

**CHILDREN WITH AUTISM SPECTRUM DISORDER IN
MIZORAM: KNOWLEDGE, ATTITUDE AND PRACTICES OF
PRIMARY AND SECONDARY CARE GIVERS**

**A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE OF DOCTOR OF
PHILOSOPHY**

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**CHILDREN WITH AUTISM SPECTRUM DISORDER IN MIZORAM:
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SECONDARY CARE GIVERS**

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In partial fulfillment of the requirement of the Degree of Doctor of Philosophy in
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CERTIFICATE

This is to certify that the thesis **“Children with Autism Spectrum Disorder in Mizoram: Knowledge, Attitude and Practices of Primary and Secondary Care Givers”** submitted by Tecie Lalduhzuali for the award of the degree of Doctor of Philosophy in Social Work is carried out under my guidance and incorporates the student’s bonafide research and this has not submitted for award of any degree in this or any other University or Institute of learning.

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I **TECIE LALDUHZUALI**, hereby declare that the subject matter of this thesis is the record of work done by me, that the contents of this thesis did not form basis of the award of any previous degree to me or to do the best of my knowledge to anybody else, and that the thesis has not been submitted by me for any research degree in any other University/ Institute.

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LIST OF ABBREVIATIONS

ABA	: Applied Behaviour Analysis
AFA	: Action for Autism
AOTF.	: Association for Occupational Therapy Foundation
APA	: American Psychiatric Association
ASD	: Autism Spectrum Disorder
ASI	: Ayes Sensory Integration
CAM	: Complementary and Alternative Medicine
CARS	: Childhood Autism Rating Scale
CDC	: Centres for Disease Control and Prevention
CI	: Cognitive Impairment
COMDEALL	: Communication DEALL (Developmental Eclectic Approach to Language
CARS	: Childhood Autism Rating Scale
CDC	: Centres for Disease Control and Prevention
CI	: Confidence Interval
COVID	: Coronavirus Disease
CWA	: Child Welfare Agency
DDRS	: Deendayal Disabled Rehabilitation Scheme
DSM	: Diagnostic and Statistical Manual of Mental Disorders
DTT	: Discrete Trial Training
EI	: Early Intervention
GP	: General Practitioner
ICCONS	: Institute of Communicative and Cognitive Neurosciences
ICD	: International Classification of Diseases
INCLIN	: International Clinical Epidemiology Network
IQ	: Intelligence Quotient
ISAA	: Indian Scale for Assessment of Autism
NALSA	: National Legal Services Authority
NASW	: National Association of Social Workers
NGO	: Non-Governmental Organization
NHFDC Corporation	: National Handicapped Finance and Development
NIMH	: National Institute for the Empowerment of Persons with Intellectual Disabilities
NRC	: National Resource Centre
PDDNOS	: Pervasive Developmental Disorder Not Otherwise Specified.
PWD	: Persons with Disabilities
QOL	: Quality of Life
RCT	: Randomized Controlled Trial
SCERTS	: State Council of Educational Research and Training
SEA	: State Education AgencyS
SI	: Sensory Integration
UNCRPD Disabilities	: United Conventions on the right of the persons with
UNESCO	: United Nations Educational Scientific and Cultural

Organizations

VSMS : Vineyard Maturity Scale

WHO : World Health Organization

WHOCST : World Health Organizations Caregiver Skills Training

CHAPTER I

INTRODUCTION

The present study aims to find out the knowledge, attitude and intervention practices of primary and secondary caregivers of children with Autism Spectrum Disorder (ASD) in Mizoram. It will also try to understand the challenges faced by the primary and secondary caregivers and try to understand the relationship between knowledge, attitude and practices of primary and secondary caregivers of children with autism spectrum disorders. Further it will suggest measures for social work intervention and policy making.

Autism spectrum disorder (ASD) is a developmental disorder, considered by researchers to be one of the most widespread and serious developmental disorders of childhood, with the most implications in all spheres of development. Every family member is impacted by the Autism spectrum disorder diagnosis in a unique way. Helping a child with autism requires all of a parent's attention, which can be difficult and have an impact on marriage, other couples' children, employment, savings, connections with others, and obligations.

Autism is considered a spectrum disorder, which implies that a child's symptoms can range from moderate to severe. Autism can be detected in some children as early as 12 months with babies do not babble, while others may develop normal language and social skills for a while before regressing with autism, a condition known as "regressive autism". Early identification and diagnosis will assist parents in developing a good and efficient intervention plan, reducing stress as they discuss and share their burden with specialised specialists to arrive at a correct diagnosis. Lack of awareness increases the probability of misdiagnosis or late diagnosis, especially the signs of this diseases parents who are the first to notice any unusual behaviour compared to other children or siblings of the same age group.

Parents are a crucial component of family intervention. Parental understanding and awareness will influence the diagnosis, treatment, and prognosis of children with autism spectrum disorder. A comprehensive assessment into parents'

understanding of autism spectrum disorder can elucidate specific knowledge gaps, facilitating the development of tailored parental training programs. Crucially, it can assist in determining the efficacy of knowledge training. Emphasising parents' understanding of ASD and utilising it as a criterion for assessing the impact of training are crucial elements in instructing parents to do family training. In a study completed by Vivanti et. al. (2016), it was found that early interventions significantly improved the cognitive, linguistic and social functioning of children with autism spectrum disorder, highlighting the benefits of the early autism spectrum diagnosis. Grzadinski et. al., (2014) reported that parents who received an early diagnosis of their child's autism spectrum disorder experienced lower levels of stress and anxiety. As a result, these parents were more likely to access the services and support needed for their child, contributing to reduced parental stress and improved family functioning.

For parents and families, raising a child with Autism spectrum disorder (ASD) can be a daunting task. In comparison to parents of typically developing children and children with other developmental disorders, carers of children with ASD face numerous challenges due to the widespread and severe deficits that are frequently present in these children. These challenges include a decrease in parenting efficacy, an increase in parenting stress, and a rise in mental and physical health issues. Having a child with an ASD may put a lot of strain on families, as evidenced by the high divorce rates and decreased general family well-being, in addition to the obvious time and financial demands. The diagnosed kid is negatively impacted by these parent and family influences, which also have the potential to lessen the beneficial benefits of intervention. The majority of ASD therapies, however, are solely assessed in terms of the outcomes for the children, ignoring the parent and family characteristics that could affect the therapy's short-term and long-term consequences. Given that the time and cost of intervention can cause more family disruption, it cannot be assumed that even notable improvements in the diagnosed kid will lessen the existing parent and family suffering. In order to better reflect the transactional nature of these connections, a new model of intervention assessment is presented that takes these elements into account (Karst & Hecke, 2012).

Research shows that when symptoms of developmental disorders are not recognized early, children can become more socially isolated, making later interventions more difficult. Parents may experience emotional distress, as their expectations for family life shift dramatically following a diagnosis (Volkmar & Wiesner, 2009; McConachie & Diggle, 2007). The more the parent is ignorant to the symptomatology illustrated by the child, the more he sinks into the isolation characteristic of the outside world and the therapeutic intervention will be much more difficult, the child starting late in the recovery program. At the time of diagnosis or before this time, when parents notice the first symptoms, they begin to develop certain feelings and attitudes toward their troubled child.

Families of children with autism spectrum disorders (ASD) encounter persistent issues that might impact their familial dynamics. Assisting families in managing the effects of ASD and fostering improved outcomes for both family and child necessitates study to enhance comprehension of the varying dimensions of quality of life for these families (Peunte et. al., 2022).

The diagnosis of ASD is a significant challenge for the family, leading to a shift in perspective and a profound sense of the necessity for assistance and adjustment to the new circumstances (Critchley et. al., 2021). Parents initially anticipate the birth of a healthy child who will mature into an autonomous adult; when this expectation is unmet, they must recalibrate their aspirations and future plans for both themselves and their child (Baña, 2015; Cuevas et. al., 2018). Parents try to meet first the needs of the child with autism, and then the family. Even if they put their own life on hold and the couple shares the understanding of the need to make sacrifices by sharing between the children, few of them manage to offer the same attention and care to both parties.

Stress reduction is a variable that enhances the quality of life for families with children diagnosed with ASD (Hsiao et al., 2017; Wang et al., 2020). Parents of children with Autism Spectrum Disorder (ASD) exhibit significant psychological discomfort, notably anxiety (Shepherd, Landon, Goedeke, & Meads, 2021), and

mothers of children with ASD experience elevated stress levels compared to mothers of children with other disabilities (McStay, Trembath, & Dissanayake, 2014).

The family perceives the autistic child as a burden, and every child is sensitive to such perceptions. The child will be influenced by signals conveyed to him or her, whether knowingly, intentionally, or inadvertently. Consequently, carers of children with ASD endure heightened levels of load and diminished quality of life. Nierkerk et. al. (2024) indicate that carers of children and adolescents diagnosed with ASD are predominantly women, who have mild to moderate carer burden, highlighting the necessity for enhanced screening and psychosocial support programs.

The diagnosis of autism spectrum disorder affects each family member differently. Parents need to focus all their attention on helping the child with autism, which can be stressful and can affect marriage, other couple's children, work, savings, interpersonal relationships, and responsibilities. Parents should spend a significant amount of time and money on treatments and therapies, excluding other priorities. The needs of these children complicate family relationships, especially with the siblings. Quantitative analyses of the sibling experience, wherein researchers classify siblings as clinical or nonclinical and assess their symptomatology across specified emotional and behavioural domains, indicate that siblings are generally well-adjusted, barring a minor subset of vulnerable children. Qualitative research, however, uncovers significant emotional and cognitive difficulties faced by siblings of individuals with ASD, warranting further exploration of subjective well-being outcomes. These siblings may exhibit outwardly positive behaviour and coping mechanisms, while inside grappling with turmoil (Green, 2013).

By not being able to do things as a single family, a spousal relationship can be affected. Most of the time, spouses cannot spend time alone because of the needs of the child and because of the lack of qualified personnel who can supervise a child with autism in their absence. However, a dyadic study using an actor-partner independence model completed by He et. al., (2022) confirmed that parents of

children with ASD are more likely to be satisfied with their relationships if they feel supported by their family. This is true regardless of how severe the child's autistic behaviours are or how long they have to care for them. The compatibility of people's behavioural styles did not have an effect on how satisfied they were with their relationships. Their study has implications for programs that aim to help people learn skills that will get family support.

Primary carers of autistic people often have a range of attitudes, from accepting them to questioning their views. These attitudes are affected by things like knowledge, social support, and personal experiences. Many carers know a lot about autism and have positive feelings about it. However, others may have problems because of public awareness, stigma, and the mental effects of caring for a kid with autism.

A study completed by Columbo-Dougorito & Joshi (2025) reported an overall perception of caregivers' positive acceptance of their child's diagnosis; however, caregivers perceived more pervasive negative responses from their spouses and those from their community (i.e. society). Their findings also suggest that empowering caregivers with knowledge about autism is an important first step to ensuring the acceptance of their child's diagnosis, particularly for two-parent households. Additionally, the misconceptions about autism need to be counteracted at the societal level to reduce the additional burden on caregivers.

Caring for a child with autism spectrum disorder (ASD) presents unique challenges that can significantly impact the well-being of primary caregivers. Research evidence suggest that parents of disabled children are particularly vulnerable to stress. High levels of distress have been found in up to 70 per cent of mothers and 40 per cent of fathers of severely disabled children (Sloper & Turner,1993).

According to Uke et.al.(2024), the diagnosis and management of autism is quite complex as such the assessment and management should be done with the help of a multidisciplinary team which consists of a development paediatrician,

psychiatrist, psychologist, audiologist, occupational therapist, speech therapist, special educator and social worker depicted in the figure below:

Families play several roles in their children's lives, particularly if their child is diagnosed with Autistic Spectrum Disorder (Harris, 1994). They provide emotional support, serve as role models for behavior and social interaction, and advocate for services. Many children still lack adequate treatment at the appropriate time due to the continued inadequacy of early diagnosis and intervention. Having a child with autism can have a significant impact on the family, particularly on women, who are typically the primary caretakers for children with autism. It has also been said that having a child with autism can have a significant influence on the family, particularly on mothers, who are typically the primary caretakers for children with autism. Parents occasionally lack the essential information and understanding about autism, its possible effects, and the available intervention and support strategies, the reason for which they face several dynamic challenges.

1.1 International Scenario

Autism was first identified by an American psychiatrist named Leo Kanner in a paper published in 1943 entitled 'Autistic disturbances of affective contact'. A year later an Austrian medical student called Hans Asperger published a paper in 1944 entitled '*Autistic Psychopathy in Childhood*'. The individuals described by both Kanner and Asperger differed from each other in some respects and also considerable overlap between the descriptions. However, both the works of these two researchers led to the evolvement of identifying autism over the years (Boucher, 2022).

Through the 1970s, research began to shift toward biological and neurological explanations. Autism was recognized as a neurodevelopmental disorder, not a result of parenting style. In 1980 Autism was formally included in the DSM-III (Diagnostic and Statistical Manual of Mental Disorders). Between 1981 – 1994, Asperger's syndrome was re-evaluated and included in the DSM-IV in 1994 as a distinct diagnosis. In 2013, in the DSM- 5, the separate diagnosis of autistic disorder,

Asperger's Syndrome and PDD-NOS were unified under the umbrella term Autism Spectrum Disorder.

The prevalence of Autism spectrum disorder is increasing drastically all over the world. Autism spectrum disorder prevalence may be rising for a number of reasons, including expanding the diagnostic criteria through frequent, timely modifications of the DSM, along with PDD and other autistic conditions considered as single entities as ASD in recent times. Public awareness about the symptomology of the condition and increased practice of universal screening for ASD by health practitioners led to early and increased detection of children with autism. Easily available facilities of early intervention and active school participation in providing school-based services for children with ASD might add to increased prevalence and improved outcomes (Uke et. al., 2024).

The prevalence of Autism spectrum disorders which was previously in the order of 1 to 650 to 1000 is now according to CDC's Autism and Developmental Disabilities Monitoring Network released data in 2007 to be about 1 in 150 8-year-old children in multiple areas of the United States. The exact reason for this has been debated and a consensus was not reached to the satisfaction of many (CDC's Autism and Developmental Disabilities Monitoring Network, 2007).

ASD impacts about 5 million children in America, with a 1.7% estimated prevalence in 1 in 59 individuals. Systematic epidemiological research is lacking in the field of autism in India, as compared to developed countries, because of which many cases go undiagnosed, resulting in a reduced prevalence rate than the actual value. Therefore, the cases that come to health facilities may represent only the tip of the iceberg, with many cases remaining hidden and undiagnosed (Centre for Disease Control and Prevention. 2020).

Studies using epidemiological methods have shown a consistent rise in the number of autism diagnoses (Fombonne, 1999; London & Etzel, 2000). According to early studies, 4 to 6 people out of 10,000 could have autism (strictly confined to youngsters who meet all criteria for the illness) (Wing & Gould, 1979).

Autism Spectrum Disorders (ASD) are the most common developmental disability in the world, and their incidence is rising daily. According to WHO estimates from April 2017, 1 in 160 children globally suffers from autism spectrum disorders. The global prevalence of Autism Spectrum Disorder varies across regions and studies, influenced by factors such as diagnostic criteria, awareness, and healthcare infrastructure. A comprehensive meta-analysis completed by Salara et. al. (2022) estimated that approximately 0.6 per cent of the global population is affected by ASD. Their studies also concluded the prevalence rates across different continents such as:

- Asia: 0.4 per cent
- America: 1 per cent
- Europe: 0.5 per cent
- Africa: 1 per cent
- Australia: 1.7 per cent

Another study completed by Minhas et al (2015) stated that in South Asia 1.4 per cent of people suffer from autism spectrum disorder however relatively few of them has access to any kind of medical care.

1.2 National Scenario

Autism Spectrum Disorder (ASD) was initially acknowledged in India during the early 20th century. In 1944, A. Ronald, a Viennese paediatrician who was employed in Darjeeling, described children who exhibited behaviours that are now associated with autism. However, he did not use the term "autism." The disorder's formal recognition in India was initiated in 1959 with the publication of the first explicit mention of "autism" in Indian literature. The awareness and comprehension of ASD in India were minimal during the 1960s and 1970s. The disorder was frequently misdiagnosed or confused with other conditions, as the medical community had limited exposure to it. The term "autism" was rarely employed, and

there was a dearth of specialised knowledge or resources to assist individuals with ASD.

The establishment of specialised centres and advocacy groups during the 1980s marked a significant turning point. The Tamana School of Hope in Delhi was the first institution in India to acknowledge autism as a distinct disability in 1985. The school provides specialised programs for individuals with Autism Spectrum Disorder

In 1991, Action For Autism (AFA) was founded in New Delhi as a parent-led initiative to advocate for children and adults with autism. Action For Autism played a pivotal role in raising awareness, providing training, and influencing policy changes. Their efforts led to the inclusion of autism in the National Trust for Autism, Cerebral Palsy, Mental Retardation, and Multiple Disabilities Act in 1999 and the revised Persons with Disabilities Act 2016.

Based on prevalence estimates, there could be up to 2 million autistic individuals in India. However, research on autism is still in its early stages in the Indian subcontinent. In India, the frequency of autism has been rising significantly. In India, the estimated prevalence of autism is 1 in 68 children. The prevalence of autism is higher in boys than in girls, with a male-to-female ratio of roughly 3:1 (Malhi & Sankhyani, 2021; Krishnan et al., 2021)

According to a systematic analysis completed by Raina et al 2013, the prevalence rate among children aged 0-17 in South Asian Countries (Bangladesh, India, Sri Lanka) ranges from 0.09% to 1.07% for ASD. This discrepancy is attributed to underdiagnoses, lack of awareness, and limited mental health services.

In 2011, a study completed by Juneja et. al. in New Delhi reported an ASD prevalence of 1 in 125 in children aged 2–6 years. A 2020 community-based study in Kerala using the INCLIN Diagnostic Tool for Autism Spectrum Disorder (INDT-ASD) found a prevalence of 0.36% in children aged 1–10 years where another study

conducted in Chandigarh by Arora et al. (2018) reported a prevalence rate of 0.9 per cent in school-going children.

In recent years, there has been a concerted initiative to enhance services and support for individuals with Autism Spectrum Disorder (ASD). The Indian Scale for Assessment of Autism (ISAA) was created as a culturally relevant instrument for diagnosing Autism Spectrum Disorder (ASD) in Indian youngsters. Research indicates that around 1 in 100 children under the age of 10 in India are diagnosed with autism (Manohar et. al., 2024).

Despite these advancements, challenges persist, including a shortage of trained professionals, regional disparities in service availability, and societal stigma in India.

1.3 Regional Scenario

As per the 2011 Census, Mizoram had a total of 15,160 persons with disabilities (PwDs), accounting for approximately 1.38 per cent of the state's population. The breakdown of disabilities were as follows:

- Hearing Impairment: 3,354
- Visually Impaired: 2,035
- Speech Impairment: 1,163
- Orthopedic Disabilities: 1,976
- Mental Retardation: 1,585
- Mental Illness: 1,050
- Multiple Disabilities: 2,083
- Other Disabilities: 1,914

These figures were based on the 2011 Census data, and the next comprehensive data collection on disabilities is expected in the 2021 Census. However, the detailed disability data from the 2021 Census has not been released yet. In the interim, a 2021 survey reported that there were 13,418 registered Persons with Disabilities in Mizoram, with 27.9 per cent residing in the Aizawl district. However, there is no record of autism population according to 2011 census.

Although global prevalence rates have been found and presented, there is a scarcity of data that pertains to Mizoram, a state in the north eastern region of India. Studies from neighbouring regions provide some insights, despite the absence of first-hand data from Mizoram. For example, a study conducted in Himachal Pradesh revealed a prevalence of 0.9 per 1,000 children between the ages of 1 and 10 (Raina et. al.,2017). It is conceivable that the prevalence of ASD in Mizoram may be within a similar range, given the socio-economic and cultural similarities between Himachal Pradesh and Mizoram. Although there is no direct data on the prevalence of ASD in Mizoram, the prevalence may be comparable to other north-eastern states based on extrapolation from regional studies. Nevertheless, the absence of specific studies emphasises the necessity of targeted research in Mizoram to assess the prevalence of ASD.

1.4 Definition and Concepts

1.4.1 Autism Spectrum Disorder

Autism spectrum Disorders are a group of neuropsychiatric disorders with specific delays and deviance in social, communicative and cognitive development. ASD includes autism, Asperger's syndrome and pervasive developmental disorder-not otherwise specified (PDD-NOS) (Kommu, 2011).

According to National Institute of Mental Health (2024), Autism Spectrum Disorder is a neurological and developmental disorder that affects how people interact with others, communicate, learn and behave. Although Autism can be

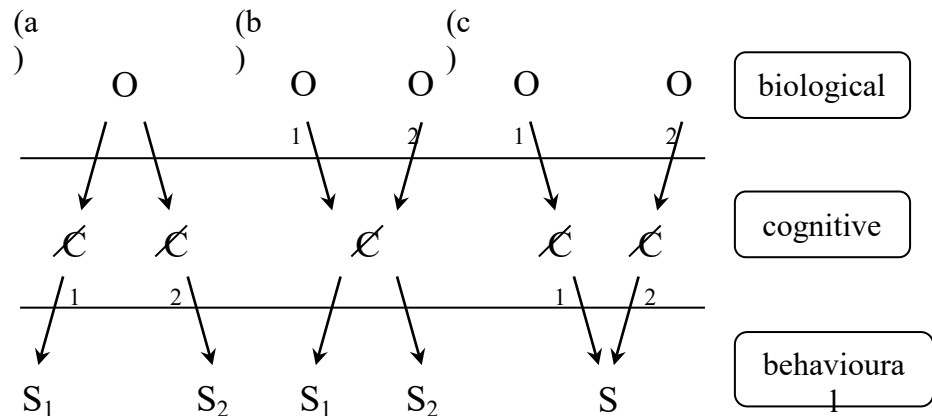
diagnosed at any age, it is described as a developmental disorder because symptoms generally appear in the first two years of life.

The Centre for Disease Control and Prevention defines ASD as a developmental disability that causes significant social, communication, and behavioural challenges. It emphasizes the importance of early identification and intervention to support individuals with ASD in reaching their full potential. The CDC provides resources for understanding signs, symptoms, and available support for individuals with autism spectrum disorder (Centre for Disease Control and Prevention, 2025).

According to the Persons with Disabilities Act 2016, Autism spectrum disorder is defined as a neuro-developmental condition that typically appears in the first three years of life. This condition slightly affects a person's ability to communicate, understand relationships and interact with others. It is often associated with unusual or stereotypical behaviours and rituals (Government of India, 2016).

According to Watson & Happe (2019), Autistic spectrum disorder is a broad term. To provide an answer to the question in any given situation. The contrast between the various meanings of question in terms of the various degrees of explanation is another possible interpretation of this concept. The biological, cognitive, and behavioural levels are particularly helpful in the academic study of autism. These three levels are the most important. In 1995, Morton and Frith presented a particular diagrammatic tool that was designed to facilitate the process of thinking about the levels of explanation that are present in developmental problems such as autism.

Figure 1: Causal Models of three different types of disorders



Pattern A is the level of biological origin, which has the potential to have a variety of consequences on an individual's cognitive and behavioural performance. Another example that was provided by Watson and Happe (2019) suggested that this kind of disorder could be referred to as fragile X syndrome: The existence of a particular gene mutation on the X chromosomes helps to determine whether an individual has fragile X syndrome. Nevertheless, not all people who are characterised in this way have the same cognitive or behavioural characteristics. While many people will have severe issues with learning and social anxiety, others may have an IQ score that falls within the average range and appear to have a high level of social confidence.

Pattern B demonstrates an illness that has various biological causes and a variety of behavioural expressions, but there is only one cognitive characteristic that helps to define the disorder. As an illustration, dyslexia may be an example, according to certain cognitive theories.

Pattern C is the case of definition that is defined solely by its behavioural characteristics, with many biological origins and cognitive theories. One possible scenario is having a conduct disorder.

According to World Health Organization (2016), the ICD 10 categorizes pervasive developmental disorders into the following sub types:

- **Childhood Autism:**

A pervasive developmental disorder which is defined by the presence of abnormal and/ or impaired development that is manifested before the age of 3 years, and by the characteristic type of abnormal functioning in all three areas of social interaction, communication, and restricted, repetitive behavior. The disorder occurs in boys three to four times more often than in girls. Usually there is no period of unequivocally normal development but, if it is there, abnormalities become apparent before the age of 3 years. There are always qualitative impairments in reciprocal social interaction. These take the form of an inadequate appreciation of socio emotional cues, as shown by a lack of response to other people's emotion and /or a lack of modulation of behavior according to social context, poor use of social signals and a weak integration of social emotional and communicative behaviors and a lack of socio emotional reciprocity. Similarly, qualitative impairments in Communication is universal. These take the form of a lack of social usage of whatever Language skills are present; impairment in make believe and social imitative play; poor Synchrony and lack of reciprocity in conversational interchange; poor flexibility in Language expression; lack of emotional response to other people's verbal and non-verbal overtures, etc.

- **Atypical Autism**

A type of pervasive developmental disorder that differs from childhood autism either in age of onset or in failing to fulfill all three sets of diagnostic criteria. This subcategory should be used when there is abnormal and impaired development that is present only after age three years, and a lack of sufficient demonstrable abnormalities in one or two of the three areas of psychopathology required for the diagnosis of

autism (namely, reciprocal social interactions, communication, and restricted, stereotyped, repetitive behavior) despite characteristic abnormalities in the other area(s). Atypical autism arises most often in profoundly retarded individuals and in individuals with a severe specific developmental disorder of receptive language.

- **Rett's Syndrome**

A condition, so far found only in girls, in which apparently normal early development is followed by partial or complete loss of speech and of skills in locomotion and use of hands, together with deceleration in head growth, usually with an onset between seven and 24 months of age. Loss of purposive hand movements, hand-wringing stereotypies, and hyperventilation are characteristic. Social and play development are arrested but social interest tends to be maintained. Trunk ataxia and apraxia start to develop by age four years and choreoathetoid movements frequently follow. Severe mental retardation almost invariably results.

- **Other Childhood Disintegrative Disorders:**

A type of pervasive developmental disorder that is defined by a period of entirely normal development before the onset of the disorder, followed by a definite loss of previously acquired skills in several areas of development over the course of a few months. Typically, this is accompanied by a general loss of interest in the environment, by stereotyped, repetitive motor mannerisms, and by autistic-like abnormalities in social interaction and communication. In some cases, the disorder can be shown to be due to some associated encephalopathy, but the diagnosis should be made on the behavioral features.

- **Asperger's Syndrome:**

A disorder of uncertain nosologically validity, characterized by the same type of qualitative abnormalities of reciprocal social interaction that typify autism, together with a restricted, stereotyped, repetitive repertoire of interests and activities. It differs from autism primarily in the fact that there is no general delay or retardation in language or in cognitive development. This disorder is often associated with marked

clumsiness. There is a strong tendency for the abnormalities to persist into adolescence and adult life. Psychotic episodes occasionally occur in early adult life.

- **Pervasive developmental Disorder, Unspecified:**

This is a residual diagnostic category that is used for disorders which fit the general description for pervasive developmental disorders but in which a lack of adequate information, or contradictory findings, means that the criteria for any of the above said disorders cannot be met. Through the commitment of a community of parents, siblings, other relatives, and autistic people themselves, people with autism and their families now have a voice in the disability legislation and movement in India. It is also providing hope to the Autistic people and their families that Autism now receives recognition; there are still many issues to be negotiated, legal and otherwise.

Children with Autism Spectrum Disorder has specific characteristics in nature. According to DSM V, Autism spectrum disorder is presented with two main core features i.e. the deficit in social/communication and restrictive, repetitive patterns of behaviour.

The exact causes of autism spectrum disorder are not known. However, a consensus of the scientific research concluded that the cause is biological, most likely neurological as against the widely held earlier theories of psychological causes. It could be well that there may be more than one or a combination of factors. Though the general believed is that the irrespective of the exact biological cause, children with ASD have a typical neurological development resulting in the range of developmental difficulties, it is likely that these difficulties are exacerbated by environmental causes. Below are the theories which are commonly used for understanding Autism Spectrum Disorder.

- **Theory of Mind Model**

This theory is one of the most influential framework in understanding autism. It was proposed by Simon Baron- Cohen and his colleagues in the late 1980s. They

have stated that individuals with Autism Spectrum Disorder have difficulty attributing mental states -such as beliefs, intentions or emotions to themselves and others. This may explain why people with autism struggle with social reciprocity and understanding others perspectives (Baron-Cohen, 1985).

- **Executive Dysfunction Theory**

According to executive dysfunction theory, people with Autism Spectrum Disorder may have impairments in executive functions such as planning, flexibility, working memory, inhibition and working memory. Executive dysfunction may underlie the rigid and repetitive behaviours often observed in autism spectrum disorder as well as difficulties in adapting to new situations or managing tasks that requires complex organisations (Ozonoff et. al.,1991)

- **Weak Central Coherence Theory**

This theory was proposed by Uta Frith, the weak central coherence theory posits that individuals with autism have cognitive style that favours local over global processing. This means they may excel in focusing details while missing the bigger picture. This framework helps explain both strengths (superior performance in pattern recognition) and challenges (difficulty in integrating social cues) (Frith, 1989).

- **Enhanced Perceptual Functioning**

Enhanced Perceptual Functioning theory suggests that individuals with Autism Spectrum Disorder possess heightened perceptual abilities. This heightened sensitivity to sensory input may contribute to both the strengths and challenges associated with autism. Some individuals with autism spectrum disorder have exceptional skills in visual or auditory processing (Mottron et. al., 2009)

- **Social Motivation Theory**

Social Motivation Theory focuses on the social aspects of autism proposing that individuals with autism spectrum disorder are less intrinsically motivated to engage in social interactions. This reduced social motivation may lead to fewer opportunities to practice and develop-social-cognitive skills, contributing to the later social difficulties.

Each theories contributes a different piece to understanding ASD. While no single theory fully explains the spectrum, they collectively help researchers and clinicians interpret the wide range of characteristics seen in autistic individuals (Chevallier et. al., 2012).

1.4.2 Caregiver

A caregiver is an individual who provides assistance and assumes the responsibility for the physical and emotional needs of another individual who is incapable of self-care (Mathur et. al., 2018)

1.4.3 Primary Caregivers

A study published in the *Indian Journal of Social Psychiatry* defines a primary caregiver as a person, usually over the age of 18, who provides care for another individual who is no longer able to perform essential tasks of personal or household care necessary for everyday survival (Kranti et. al., 2020).

In the *Encyclopedia of Gerontology and Population Aging*, primary caregivers are described as individuals responsible for providing care to someone who cannot take care of themselves. They can be further categorized into formal caregivers, who are paid professionals, and informal caregivers, who are unpaid family members or friends.

According to a study in the *International Breastfeeding Journal*, primary family caregivers are those who provide the most care to both the mother and infant

during the antenatal and postnatal periods, as identified by the mothers in each household (Nie et. al., 2023).

1.4.4 Secondary Caregivers

According to a systematic literature review published in BMC Geriatrics, secondary caregivers are defined as individuals who assist primary caregivers by helping with decision-making and providing hands-on care (D'amen et. al., 2021)

1.4.5 Knowledge

Knowledge refers to the capacity to acquire, retain, and utilize information. It encompasses comprehension, experience, discernment, and skill. The nature of knowledge depends on various modes of acquisition, including perception, imagination, memory, judgment, abstraction, and reasoning. Proper education is essential for acquiring knowledge, and basic intellect is necessary to understand and apply it effectively (Sharma, 2024).

1.4.6 Attitude

Attitude is a learned predisposition to respond in a favourable or unfavourable manner toward people, an object, an idea, or a situation. A positive attitude is crucial for achieving favourable outcomes. Proper knowledge often leads to a positive attitude, which in turn can influence behaviour and decision-making (Sharma, 2024).

1.4.5 Practice

Practice involves the application of rules and knowledge that lead to action. It refers to the actual behaviours or actions individuals undertake, reflecting how they implement their knowledge and attitudes in real-life situations (Ratala et. al, 2024).

There are several models of caregiving and intervention practices associated with Autism spectrum disorder that can be used by caregivers on their children with Autism spectrum disorder. These practices are as follows:

- **Life Skills Development**

Life skill development is a holistic method for assessing skill outcomes that gauges an individual's proficiency in skill acquisition. In developing countries children with disabilities have very little access to basic education. Only 1-2 per cent of such children have access to basic education and girls have even lesser access than boys (UNESCO). A cross-sectional study of 158 autistic children aged 5-20 in Dhaka, Bangladesh, found that over 90% were diagnosed within 2 to 3 years of age, and 99.4% received formal education. After special intervention, 61.39% could utter words but couldn't make sentences, while 37.97% could communicate with sentences. The study also found that intervention therapies like SCERTS (Social Communication, Emotional regulation, Transactional support) could improve daily living skills (Sultana et. al., 2019).

Self-care skill refers to an individual's ability to take care of themselves, with good self-care skills effectively contributing to an individual's development and improving their quality of life. The general lack of self-care skills among children with autism creates significant stress for their parents and teachers, who report that some of their stress is due to a lack of either professional guidance or available teaching materials. A study completed by Ding & Toran (2024) found that the current teaching of self-care skills to children with autism suffers from a lack of attention as well as a lack of teaching frequency and materials and suggested that both parents and teachers have a strong need for teaching modules and provided suggestions for their development.

- **Occupational Therapy**

Occupational therapy is a therapeutic method focusing on improving activity participation skills by addressing personal characteristics, activity, and environment that affect an individual's role performance (American Occupational Therapy Foundation, 2011).

A study completed by Jaicks (2024) found that occupational therapy enhances sensory, relationship-building, body and object utilisation, language, social, and self-

care skills in ASD children. Their study also found that these benefits are greatest in the early phases of therapy, but the pace of improvement decreases over time. This shows that while occupational therapy can improve quality of life and daily life engagement for children with ASD, ongoing and possibly diversified interventions may be needed to preserve and build on these benefits.

Counselling

The management of children with autism spectrum disorder is quite complex. Parents can never be prepared and ready to face the hurdles in managing their children's behaviour and symptoms. Nurhastuti (2018) completed a study on family counselling program for parents who have autistic children and the finding suggest that family counselling is a good alternative method doer the family who have children with autism. The inclusive school can implement this method for caring an effective counselling to the parents with autistic children. Family Counselling can also include strengthening relationships, building resiliency and helping the family develop new approaches to problem-solving that can be directly applied to challenges that result from coping with their child's autism spectrum disorder (Kurz, 2018, Nurhastuti & Fatmawati, 2018).

- **Early Intervention**

Early Intervention refers to providing therapeutic support and services to children with autism spectrum disorder as early as possible ideally before the age of 3. The aim is to the minimise developmental delays, improve a child's potential to reach developmental milestones and enhance quality of life.

Maksimovic et. al. (2023) has stated that children diagnosed with ASD exhibit altered behaviour in the form of repetitive pattern, lack of social interaction and socio- emotional reciprocity and speech language development in these children is also deviant and delayed. Many studies have addressed the significance of early intervention for autism symptoms. Their study highlights the importance of emphasizing the exact age when using the terms 'early intervention' and 'early development' in future studies and practice because it is necessary to determine and

make guidelines about which particular ages are crucial for starting treatment in certain developmental aspects. Social Communication represents a special challenge for children four years and older, and thus the process of therapy methods creating, special attention should be paid to this developmental aspect.

- **Applied Behavioural Analysis**

There is a range of intervention that are being advocated for ASD, among the many interventions that have evolved for autism, the most widely used documented is APA or ABA, (Lovas, 1987). The APA sessions involved the child receiving two years of one-on-one instruction for forty hours per week. Applied Behaviour Analysis uses the principles of learning such as operant and respondent conditioning to modify socially significant behaviours.

According to Osbourne et al 2008, the behavioural treatment interventions are most effective when the environment is stable and creates ideal conditions for the child to progress through their interventions while the family members learn new ways of providing support.

A study conducted by Hamdan et. al. (2023) completed a systematically review on the effectiveness of interventions in the use of ABA method to manage and improve stereotype behaviours and behavioural issues in children with ASD. A total of 14 studies were selected and reviewed. However, their findings conclude that the prevalence of autism spectrum disorder in many Asian countries is still unknown especially in South Asian Countries. Moreover, no studies were found in this region that reported the ABA's method's application on children with ASD. This review noted about two studies conducted in middle-east countries and this review suggest that continuous efforts are needed to raise awareness of autism and improve the quality of life affected families in Asian countries.

As autism spectrum disorder (ASD) has become more common, it has been evident that children with this neurodevelopmental illness vary greatly from one another. Similar to this, there are numerous medical and educational treatments for ASD. Some children with ASD have benefited from early, intensive behavioural and

developmental therapies, such as the applied behaviour analysis treatment discussed in this Medical Progress article. However, the community of children with ASD has become more diverse as a result of both the greater awareness of ASD and the screening of a larger variety of children for ASD. