951
	Semi-urban	19.18	3.71	.927
	Rural	28.80	9.78	.958

\*  $p < 0.05$ , \*\* $p < 0.01$

The table results indicate based on place of residence of parents of CWDD, on perceived social support and psychological distress, Urban ( $M = 5.03$  &  $M = 25.54$ ), ( $SD = 1.32$  &  $SD = 9.00$ ) and corresponding  $W$  score is .946 & .951 respectively. On Semi-urban ( $M = 5.51$  &  $M = 19.18$ ), ( $SD = 0.86$  &  $SD = 3.71$ ), corresponding  $W$  score is .856 & .927 respectively. And in Rural ( $M = 4.61$  &  $M = 28.80$ ), ( $SD = 1.81$  &  $SD = 9.78$ ), corresponding  $W$  score is .928 & .958 respectively.

**Table 4.12**

***Results of one-way ANOVA show differences in perceived social support and psychological distress among parents of children with developmental delay based on their residence.***

Variables	BMS	WMS	F	Sig.
Perceived Social Support	2.625	2.003	1.311	.102
Psychological Distress	297.643	71.149	4.183	.295

The one-way ANOVA results found perceived social support and psychological distress on between ( $M^2 = 2.625$  &  $M^2 = 297.643$ ), within ( $M^2 = 2.003$  &  $M^2 = 71.149$ ), corresponding  $F$  ratio is 1.311 & 4.183 respectively, which is not significant to the study variables.

Hence, no significant difference was observed between perceived social support and psychological distress among parents of children with developmental delay based on their residence in the current sample (Tables 4.11 & 4.12).

#### 4.13

#### *Perceived social support and psychological distress among parents of children with developmental delay based on the type of family.*

Variables	Type of Family	M	SD	W	't'	Sig.
Perceived Social Support	Nuclear Family	4.92	1.39	.934	-.522	.957
	Joint Family	5.14	1.49	.897		
Psychological Distress	Nuclear Family	25.97	8.90	.942	.815	.693
	Joint Family	23.85	9.13	.929		

The table results indicate based on type of family on the perceived social support and psychological distress on parents of CWDD, parents from nuclear family mean score is 4.92 & 25.97, standard deviation is 1.39 & 8.90, corresponding W score is .934 & .942 respectively. On the other hand, joint family mean score is 5.14 & 23.85, standard deviation is 1.49 & 9.13, corresponding W score is .897 & .929 respectively. The T value is -.522 & .815 respectively for both groups.

Hence, no significant difference was observed between perceived social support and psychological distress among parents of children with developmental delay based on the type of family in the current sample (Table 4.13).

#### **Discussion**

The relationship between perceived social support and psychological distress among parents of children with developmental delay; the results are given in Table 4.3. A significant relationship was found between perceived social support and psychological distress. Which means perceived social support increases psychological distress will be decreased.

Perceived social support is a predictor of psychological distress; the results in Table 4.4, indicate significant predictor role in psychological distress, social support has been linked to positive effects on one's physical health and well-being. Cassel, (1976) proposed that social support buffers against the negative consequences of stress. Social support has been shown to be negatively associated with depression and burnout, and positively associated with mental and physical health (Cutrona CE et.al, 1987) and is associated with well-being across a variety of ages (Tian L et.al, 2013) and (Siedlecki KL et.al, 2014). Perceived social support refers to people's beliefs about the supports that are available to them, whether they are positive or negative, and whether they meet their needs. It is thought that the perception of social support is even more important than the actual supports that exist (Zamani-Alavijeh F, 2017).

Based on the income, the table no.4.5 & 4.6 shows there is no difference between income wise classification of parents of CWDD. Indicates that the income levels don't predict the perceived social support and psychological distress. Psychological distress among the parents results due to lack of social support irrespective of their income or economic background this might be because that we applied a broader measure for financial worries, including not only debt-related worries (such as medical bills) but also worries about day-to-day financial expenses.

