

CHAPTER I

INTRODUCTION

In India, pregnancy is traditionally celebrated with immense joy, as it symbolizes blessings and the continuation of family lineage. Families look forward to the birth of a child with great anticipation, imagining a bright and promising future. Parents and families may encounter feelings of shock, denial, sadness, guilt, and grief when the child grows up with certain challenges, with any physical or mental impairments, disorders, or disabilities like cerebral palsy, ADHD, and autism, being one important disorder, turning the joyous journey quickly into an emotionally complex experience. This is not only due to the diagnosis itself but also due to the loss of expected hopes for the child's future. This grief is often intensified by societal stigma, cultural misconceptions, and a lack of awareness, which in some cases leads to blame being directed at the parents, particularly mothers, or attributing the condition to karma or past wrongdoings (Daley, 2004). According to Hyman *et al.*, (2020), children are the most precious gift, and they build the future of our society. Therefore, it is imperative to support their social-emotional, linguistic, and cognitive growth with the major pre-requisite skills that are necessary for their daily life. Parents of autistic children should strive to improve their understanding of their child's condition, as this knowledge enables them to offer more effective support with a positive and empathetic attitude. With greater awareness, they can also encourage and guide their child toward developing independence and self-confidence.

According to WHO (2023), Autism spectrum disorder (ASD) is a neurodevelopmental disorder that can affect how a person interacts with others, communicates, learns, and behaves. The term "autism" was first introduced in 1911 by Swiss psychiatrist Eugen Bleuler. However, it wasn't until the 1940s that the condition began to be more thoroughly understood. In 1943, Dr. Leo Kanner, while working at Johns Hopkins University, encountered a boy named Donald who displayed an extraordinary memory but struggled with typical social interaction and communication. This encounter led Kanner to identify a pattern among several children who shared similar traits like intense inward focus and significant challenges in social behaviour, communication, and adaptability. He termed this condition "Early Infantile Autism". Since then, the understanding and classification of ASD have evolved significantly. Today, it is recognised as Autism Spectrum Disorder (ASD), reflecting a wide range of manifestations. This evolution has been influenced by a

variety of forces, including scientific research, shifting political attitudes, media portrayals, clinical practices, parental advocacy, and commercial interests, and the journey of understanding ASD continues to unfold.

Definition of autism

According to the WHO (2023), Autism spectrum disorders (ASD) are a diverse group of conditions. They are characterised by some degree of difficulty with social interaction and communication. Other characteristics are atypical patterns of activities and behaviours, such as difficulty with transition from one activity to another, a focus on details, and unusual reactions to sensations.

According to the National Institute of Mental Health (2024), Autism spectrum disorder is a neurological and developmental disorder that affects children's learning and behaviour. Although autism can be diagnosed at any age, it is described as a "developmental disorder" because symptoms generally appear in the first two years of life.

According to the Centers for Disease Control and Prevention (CDC) in 2024, Individuals with ASD commonly experience challenges in social communication and interaction, along with engaging in repetitive behaviours or having highly focused interests. They may also process information, move, or concentrate in ways that differ from others. These symptoms typically emerge in early childhood, though they may not be fully noticeable until social demands surpass the individual's coping abilities or may be concealed by compensatory strategies developed over time (American Psychiatric Association, DSM-5, 2013).

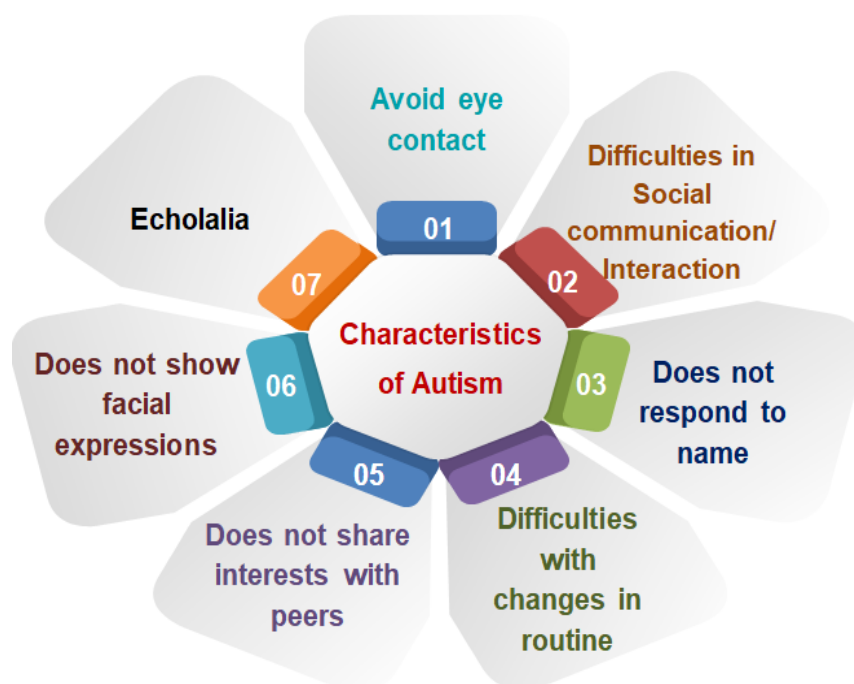
People with autism may have problems with how to cope up with change, reacting to stories, and having imagination. Different children on the spectrum exhibit different strengths and difficulties and therefore need different approaches, but universally it is agreed that children on the spectrum should be educated as early as possible and their skills should be nurtured (Kurzrok, 2021). However, these cannot work if the parents do not cooperate, since they are the main caregivers and early sensitization enablers. The two scientific findings that support the idea that early development is impacted by the onset of ASD are genetic and environmental factors (WHO, 2023). At this period, a child's growing brain is extremely malleable and adaptable due to billions of interconnected neurons. ASD mostly arises in the age of two years and is considered a dysfunctional neural development that includes symptoms (Asperger Syndrome) of recurrent

monotonous behaviours, retarded language, struggling to recognise names, limited interests, and difficulties with social contact (Mohammed, 2024). In 1926, a Soviet physician named Dr. Sucharewa became the first person to document autism (Sher DA and Gibson, 2023). It is quite frequent in men and prematurely conceived babies, and there is a strong genetic association between autism and fragile X syndrome.

According to Iida et.al, (2018), the term “spectrum” focuses on the broad pattern of features of the disorder, and the severity of which might differ in different individuals. ASD impacts at least millions of people around the world in remarkable ways in which they relate to other people, how they process information in their environment, as well as how they undertake their daily activities. Although the causes of these disorders have not been fully unraveled, it has been postulated that genetic, neurological, and environmental factors could somehow cause them.

Characteristics of Autism Spectrum Disorder (ASD)

The term ‘spectrum’ stresses that there are quite diverse differences in individuals with autism, from mild symptoms to severe ones. Each person with ASD may experience difficulty in interpreting information from the atmosphere, like gestures, accents, and expressions (Abdel Maboud *et al.*, 2018). Though the characteristics are the same for all autistic children, the expressions are different, making each child unique. Hence, this disorder is more complicated and challenging for parents. Below are some key and commonly observed characteristics in children with autism.



- **Avoid eye contact**

Autistic children may avoid eye contact due to sensory sensitivities, discomfort, or difficulty interpreting social cues. For many, making eye contact can be overwhelming or distracting, and avoiding it can help them focus better during interactions according to American Psychiatric Association (2013) avoiding eye contact is not an intentional behaviour rather is a general mannerism of children with autism reflecting neurological differences.

- **Difficulties in social communication/ interaction**

Children with Autism often face challenges in social communication and interaction. Due to these challenges, they have difficulties in understanding and responding to social cues, such as body language, tone of voice and facial expressions. According to American Psychiatric Association (2013), children may struggle to maintain conversations, take turns while speaking and understanding others' emotions. For example, children with ASD may talk about a favourite topic without noticing the listener's interest level. These challenges are key features of an autistic child that can vary in severity.

- **Does not respond to name**

According to Lord *et al.*, (2006), autistic children may not respond to their name. This can happen because children with autism have difference in social attention or sensory processing which makes it hard for the child to make out that someone is calling them by their name. Example, a child may continue playing without turning their head when called, repeatedly. This lack of response is often an early indicator of autism among children.

- **Difficulties with changes in routine**

American Psychiatric Association (2013), states that children with autism mostly prefer structured and familiar environments because it helps them not be anxious and feel safe. Disruption in their routine, daily schedule or changed teacher or unexpected visitor makes autistic children distressed and anxious. For example, child, who is used to sitting in the same place or seat every day, may become upset if someone else takes that place.

- **Does not share interests with peers**

According to American Psychiatric Association (2013), Mundy and Sigman (2006), children with autism has the difficulty in sharing interests, emotions or doing any activity with others, specially with peers. They usually are deficit in social, emotional reciprocity and joint attention skills that typically developing children use to connect with others. For example, while a neurotypical child might bring his or her favorite toy alone not showing to others. This is not due to lack of interest in others but rather a difficulty in understanding how to involve others in their experience or how to read social cues. These challenges make harder for children with autism to build friendship.

- **Does not show facial expressions**

Children with autism may show limited facial responsiveness or may not use typical expressions such as smiling or showing surprise expression. These challenges often linked to non-verbal communication, social and emotional reciprocity. For example, normal children make eye contact and show facial expressions like making eye contact, smiling while taking gift, but at the same time children with autism will take the gift without showing any facial expression. This lack of expressive facial behavior can make others to interpret the child's emotions, which may sometimes lead to misunderstanding in social situations.

- **Echolalia**

Echolalia is a common speech characteristic observed in many autistic individuals, particularly children. It involves the repetition of words, phrases, or sentences that the child has heard, either immediately (immediate echolalia) or after a delay (delayed echolalia). While echolalia was once considered non-functional or meaningless, research now shows it can serve important purposes in communication, such as expressing needs, practicing language, or self-regulation (Prizant and Rydell, 1984). In autism, echolalia may affect communication by making it harder for others to understand the child's intentions, especially if the repeated speech doesn't match the context. For example, a child might say, "Do you want a cookie?" when they mean they want a cookie themselves, repeating what others typically say in that situation. Though it may seem confusing, echolalia can be a developmental step toward more independent and meaningful language use.

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (2013), traits of autism spectrum disorder (ASD) are not consistent across all individuals

or situations, and may fluctuate over time, making daily life and social functioning particularly challenging.

According to Alshehri (2022), autistic individuals often exhibit RRBs (restricted and repetitive behaviours), which can be defined in several ways and which are characteristic of autism. These may include the following, among others: hand flapping or rocking, and an insistence on sameness. Any alterations in the daily or physical environment can cause a great deal of discomfort and stress in people with ASD. Furthermore, they may develop special interests in certain subjects or objects, and get very knowledgeable about them. On the one hand, these interests may be a source of power; on the other hand, they may become a weakness because of rigidity in new situations.

According to the National Center on Birth Defects and Developmental Disabilities and the Centers for Disease Control and Prevention (CDC, 2022), children with autism often experience a typical sensory processing, which can significantly influence them to do their daily activities and behaviour. Children with autism show hypersensitivity or hyposensitivity to sensory stimuli like sharp light, sound, smell and touch. For example, a child may experience distress or even a meltdown in a noisy environment due to auditory sensitivity. Some children with ASD may seek out sensory input by engaging in behaviours like spinning, jumping, or touching objects. Ghallab *et al.*, (2024) emphasises that intelligence levels in autistic individuals can range widely, from below average to exceptionally high. They can be extremely talented in music and arts and exceptionally good at math, while, performing poorly in other academic subjects. This unsteady cognitive expression can make educational demands challenging.

Prevalence of autism

The latest research that came out in 2023 from the CDC showed that one in 36 children was diagnosed with autism. The report, when released, stated that the data would likely stay the same through 2024. Previously, the CDC in 2022 reported that 1 in 44 children were identified with ASD, indicating a decreased prevalence in 2023-2024. According to the World Health Organisation, 1 in 100 children is affected by this disorder globally. It stated that it is 4 times more common in boys than in girls (Zeidan *et al.*, 2022). WHO in 2018-19 estimated that 1 in 160 children worldwide (or 62.5 per 10,000) were documented with ASD. The Centers for Disease Control and Prevention (2020) professional sensitizations for the children with autism, reported that 1 in 54 children were diagnosed with ASD. The

statistics on the prevalence of autism globally, according to the CDC, show a gradual decline.

The prevalence rate in India showed that every 1 in 100 children below 10 years has autism (Seher, 2022). Arora, Nair, and Gulati, *et al.*, (2018), discussed prevalence rates of autism in India, stating that it was 1 in 125 children between 2-6 years of age and one in 80 among children in 6-9 years, and the overall prevalence was estimated to be 1 in 89. The occurrence of Autism in India has shown a rising trend over recent years. A study published in the Indian Journal of Pediatrics during 2021 estimates that, approximately 1 in every 68 children in the country is affected by Autism. The condition is more frequently diagnosed in boys than in girls, with a male-to-female ratio of about 3 to 1.

India, currently the most populous country in the world, has a significant proportion of its population, nearly one-third under the age of 15. It is estimated that approximately 2 million individuals in India may have some form of Autism Spectrum Disorder (ASD). Chauhan *et al.* in their study in 2019 stated that, most published studies on ASD in India rely on hospital-based data, which may not accurately reflect the true prevalence of the disorder in the broader community due to the underutilisation of standardised autism diagnostic tools and delays in early diagnosis.

With regard to the prevalence in Tamil Nadu, ASD is recognised widely. However, there is no ample study based on incidence of autism specifically in Coimbatore. A study in Tamil Nadu indicated 1.3% of autism prevalent in children aged 16 to 30 months based on the clinical data that may not provide a wider population cover (Panchanathan *et al.*, 2023). A case control study in Coimbatore did not show the incidence of ASD however identified risk factors for ASD like increased paternal age and perinatal complications (Pradeep *et al.*, 2021). National estimates indicate a community prevalence of around 0.15% among children aged 1 to 10 years, which may be reflective of Tamil Nadu as well (Raina *et al.*, 2017). These findings suggest that while clinical identification of ASD is increasing in Tamil Nadu, there is a critical need for more representative, large-scale, community-based prevalence studies, especially in urban areas like Coimbatore.

Karimi *et al.*, (2017) stated, ASD may be affected by genetic and environmental etiology; besides this, what causes its development is a matter of debate. It has been found that a child is at higher risk of suffering from autism when there was exposure of the mother to excessive radiation, frequent vomiting during pregnancy, abnormal weight gain,

and diabetes. According to the latest studies, the age of parents has been found indirect correlation with the chance for ASD in their children (Francis *et al.*, 2021).

Guy (2021) deliberates that, even after a lot of research, the primary causes of autism are still unknown, and therefore, it is hard to identify specific ways of preventing it. ASD is thought to be caused by a combination of genetic and environmental factors, and though prevention is not always possible, various strategies seek to minimise possible causes of ASD. The heritability of autism is beyond doubt. Many researchers have also pointed out that specific genes can predispose a particular person to ASD. It is impossible to alter the genetic makeup, but it is possible to identify the genetic risk and make an early sensitization. In families with an increased risk of autism, genetic counseling is helpful, enabling the parents to know the chances of passing on genes related to autism, and may assist in early management in case of this disorder.

Environmental factors are regarded as the other major cause of autism. There is no known environmental cause of autism, but studies have shown that certain chemicals and toxins can raise the risk of the condition during pregnancy and early childhood. These environmental risks can be prevented to some extent, although it does not mean that autism will be prevented.

Role of parents

Parenting is a fundamental and demanding responsibility that requires guiding children through various developmental stages to support their physical, emotional, and cognitive growth. Effective parenting involves adapting strategies to meet the changing needs of the child at each stage of development. When a child has a disability, the parenting experience becomes significantly more complex. Parents of children with disabilities often encounter additional challenges and must navigate environments that may not be fully inclusive or responsive to their child's specific needs (American Psychological Association, 2020).

Autistic children often struggle with tasks related to personal hygiene, eating, dressing, toileting, and transitioning between activities due to difficulties with sensory processing, communication, and executive functioning. Parents and care givers must address these challenges by gaining necessary knowledge and techniques to teach pre-requisite skills effectively. Pre-requisite skills such as scheduling, imitation, attention, and basic communication form the foundation for learning more complex daily living tasks.

Without understanding and applying these foundational techniques, parents may struggle to effectively teach or rehabilitate these skills in their children. Consistent reinforcement and positive encouragement are also key strategies in promoting independence and reducing behavioural frustration (Karst and Van Hecke, 2012).

Woodgate, Ateah, and Secco (2008) highlight that hands-on guidance from parents and family members helps children with autism build self-efficacy and independence in daily living skills, ultimately improving their long-term outcomes and quality of life. However, it is important to recognise that the caregiving role is demanding and can lead to significant emotional and physical stress for parents. Therefore, parents should be encouraged to seek supportive networks, professional guidance, and opportunities for respite care to avoid burnout and maintain their ability to care effectively.

Pre-requisite skills

Parents of children with ASD, often imagine a future where their child can live independently, secure employment, and engage meaningfully in society. Yet, achieving such milestones remains challenging. Research shows that only around 6% of adults with autism are employed in any capacity, and even fewer work full-time or earn competitive wages (Anderson *et al.*, 2021). This troubling statistic highlights the gap in transition planning and vocational readiness among autistic youth. Despite the availability of vocational training in many educational settings, many children with ASD are unable to fully benefit from these opportunities due to a lack of pre-requisite skills. These include essential competencies such as basic communication, daily living abilities, emotional regulation, and job preparedness, all of which are necessary to thrive in a work environment.

Developing pre-vocational and life skills must begin early in life, as children with autism often need extended time and individualised interventions to acquire these competencies effectively (Wehman *et al.*, 2014). Importantly, children must learn adaptive skills such as handling change, managing anxiety, and communicating effectively along with the job skills.

Pre-requisite skills are a set of skills that are acquired before moving to learn more advanced skills. Pre-requisite skills are different from functional skills and self-help skills. Functional skills and self-help skills are interrelated, where functional skills are a broad range of skills that help children navigate daily life. They are also known as skills for

activities of daily life. Self-help skills are skills that help people care for themselves and manage their needs, example- eating, dressing, and personal hygiene (Wehman *et al.*, 2018). For children with autism spectrum disorder (ASD), these foundational competencies are vital for engaging with their environment and progressing in educational and social contexts. Parenting a child with autism goes beyond emotional nurturing; it also involves promoting the development of key life skills that aid in communication, self-regulation, and learning (Lai, 2013). Core pre-requisites often include cognitive, emotional, social, and physical capabilities that set the stage for future learning. For example, a child with ASD may first need to learn to express needs through spoken language, sign language, or assistive communication devices.

Scheduling, Attention, Socialisation, Communication, Self-control, Imitation, Self-advocacy, and Safety are several important dimensions of pre-requisite skills that support the development of independence in children with autism (Dundon, 2019). These foundational abilities are essential for autistic individuals to not only secure employment but also to maintain and sustain meaningful work throughout their lives (Hong *et al.*, 2018). One important dimension is **scheduling**, which helps children build routine and reduce anxiety (Shook, 2020). Similarly, **attention** is vital for learning, communication, and interaction (Murray *et al.*, 2005).

Socialisation skills, including making friends and understanding social cues, are also often impaired in autistic children (White *et al.*, 2007). **Self-control** plays a key role in helping children regulate emotions and behaviour (Mazefsky *et al.*, 2013).

Another vital domain is **imitation**, which supports the learning of new behaviours through observation (Murray, 2012). As children grow, **self-advocacy** becomes essential, enabling them to express their preferences, make decisions, and participate in their care (Advanced Autism Services, 2025). Lastly, **safety** awareness is critical, as children with autism may lack instinctual responses to danger (Ordaz-Villegas, 2019). Collectively, these skills are foundational in helping children with autism lead safer, more independent, and socially integrated lives and long-term outcomes. According to the Individuals with Disabilities Education Act (IDEA, 2004), preparing children with disabilities for "further education, employment, and independent living" is a fundamental objective. Mastery of pre-requisite skills sets the stage for achieving this goal. Parents recognising, nurturing, and reinforcing these foundational abilities of prerequisite skills they help their children gain confidence and competence in daily routines. In essence, focusing on pre-requisite

skills is not just about early childhood development; it's about empowering children with autism to lead more independent, fulfilling lives.

Parents' Knowledge, Attitude, and Practices (KAP) on Pre-requisite Skills

Understanding and assessing Knowledge, Attitude, and Practices (KAP) among parents of children with autism is essential, as these components collectively influence how a parent perceives, reacts to, and supports their child's development. KAP aims to uncover what individuals know (knowledge), believe (attitudes), and do (practices) within a specific context.

Parents are not only front liners in care giving; they are the emotional anchors, and often the strongest advocates for their children. These significant roles of parents obligate them to gain appropriate knowledge regarding the developmental needs of autistic children, particularly pre-requisite skills such as communication, self-care, social engagement, and behavioural regulation. These skills allow children to function independently at home, school, and in the broader community. However, knowledge alone is not enough. Attitude plays a critical role in determining how that knowledge is applied. A parent's attitude is shaped by their perceptions, which in turn are influenced by personal beliefs, cultural norms, and societal expectations. These attitudes can either enhance or hinder the caregiving process (Fayız, 2023).

Attitudes greatly affect parents' motivation to seek help and persevere through challenges. Research by Fields (2018) emphasises that self-acceptance of the diagnosis and optimism about the child's future are closely associated with increased participation in therapeutic programmes. These parents are more likely to engage in problem-solving, remain resilient in the face of setbacks, and actively pursue beneficial opportunities for their children. Conversely, attitudes rooted in hopelessness or shame can impair responsiveness to interventions and reduce the overall quality of parental support.

Ultimately, it is the practices, the concrete actions taken by parents, have the most direct impact on the child's development. Practices like caregiving routines, therapeutic involvement, use of structured teaching strategies, and behaviour management often are guided by the parents' level of knowledge and shaped by their attitudes.

Importantly, parents' practices are linked to positive developmental outcomes, including improvements in language, social interaction, and adaptive behaviour (Estes *et al.*, 2014). However, it must be acknowledged that parenting a child with autism can be

emotionally, physically, and financially taxing. Numerous studies have documented that parents of autistic children report higher levels of stress, anxiety, and depression compared to those of neurotypical children (Hayes and Watson, 2013).

Therefore, supporting parents is not just a matter of compassion but a strategic approach to strengthen the child's developmental trajectory. According to Woodgate, Ateah, and Secco (2008), empowering parents enhances their ability to advocate for services, navigate complex healthcare and educational systems, and challenge societal stigma.

In conclusion, the knowledge, attitudes, and practices of parents of autistic children are deeply interconnected. Their knowledge helps them understand autism; their attitudes shape their emotional and behavioural responses; and their practices determine the day-to-day support that the child receives. Fostering positive development in autistic children requires a holistic focus on all three aspects of KAP, as they form the foundation for informed caregiving, effective intervention, and ultimately, better outcomes for both the child and the family.

Mental Health (MH) and Self-efficacy (SE) of Parents of Children with Autism

Mental health refers to an individual's emotional, psychological, and social well-being, reflecting how effectively they handle stress, relate to others, and make choices. In contrast, self-efficacy is the belief in one's ability to successfully manage specific tasks or situations. While mental health indicates how well a person copes with life's demands, self-efficacy represents the confidence they have in their capacity to face and overcome those challenges. The parents of children with autism have a special status, and their mental health is an important area of research. Gibson (2022) says that, '*if you've met one child with autism, you've met one child with autism*' (attributed to advocate Stephen Shore). This uniqueness and complexity make parents ambiguous of how to respond leading them to quest for various sources of information.

Self-efficacy is a belief in a person's ability. Albert Bandura (1977) defined it as a person's expectation of his or her capabilities to achieve specific results. Concerning the parenting of children with ASD, self-efficacy is the key factor that defines parents' reactions to the encountered difficulties. It includes the extent to which parents are confident about their capacity to address the child's needs, put into practice the strategies, and negotiate the autism repertoire. Parents of children with autism may experience self-

efficacy threats that are not common among other parents (Fields, 2006). These are: learning about autism, handling behavioural problems, getting the right services, and working with other people who are involved in the care of the child. High self-efficacy enhances the parents' motivation to participate in the development of their child, and in this way, the child and the family benefit from it.

Parents of children with autism often encounter significant emotional and practical challenges. Emotionally, they may struggle with feelings of stress, guilt, sadness, and grief as they come to terms with their child's diagnosis and the lasting impact it may have on their lives. These emotional challenges can contribute to isolation and a reduced sense of efficacy in their parenting role. Mothers, who frequently bear the primary responsibility for caregiving, may face adverse effects on their mental health, social life, and employment opportunities. Mothers often internalize guilt, blaming themselves for not taking proper care during pregnancy or for their child's condition, even when there is no scientific basis for such beliefs. Constantly preoccupied with their child's development, therapies, and future, many parents tend to neglect their own emotional and physical well-being. They carry the burden of caregiving like an invisible weight, often forgetting to care for themselves. On the other side, daily routines may need to be adjusted to accommodate frequent therapy sessions, medical appointments, and special education services. Homes may also require modifications, such as sensory-friendly spaces or adaptive equipment. Financial strain is another common concern, as the costs associated with autism-related therapies, medical care, and specialised interventions can be substantial. Many families must seek financial assistance and navigate complex healthcare and insurance systems to ensure their child receives the necessary support (Hayes and Watson, 2013).

Parents of children with autism often experience loneliness, social isolation, and anxiety due to societal misunderstandings and stigma, which can lead to depression, strained relationships, and concerns about their child's future independence and social integration (Clarke *et al.*, 2022). Cultural and familial pressures may further intensify stress, sometimes resulting in marital conflict or poor mental health. A parent's mental well-being plays a vital role in how effectively they can support and interact with their child, as noted by Kurzrok (2021). Promoting parental self-efficacy through education, therapy, and support groups can empower caregivers, improve coping skills, and enhance outcomes for both parent and child. Increased autism awareness and timely intervention

are essential, as they enable parents to better understand their child's needs, manage challenging behaviours, and navigate available support systems, thereby reducing feelings of helplessness and fostering confidence in their caregiving roles. Effective strategies such as parent training, counseling, and peer support not only provide practical tools but also offer emotional reinforcement, ultimately enhancing parental self-efficacy and overall well-being (Kuhn and Carter, 2006).

Sensitization and intervention

Sensitization and intervention are both important components in promoting awareness and support, especially in contexts such as health, education, and disability services, but they serve distinctly different purposes. Sensitization refers to the process of raising awareness and improving understanding about a particular issue among individuals or groups. Its primary goal is to inform, shape perceptions, and promote positive attitudes. In contrast, intervention is a more targeted and action-oriented process aimed at addressing specific problems or challenges. It involves structured strategies, therapies, or programs designed to improve outcomes. While sensitization focuses on changing knowledge and attitudes, intervention focuses on changing behaviours and delivering support. In essence, sensitization lays the groundwork for understanding and openness, whereas intervention builds on that foundation to bring about measurable change. Both are necessary, while sensitization fosters acceptance and readiness, and intervention delivers direct help and improvement.

Parents are overwhelmed with stress due to parental responsibilities, lack of knowledge regarding the condition, and isolation. The challenges laid the basis of sensitization programmes for parents since they ensure that parents manage the challenges appropriately. Such programs help parents to have strategies, knowledge, and emotional capacity that will enable them to foster the development of the child as well as protect him or her.

Smile Foundation (2024) mentioned that parents are the first and most important teachers in a child's life. Even before children step into a classroom, they learn by observing and interacting with their parents, who provide guidance, support, and a safe space to grow. The values, behaviours, and skills that children pick up from their parents during these early years stay with them for life and shape their personality. Alongside parents, plays a vital role in a child's learning. Teaching pre-requisite skills to the children

provides the social environment where children develop friendships, learn societal norms, and build their identity.

Parents play a key role in raising their children, regardless of their financial or social background. For educating parents about pre-requisite skills to be truly effective, there needs to be strong collaboration between parents, communities, and schools. **Jelić and Stojković, (2021)** mentioned that when parents and children work together, children receive consistent support both at home and in their surroundings. Schools can create a sensitization programme by involving parents and children in educational activities and equipping them with the tools to support children's learning. These collaborations lead to better family and community involvement, improved teaching practices, and greater accountability in education. By working together, schools and parents can create a supportive environment where children thrive and reach their full potential.

The first goal of any sensitization programme is to ensure that parents are informed of the condition, which for many of them is a new experience when their child is diagnosed with autism. In some cases, parents themselves do not know everything about autism, about its features, about what helps deal with the consequences. The nature of autism and the range of severity of the condition mean that there is a lot of depth and detail to understanding how best to address behaviours such as communication impairments, sensitivity to certain stimuli, or social interaction issues. Sensitization programmes provide parents with complete details about the condition, from the definition of autism, the fundamental aspects of the disorder, to the individual needs of the child (Ajeely, 2023). There is also another significant area of necessity for sensitization programmes, which is to enhance the quality of parenting practices. Caring for a child with autism may entail using methods that are quite distinct from those used in normal child rearing. Parents may have problems with the child's behaviour, tantrums, or problems with speech development, which makes them stressed, bewildered, or powerless (Karst and Van Hecke 2012).

Care for children with Autism Spectrum Disorder (ASD) is limited in India due to the following gaps: High cost of social care provisions, the sensitizations that are available in India are very expensive and most often unaffordable to the majority of the population in India. Quality sensitization for Autism is limited and restricted to the metros in India (Dorsett, 2015). The rich and the connected get appropriate care. Now, in the present scenario in Educating children in India about ASD, there is a huge disparity between

treatment for families in poverty who have a person with ASD and treatment and sensitization for affluent families.

Secondly, Societal causes like lack of awareness, stigma, illiteracy, religious practices, geographical location, blame on mothers, poverty, and finally, the professional's lack of training are also major deterrents in early sensitization and treatment. Many families in India go through a tough time seeking a diagnosis. Doctors are the prime sources for diagnosis, who often fail to diagnose or refer during the early stages of the child's life. Most parents in India silently watch their children suffer and leave the world without a solution to the struggles and challenges faced by their children with Autism. Many families are struggling with a diagnosis of autism spectrum disorder in India. There are two factors that are very stressful for the families of low-income groups: lack of appropriate knowledge and access to resources (Dorsett, 2015).

Dunst *et al.*, (2016) stated that sensitization programs educate parents on how to use these challenges to address them effectively using empirically supported strategies. For example, programs emphasise such aspects as parents are encouraged to learn that it is right to reward good behaviour rather than punishing bad behaviour. They also familiarize parents with the use of schedules and visual timetables, which are helpful to children with autism, as they like structure and clear instructions. It helps parents to be in a position to help their child develop while at the same time helping in reducing the stress that is likely to be incurred while performing the daily care giving activities.

Theoretical perspective on the education of parents of autistic children

Theoretical perspectives on training parents of autistic children emphasizing educational approaches to autism treatment, highlight effective parenting.

Parents play a central and influential role in the development and well-being of children with Autism Spectrum Disorder (ASD) by applying a range of evidence-based approaches tailored to their child's unique needs. One such approach is the *Theory of Mind (ToM)*, which focuses on helping children recognise that others have different thoughts, feelings, and perspectives. Activities like emotional labeling, perspective-taking conversations, and pretend play, parents can foster their child's social understanding and empathy (Wellman, 2018). *Applied Behaviour Analysis (ABA)* is a method that empowers parents to improve communication, social interaction, and reduce problematic behaviours by using structured and consistent reinforcement strategies. With professional

guidance, parents can integrate ABA techniques into daily routines to create a predictable and supportive learning environment (Leaf *et al.*, 2016). The *Developmental Social Pragmatic (DSP)* model emphasises natural, relationship-based interactions that promote shared attention, emotional connection, and turn-taking. By following their child's lead and responding to their interests during everyday activities, parents can nurture spontaneous communication and motivation to interact (Prizant *et al.*, 2006). *Cognitive Behavioural Therapy (CBT)* supports emotional and behavioural regulation, helping children identify and reframe negative thoughts while learning coping mechanisms for anxiety and stress. Parents trained in CBT techniques can reinforce these skills at home, modeling emotional regulation and guiding their child through structured problem-solving (Wood *et al.*, 2009). Additionally, Bronfenbrenner's *Ecological Systems Theory* underscores the importance of broader environmental influences family, school, community, and culture, on child development. Parents are key agents within these systems, and their involvement in building strong relationships with educators, advocating for inclusive settings, and accessing culturally sensitive support services can significantly enhance their child's developmental outcomes (Bronfenbrenner, 1979). Overall, when parents are provided with training, emotional support, and practical tools across these models, they become empowered to better support their child's growth, leading to improved social, emotional, and cognitive functioning and a more resilient family dynamic.

Rationale of the study

Children with autism need assistance from their parents or caretakers in performing daily living skills such as bathing, brushing, dressing, taking a meal, doing household chores, laundry, taking medicine, managing money, etc. (Cho and Kahng, 2015; Ministry of Health and Welfare [MOHW] and Korea Institute for Health and Social Affairs [KIHASA], 2011). Also, it is well understood that autistic children have impaired social skills; they are unwilling to make eye contact and have difficulty making friends. They also have difficulty in understanding other people around them and do not share their emotions with others (Research Autism, 2017), making pre-requisite skills an important aspect.

However, parents, as the primary caregivers, play an important role in dealing with the issues associated with their autistic child and also maintain the household chores. Parents of children with autism also have time constraints to take care of themselves as

individuals (Ravindranadan and Raju, 2008) and the other family members, including their typically developing children and spouse. This is due to the extra amount of time that parents require in taking care of their autistic child's needs (Sawyer *et al.*, 2010). These place a set of extra demands, challenges, and burdens in their life.

In addition, children with autism often have problems in transferring a learnt skill from one setting to another setting, place, or time. These processes of generalisation of learning needs are to be anticipated and supported. Therefore, parents of children with autism need to be more closely involved in the educational process of teaching pre-requisite skills. But it is difficult and strenuous for parents to care for their autistic children and keep them safe from harm throughout the day. It is important that parents learn the techniques of teaching skills that are required in the day-to-day life as well as managing the maladaptive behaviours of their autistic child (National Research Council, 2001).

Raising awareness about autism in Tamil Nadu, particularly in urban hubs like Coimbatore, is essential due to various interlinked social, service-related, and cultural factors. In many parts of Tamil Nadu, public awareness of autism remains low, often leading to the denial or late recognition of early signs, especially in girls, due to stigma and misunderstanding (The Times of India, 2022). In Coimbatore, parents have reported facing significant social stigma that prevents them from accessing timely diagnosis and support services for their children. Moreover, an article published by The Times of India (2022) highlights lack of awareness results in delays in early detection, which is critical for improving long-term developmental outcomes. Although Tamil Nadu's health insurance scheme provides coverage of up to 1 lakh per year for autism therapy, only a few families in Coimbatore have benefited, highlighting a serious gap in outreach and service utilisation. Therefore, raising autism awareness is vital to reducing stigma, encouraging early diagnosis, improving access to professional support, and building a more inclusive and supportive environment for children with autism and their families.

Autism affects the health of the whole family and also creates a significant long-term economic burden to society (Rosanaff *et al.*, 2015). It is important to address this issue in India, as this is a hidden epidemic. When reviewing the global scenario concerning ASD, it is evident that India still needs action-oriented research in areas of institutionalized persons with ASD. There is high inequality in providing care, particularly to the disadvantaged families in India. Therefore, there is a need to educate the parents of children with autism about the importance of pre-requisite skills and to train them on the

techniques of teaching pre-requisite skills to their autistic child to enable their child to live more independently and leading to a better adulthood. It will also help their children in reducing their problematic behaviours and facilitate them towards being self-reliant at home, school, and community, as well as lessen the burden on parents and caregivers, thereby improving the quality of family life.

Additionally, Parents of children with autism often face numerous challenges that significantly impact their mental health and sense of self-efficacy. Many experience stress, anxiety, and even depression due to the emotional, financial, and social demands of caregiving. When parents lack adequate knowledge about autism, they may struggle to access appropriate interventions and support services. Moreover, if their attitudes do not evolve to accept their child's condition, it becomes harder for them to engage effectively in their child's development. Low self-efficacy can lead to inconsistent practices and reduced involvement in teaching necessary life skills at home. Therefore, addressing parents' mental health and building their confidence is not only essential for their well-being but also crucial for the child's progress. Empowered and informed parents are better equipped to support their children with patience, positivity, and resilience. Eventually, this will help the autistic children generate better employment opportunities, thereby becoming successful adults.

Scope of the study

This study focuses on training parents to teach pre-requisite skills that increase their confidence and ability to reinforce learning consistently at home, which enhances their child's chances of acquiring and generalising the skills across settings. Parental involvement also promotes continuity between home and educational or therapeutic environments, resulting in more meaningful and sustained developmental progress (Li *et al.*, 2023). Furthermore, when children learn to express needs, follow instructions, and engage in appropriate behaviours, problem behaviours decrease and independence increases. This not only improves the child's overall quality of life but also strengthens the parent-child bond. Over time, it reduces the family's reliance on professional interventions and increases opportunities for autistic individuals to access education, employment, and social inclusion, ultimately enabling them to lead more independent and fulfilling lives.

Additionally, this study aims to explore the critical importance of improving mental health and self-efficacy among parents of children with autism. Given the

substantial emotional, financial, and social pressures they face, parents often report poor mental well-being and low confidence in managing their child's needs. These challenges can hinder their ability to access appropriate support services, accept their child's diagnosis, and effectively engage in day-to-day caregiving. By focusing on strategies to enhance parental mental health and build positive self-efficacy, this study seeks to highlight how these improvements can lead to better outcomes not only for the child's development but also for the parents' overall quality of life. Empowered, knowledgeable, and emotionally resilient parents are more capable of creating supportive home environments and ensuring their long-term well-being. Thus, addressing these areas is essential for fostering healthier families and more sustainable caregiving.

Research gap

In India, lack of resources and lack of awareness are the two major restraints, and it leaves a huge scar on the existing population of ASD who are transitioning into adults with low cognitive capacities and fewer job skills, which are crucial for successful social and economic inclusion for persons with ASD. Most parents in India silently watch their children suffer and leave the world without a solution to the struggles and challenges faced by their children with autism. Many families are struggling with a diagnosis of autism spectrum disorder in India.

Most existing studies on autism interventions have primarily focused on children rather than parents, resulting in limited evidence on parental involvement. Research has largely emphasised training children in self-help or functional skills, with little attention given to pre-requisite skills. In earlier studies where parents were involved, the focus tended to be on caregiving strategies rather than enhancing their knowledge, attitude, and practices (KAP) regarding pre-requisite skills. Additionally, while existing research often emphasises the poor mental health status of parents, there is limited exploration into how they can actively care for their well-being and develop positive self-efficacy. Supporting parents in managing their mental health is crucial, as a positive mindset enables them to accept their child's condition more openly and engage in learning and teaching essential pre-requisite skills at home. There is not much action-based scientific research on the caregivers' early sensitization of the autism spectrum in India. So, this research will contribute to bridging this gap.

Statement of problem

Having a child with a severe disability significantly impacts the entire family system (Powers, 1991). In particular, parenting a child with autism presents unique challenges due to core symptoms such as communication deficits, difficulties with social interaction, rigid and repetitive behaviours, and resistance to change (Ludlow *et al.*, 2012). These behaviours often lead to increased stress among family members, affect sibling relationships, and reduce the perceived support available to the family (Mount and Dillon, 2014). Few significant features determine how families manage and support their child with autism:

Parental knowledge: Understanding a child with ASD is vital for parents to care and support efficiently. Parents who are well-informed are better prepared to seek appropriate treatments and make necessary decisions for their child (Ludlow, Skelly, and Rohleder, 2012). Enhanced parental knowledge about prerequisite skills for autistic children makes them more proactive and confident in caregiving.

Parental attitudes: Parents' attitude towards their autistic child usually is conditioned by family reactions, societal judgment and social stigma. Knowingly or unknowingly if parents condition their thoughts based on the facts surrounding them, it certainly creates emotional barriers between themselves and their child, taking them away from accepting the child and follow the needed treatment (Mount and Dillon, 2014). Hence, parents need to be provided with accurate information and enhanced awareness can help them shift attitudes towards acceptance and empowerment.

Parental acceptance and practice: With regard to parents' practices and acceptance is a crucial step in child rearing practices. When parents are able to accept their child's conditions parents are more likely to be involved in supportive teaching of essential and adaptive skills to their child. These practice skills are important for increasing and boosting the child's autonomy while improving their quality of life (Hastings and Petalas, 2014).

Effect on parents' mental health: Caring for a child with autism can emotionally and financially drain parents leading to serious mental health issues such as stress, anxiety and depression. These mental health issues if not treated can reduce their ability to cope up their day-to-day activities and negatively affect family dynamics (Hayes and Watson, 2013). Supporting parent's mental wellbeing through counselling, stress management programme and social support is essential. Mentally healthy parents are better prepared to care for

their child effectively and improve the quality of life for the entire family (Karst and Van Hecke, 2012).

Effect on parents' self-efficacy: Parents of children with autism often experience reduced self-efficacy, the belief in their ability to manage and support their child's needs, due to the complex and unpredictable nature of the condition. Challenges such as communication difficulties, behavioural issues, and lack of progress despite effort can lead to feelings of helplessness and self-doubt (Dempsey *et al.*, 2009). Enhancing parents' self-efficacy through education, skill-building programs, and positive feedback can empower them to feel more confident and competent in managing their child's development. Higher self-efficacy is linked to better coping strategies, lower stress levels, and more effective parenting practices, ultimately benefiting the child's progress and family well-being (Meirsschaut, Roeyers, and Warreyn, 2010).

Objectives of the study

Primary objective-

- To explore the Knowledge, Attitude, and Practices (KAP) of parents on the pre-requisite skills of children with autism
- To assess the levels of Mental health (MH) and Self-efficacy (SE) of parents of children with ASD
- To examine the influence of knowledge, attitude, and practice (KAP) of parents on pre-requisite skills on their mental health (MH) and self-efficacy (SE)
- To conduct the sensitization programme for parents on pre-requisite skills, mental health, and self-efficacy, and assess its effectiveness.

Secondary objective-

- To explore the socio-demographic determinants of parents and their predictive capacity on their knowledge, attitude, and practice (KAP), mental health (MH), and self-efficacy (SE).

Hypotheses

- H₀₁ - Parents of autistic children have lower levels of knowledge, unfavorable attitudes, and lower practices on pre-requisite skills

- H₀₂ - Parents of autistic children have poor mental health status and lower self-efficacy
- H₀₃- Parents' knowledge, attitudes, and practices do not influence mental health and self-efficacy
- H₀₄. Socio-demographic markers do not determine parents' knowledge, attitudes, and practices on pre-requisite skills, mental health, and self-efficacy
- H₀₅- Sensitizing parents do not improve their KAP on pre-requisite skills, mental health and self-efficacy.