Based on type of developmental disorder, the table no. 4.7 & 4.8 shows there is significant difference on parents of CWDD on communication disorder and developmental delay. Parents of CWDD on communication disorder group have significant on the perceived social support on the other hand the parents of CWDD on developmental delay group have significant on the psychological distress. Fathers of children with developmental delay have high in perceived

social support and psychological distress study variables compared to mothers. On the other hand, mothers of children with developmental delay expressed overburden in their caregiving. This may act as effect in the sample to all the study variables mean scores is higher in fathers of CWDD. But an important point that perceived social support study variable doesn't show any significant gender difference among the sample group.

Based on the gender of the parent table no. 4.9 shows higher level of mean score on perceived social support got by fathers and mothers got higher mean score on psychological distress. This may be the societal attitudes towards women, cultural factors, etc. Men have other opportunities to ventilate and social groups, associations, gatherings, arts & sports platforms.

Based on the gender of the child table no. 4.10 shows male child have higher mean score on perceived social support and significant difference between female children. This may due to the rearing of children, parenting style, societal attitude towards male child rearing, etc.

Based on the place of residence table no. 4.11 & 4.12 shows no significant difference between the locality the parents were coming from. This may due to the accessibility to get the rehabilitation services from an institution is easy. Also, parents are all aware the importance of getting the services & treatments timely for the betterment of their children. In this study majority of the parents are under graduation qualified so they well aware about those things, importantly mothers are the highest number participant in this study.

Based on the type of family table no. 4.13 shows there is no significant difference between study variables. Nowadays, the increased number of nuclear family set up they are managing

themselves for everything. So that is evident in the results. Earlier periods, the joint family set up lot of help, support, care and affection received from the other family members, due to various reasons like, economic or social circumstances parents were choosing nuclear family.

## **SUMMARY AND CONCLUSION**

The research study attempted to understand the impact of perceived social support on psychological distress among parents of children with developmental delay. The focus of study is on parents of children with developmental disorders of Autism spectrum disorder, Attention deficit hyper activity disorder, Developmental delay, Communication disorder and Cerebral palsy. The study aims to understand the impact of perceived social support on psychological distress among parents of children with developmental delay. The objectives of the study were as follows 1) To assess the impact of perceived social support on psychological distress among parents of children with developmental delay 2) To find out the relationship between perceived social support, and psychological distress among parents of children with developmental delay 3) To identify the significance of socio-demographic variables on perceived social support and psychological distress among parents of children with developmental delay.

The current study is correlational research to identify the relationship between the variables. Purposive sampling method was used in the study as the samples were collected from the NIEPMD, Chennai. The participants included were parents of children with developmental delay. The final samples consist of 50 participants among that include 10 fathers and 40 mothers in the sample. Socio demographic form, the tools Multidimensional Scale of Perceived Social Support (MSPSS) and Kessler Psychological Distress Scale (K10) were used for collecting the data. Descriptive statistics, t test, ANOVA and correlation method were used to analyse the gathered data. Findings indicate that among the participants based on the gender of the child male children are 40 (80%) and female children are 10 (20%), the educational background of the parents, predominantly from Under Graduation 17 (34%), based on the place of residence predominantly parents belong to Urban 24 (48%), based on family type parents belong to nuclear family 30 (60%), based on type of developmental disorder Autism Spectrum Disorder 20 (40%), Attention Deficit Hyperactivity Disorder 8 (16%), Developmental Delay



13 (26%), Communication Disorder 5 (10%), Cerebral Palsy 4 (8%) and based on family income mostly parents belong to (per month) >10,000 – 25 (50%).

The present study used to estimate the nature and inter relationship among the different variables considered in the study that is perceived social support and psychological distress.

The following results were obtained on the analysis of data.

1. A significant relationship was found between perceived social support and psychological distress.
2. There is no significant difference was observed between perceived social support and psychological distress among parents of children with developmental delay based on monthly income.
3. There is no significant difference was observed between perceived social support and psychological distress among parents of children with developmental delay based on the type of disorder.
4. Significant difference was observed in psychological distress among parents of children with developmental delay based on the gender of the parents.
5. Significant difference was observed in perceived social support among parents of children with developmental delay based on the gender of the child.
6. There is no significant difference was observed between perceived social support and psychological distress among parents of children with developmental delay based on their residence.
7. There is no significant difference was observed between perceived social support and psychological distress among parents of children with developmental delay based on the type of family.

## **5.1 IMPLICATIONS OF THE STUDY**

- The study will be helpful in identifying psychological distress among parents of children with developmental delay and provide suitable psychological interventions.
- Helpful in enhancing and encouraging parents to seek social support through various psycho-social intervention.
- To provide awareness about the various social support services such as respite care services and day care facilities, etc.

## **5.2 LIMITATIONS OF THE STUDY**

- Sample was limited hence generalising the findings will not be possible.
- Sample collected only from one organization and could not represent entire population.
- The data was collected from only Chennai region therefore, the regional and cultural factors interplay in perceived social support and psychological distress may or may not be applicable to other regions.

## **5.3 SUGGESTIONS FOR FURTHER RESEARCH**

Present research work has its own focus, scope, aim and limitations some of the future suggestions for further research work are proposed as follows:

- 1) Research work can be conducted using the same variables but the sample could be taken from a different geographical areas of the country. It could also be zonal (East, West, North, South or Central India) or could be at a National level.
- 2) The research work could be (focused on) conducted on parents of children with disabilities from the rural area, where the knowledge and services for the same is not well developed.

4) Presence of other comorbid conditions and psycho-social factors such as Single parenting, parenting style, personality type of parents and siblings' involvement may be explored their role in psychological distress and perceived social support.

7) The work can also focus on understanding and defining a well-structured and treatment plans for children with autism, intellectual disability, learning disability or other developmental disorders.

## REFERENCES

American Psychiatric Association. (2003) *Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM V)*. Washington DC: APA;

Annette Estes, Erin Olson, Jeffrey Munson, (2013). *Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorders*, *Brain and Development*, <http://doi.org/10.3451/b&d.2013/w>

Çattik. M & Aksoy. V, (2021), *An examination of the relations among social support, self-efficacy, and life satisfaction in parents of children with developmental disabilities*, *Journal of Clinical Psychology* 43(195) 65-77, DOI: [10.15390/EB.2018.7246](https://doi.org/10.15390/EB.2018.7246)

Cetinbakis, G., Bastug, G., & Ozel-Kizil, E. T. (2020). Factors contributing to higher caregiving burden in Turkish mothers of children with autism spectrum disorders. *International Journal of Developmental Disabilities*, 66(1), 46–53. <https://doi.org/10.1080/20473869.2018.1478630>

Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders*, 38(7), 1278–1291. <https://doi.org/10.1007/s10803-007-0512-z>

Francesco & Francesca Felicia Operto (2016), *Parenting stress among parents of children with Neurodevelopmental Disorders*, Psychiatry Research, Volume 242,2016, Pages 121-129, ISSN 0165-1781, <https://doi.org/10.1016/j.psychres.2016.05.016>.

Jones, J. B. (2019). Family quality of life for parents of children with Autism: The role of social support and unsupportive social interactions. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 80(3-B(E)), No-Specified. Retrieved from <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc16&NEWS=N&AN=2018-65236-032>

Kausar, N., Bibi, B., & Raza, S. B. (2021). Moderating Role of Perceived Social Support in Perceived Stress and Quality of Life among Parents of Children with Special Needs. *Global Sociological Review*, VI(I), 15–22. [https://doi.org/10.31703/gsr.2021\(vi-i\).03](https://doi.org/10.31703/gsr.2021(vi-i).03)

Keenan, B. M., Newman, L. K., Gray, K. M., & Rinehart, N. J. (2016). Parents of Children with ASD Experience More Psychological Distress, Parenting Stress, and Attachment-Related Anxiety. *Journal of Autism and Developmental Disorders*, 46(9), 2979–2991. <https://doi.org/10.1007/s10803-016-2836-z>

Kuru, N., & Piyal, B. (2018). Perceived social support and quality of life of parents of children with Autism. *Nigerian Journal of Clinical Practice*, 21(9), 1182–1189. [https://doi.org/10.4103/njcp.njcp\\_13\\_18](https://doi.org/10.4103/njcp.njcp_13_18)

Lauren E. Tobing PhD & David S. Glenwick PhD (2007) Predictors and Moderators of Psychological Distress in Mothers of Children with Pervasive Developmental Disorders, *Journal of Family Social Work*, 10:4, 1-22, DOI: 10.1300/J039v10n04\_01

Olagunju AT, Oshodi YO, Umeh CS, Aina OF, Oyibo WA, Lamikanra AE, Lesi FE, Adeyemi JD. Children with neurodevelopmental disorders: The burden and psychological effects on caregivers in Lagos, Nigeria. *J Clin Sci [serial online]* 2017 [cited 2022 Nov 27];14:2-7. Available from: <https://www.jcsjournal.org/text.asp?2017/14/1/2/199162>

Olson, L., Chen, B., Ibarra, C., Wang, T., Mash, L., Linke, A., ... Fishman, I. (2022). Externalizing Behaviors are Associated with Increased Parenting Stress in Caregivers of Young Children with Autism. *Journal of Autism and Developmental Disorders*, 52(3), 975–986. <https://doi.org/10.1007/s10803-021-04995-w>

Rajesh Kumar Mourya & R N Singh, (2016), *Quality of life among parents of children with neuro-developmental disabilities in relation to family environment, coping style and social support*, *Indian Journal of Community Psychology*.

Regina Bussing, Mirka E. Koro-Ljungberg, Faye Gary, Dana M. Mason, Cynthia W. Garvan, Exploring Help-Seeking for ADHD Symptoms: A Mixed-Methods Approach, Pages 85-101 | Received 28 Jan 2005, Accepted 03 Aug 2004, Published online: 03 Jul 2009.

Vivian Khamis, (2018) *Psychological distress among parents of children with mental retardation in the United Arab Emirates*, Social Science & Medicine, Volume 64, Issue 4, 2007, Pages 850-857, ISSN 0277-9536, <https://doi.org/10.1016/j.socscimed.2006.10.022>.

**National Institute for Empowerment of Persons with Multiple Disabilities (NIEPMD)**

**Ministry of Social Justice and Empowerment Govt. of India**

**Muttukadu, ECR Road, Chennai-603112**

**Consent to Participate in the Research Study**

**Researcher:**

Kumaraswamy H. (9496176461)

**Guide:**

Dr. S. Karthikeyan

I, **Kumaraswamy H.**, M.Phil. Clinical Psychology Scholar, NIEPMD invite you to participate in a research study on “*The Impact Of Perceived Social Support On Psychological Distress Among Parents Of Children With Developmental Delay*”

**Description of subject involvement:** If you agree to be part of the research study, you will be asked to answer a few questions according to instructions given by the researcher. These questions measure perceived social support and psychological distress.

**Benefits:** Although you may not directly benefit from being in this study, others may benefit from it as the study will be useful in identifying the problems and planning for the interventions.

**Risks and discomfort:** There are no risks associated with this study because the data collection is completely anonymous and the topic is not sensitive.

**Compensation:** There is no tangible compensation given for participation in this study. However, should the participants be interested in knowing about themselves from the analysis of their individual protocol it could be provided to them by the research investigator.

**Confidentiality:** Researcher will not identify you by name in any reports using information obtained from this study, and that the confidentiality as a participant will remain secure. Subsequent use of records and data will be subject to standard data use policies which protect the anonymity of the participant.

*The details of the study have been provided to me in writing and explained to me in my own language. I confirm that I have understood the above study and had the opportunity to ask questions. I understand that my participation in this study is voluntary and I am free to withdraw at any time. I understand that all personal information I share will be kept confidential and will not be shared with anyone other than those involve in the study.*

Date:

Signature of the participant:



## ஆராய்ச்சிப் படிப்பில் பங்கேற்க ஒப்புதல்

ஆராய்ச்சியாளர்:

ஆராய்ச்சி வழிகாட்டி:

குமாரசாமி எச். (9496176461)

டாக்டர். எஸ்.கார்த்திகேயன்

நான், குமாரசாமி எச்., எம்.பில். மருத்துவ உளவியல் அறிஞர், NIEPMD உங்களை "வளர்ச்சி தாமதம் உள்ள குழந்தைகளின் பெற்றோர்களிடையே உளவியல் துயரத்தில் உணரப்பட்ட சமூக ஆதரவின் தாக்கம்" என்ற ஆராய்ச்சி ஆய்வில் பங்கேற்க உங்களை அழைக்கிறது.

**பொருள் ஈடுபாட்டின் விளக்கம்:** நீங்கள் ஆராய்ச்சிப் படிப்பின் ஒரு பகுதியாக இருக்க ஒப்புக்கொண்டால், ஆராய்ச்சியாளர் வழங்கிய அறிவுறுத்தல்களின்படி சில கேள்விகளுக்கு பதிலளிக்கும்படி கேட்கப்படுவீர்கள். இந்த கேள்விகள் சமூக ஆதரவு மற்றும் உளவியல் துயரத்தை அளவிடுகின்றன.

**பலன்கள்:** இந்த ஆய்வில் இருந்து நீங்கள் நேரடியாகப் பலன் பெறாவிட்டாலும், சிக்கல்களைக் கண்டறிந்து, மாதிரியான முறைக்கு வழிமுறைகள் மற்றும் திட்டமிடுவதில் ஆய்வு பயனுள்ளதாக இருக்கும் என்பதால், மற்ற பெற்றோர்கள் இதிலிருந்து பயனடையலாம்.

**ஆபத்து மற்றும் அசௌகரியம்:** தகவல்கள் சேகரிப்பு முரையில் ஈந்தா ஒரு தானினாபரின் அடையாளங்களே உட்படாதித்தாலும் மேலும் உணர்ச்சி வசாபெடுகின்றதிர் அளவில் விளைவுகள் இல்லாத்திதுநாலும் இந்த ஆய்வில் ஆபத்துக்கள் ஏதும் இல்லை.

**உதவிகள்:** இந்த ஆய்வில் பங்கேற்பதற்காக உறுதியான உதவிகள் எதுவும் வழங்கப்படவில்லை. இருப்பினும், பங்கேற்பாளர்கள் தங்கள் தனிப்பட்ட நெறிமுறையின் பகுப்பாய்விலிருந்து தங்களைப் பற்றி அறிந்து கொள்வதில் ஆர்வமாக இருந்தால், அது ஆராய்ச்சியாளர் அவர்களால் வழங்கப்படலாம்.

**இரகசியத்தன்மை:** இந்த ஆய்வில் இருந்து பெறப்பட்ட தகவலைப் பயன்படுத்தி எந்தவொரு அறிக்கையிலும் ஆராய்ச்சியாளர் உங்களைப் பெயரால் அடையாளம் காணமாட்டார், மேலும் பங்கேற்பாளராக இருக்கும் ரகசியத்தன்மை பாதுகாப்பாக இருக்கும். பதிவுகள் மற்றும் தரவின் அடுத்தடுத்த பயன்பாடு, பங்கேற்பாளரின் நம்பிக்கைய பாதுகாக்கும் நிலையான தகவல்கள் பயன்பாட்டுக் கொள்கைகளுக்கு உட்பட்டது.

ஆய்வின் அனைத்து விவரங்களும் எழுத்துப்பூர்வமாக எனக்கு வழங்கப்பட்டுள்ளது மற்றும் எனது சொந்த மொழியில் எனக்கு விளக்கப்பட்டுள்ளது. மேற்கூறிய ஆய்வைப் புரிந்துகொண்டு கேள்விகளைக் கேட்கும் வாய்ப்பைப் பெற்றுள்ளேன் என்பதை உறுதிப்படுத்துகிறேன். இந்த ஆய்வில் எனது பங்கேற்பு தன்னார்வமானது என்பதையும் எந்த நேரத்திலும் நான் திரும்பப் பெறலாம் என்பதையும் புரிந்துகொள்கிறேன். நான் பகிரும் அனைத்து தனிப்பட்ட தகவல்களும் ரகசியமாக வைக்கப்படும் என்பதையும், ஆய்வில் ஈடுபடுபவர்களைத் தவிர வேறு யாருடனும் பகிரப்படமாட்டாது என்பதையும் புரிந்துகொள்கிறேன்.

நாள்:

பங்கேற்பாளரின் கையொப்பம்:

## Socio Demographic Data Schedule

Parent Age:                      Child's Age:                      Child's Date of Birth:

Parent Gender:                      Child's Gender:

Education Qualification: Illiterate  Middle School  High School  UG  PG

Place of Residence: Urban  Semi Urban  Rural

Occupation:

Type of Family: Nuclear  Joint Family

Relationship with Child: Divorced  Single Parent  Adopted

Type of child's disorder: ASD  ADHD  DD  Communication Disorder  CP

Income: Below 5,000  5,001- 10,000  Above 10,001

How would you describe your general health?    Excellent  Good  Fair  Poor   
(for past 6 months)

How many times per week do you generally exercise? 30 Mnt.  Above 30 Mnt.  No

Are you currently under any psychiatric medication? Yes  No

Are you having any difficulties with your sleep habits? Yes  No

If yes, check where applicable:

Sleeping too little  Sleeping too much  Poor quality sleep

Sleep Disturbing

Are you having any difficulty with appetite or eating? Yes  No

If yes, check where applicable:

Eating less  Eating more  Bingeing  Restricting

Child's other behavioural problems: Sleeplessness                      Non-Eating  Restlessness

Any other medical conditions or diseases:

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## MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT

Zimet GD, Dahlem NW, Zimet SG, Farley GK., 1988

Sl. No.		Very Strongly Disagree [1] மிகவும் கடுமையாக உடன்படவில்லை	Strongly Disagree [2] கடுமையாக உடன்படவில்லை	Disagree [3] உடன்படவில்லை	Neither agree or Disagree [4] உடன்படவும் இல்லை, ஒப்புக்கொள்வதில்லை	Agree [5] ஒப்புக்கொள்கிறேன்	Strongly Agree [6] கடுமையாக ஒப்புக்கொள்கிறேன்	Very Strongly Agree [7] மிகவும் உறுதியாக ஒப்புக்கொள்கிறேன்
1	There is a special person who is around when I am in need.  <b>எனக்கு தேவைப்படும் போது ஒரு சிறப்பு நபர் இருக்கிறார்</b>							
2	There is a special person with whom I can share my joys and sorrows.  <b>என் கக துக்கங்களை பகிர்ந்து கொள்ள ஒரு தனி நபர் இருக்கிறார்.</b>							
3	My family really tries to help me.  <b>என் குடும்பத்தினர் எனக்கு உதவ முயற்சி செய்கிறார்கள்.</b>							
4	I get the emotional help and support I need from my family. <b>எனது குடும்பத்தினரிடமிருந்து எனக்கு தேவையான உணர்ச்சிபூர்வமான உதவி மற்றும் ஆதரவைப்பெறுகிறேன்.</b>							

5	<p>I have a special person who is a real source of comfort to me</p> <p><b>எனக்கு ஆறுதலளிக்கும் உண்மையான ஒரு சிறப்பு நபர் என்னிடம் இருக்கிறார்</b></p>							
6	<p>My friends really try to help me</p> <p><b>என் நண்பர்கள் உண்மையிலேயே உதவ முயற்சிக்கிறார்கள்.</b></p>							
7	<p>I can count on my friends when things go wrong</p> <p><b>விஷயங்கள் தவறாக நடக்கும்போது நான் என் நண்பர்களை நம்பலாம்</b></p>							
8	<p>I can talk about my problems with my family.</p> <p><b>எனது பிரச்சினைகளை எனது குடும்பத்தாரிடம் பேச முடியும்.</b></p>							
9	<p>I have friends with whom I can share my joys and sorrows.</p> <p><b>எனது இன்ப துன்பங்களை பகிர்ந்து கொள்ள எனக்கு நண்பர்கள் உள்ளனர்.</b></p>							
10	<p>There is a special person in my life who cares about my feelings.</p> <p><b>என் உணர்வுகளைப் பற்றி அக்கறை கொண்ட ஒரு சிறப்பு நபர் என் வாழ்க்கையில் இருக்கிறார்.</b></p>							

11	My family is willing to help me make decisions.  <b>முடிவெடுப்பதில் எனக்கு உதவ எனது குடும்பத்தினர் தயாராக உள்ளனர்.</b>							
12	I can talk about my problems with my friends.  <b>எனது பிரச்சினைகளை எனது நண்பர்களிடம் பேச முடியும்.</b>							

13. Please identify that "special person

- A. Spouse/Partner
- B. Boyfriend/Girlfriend
- C. Friend
- D. Professional (e.g., teacher, doctor, counsellor, pastor)
- E. Other family member

**13. அந்த "சிறப்பு நபரை" அடையாளம் காணவும்**

1. வாழ்க்கை துணை
2. காதலன்/காதலி
3. நண்பர்
4. தொழில்முறை (எ.கா., ஆசிரியர், மருத்துவர், ஆலோசகர், போதகர்)
5. மற்ற குடும்ப உறுப்பினர்

## Kessler Psychological Distress Scale (K10)

Kessler RC, Barker PR, Colpe LJ, Epstein JF, Gfroerer JC, Hiripi E, et al., 2003

	All of the time எல்லா நேரமும் (score 5)	Most of the time பெரும்பாலும் (score 4)	Some of the time சில நேரம் (score 3)	A little of the time சிறிது நேரம் (score 2)	None of the time எந்த நேரமும் இல்லை (score 1)
1. In the past 4 weeks, about how often did you feel tired out for no good reason? கடந்த 4 வாரங்களில், எந்த காரணமும் இல்லாமல் எத்தனை முறை சோர்வாக உணர்ந்தீர்கள்?					
2. In the past 4 weeks, about how often did you feel nervous? கடந்த 4 வாரங்களில், நீங்கள் எத்தனை முறை பதற்றமாக உணர்ந்தீர்கள்?					
3. In the past 4 weeks, about how often did you feel so nervous that nothing could calm you down? கடந்த 4 வாரங்களில், எதுவுமே உங்களை அமைதிப்படுத்த முடியாத அளவுக்கு எத்தனை முறை பதற்றமாக உணர்ந்தீர்கள்?					
4. In the past 4 weeks, about how often did you feel hopeless? கடந்த 4 வாரங்களில், எத்தனை முறை நம்பிக்கையிழந்தீர்கள்?					
5. In the past 4 weeks, about how often did you feel restless or fidgety? கடந்த 4 வாரங்களில், நீங்கள் எத்தனை முறை அமைதியின்மை அல்லது பதற்றத்தை உணர்ந்தீர்கள்?					

<p>6. In the past 4 weeks, about how often did you feel so restless you could not sit still?</p> <p>கடந்த 4 வாரங்களில், நீங்கள் அமைதியாக உட்கார முடியாத அளவுக்கு எத்தனை முறை அமைதியின்றி உணர்ந்தீர்கள்?</p>					
<p>7. In the past 4 weeks, about how often did you feel depressed?</p> <p>கடந்த 4 வாரங்களில், நீங்கள் எத்தனை முறை மனச்சோர்வடைந்தீர்கள்?</p>					
<p>8. In the past 4 weeks, about how often did you feel that everything was an effort?</p> <p>கடந்த 4 வாரங்களில், எல்லாமே முயற்சி என்று எத்தனை முறை உணர்ந்தீர்கள்?</p>					
<p>9. In the past 4 weeks, about how often did you feel so sad that nothing could cheer you up?</p> <p>கடந்த 4 வாரங்களில், எதுவுமே உங்களை உற்சாகப்படுத்த முடியாத அளவுக்கு எத்தனை முறை வருத்தப்பட்டீர்கள்?</p>					
<p>10. In the past 4 weeks, about how often did you feel worthless?</p> <p>கடந்த 4 வாரங்களில், எத்தனை முறை நீங்கள் மதிப்பற்றவர்களாக உணர்ந்தீர்கள்?</p>					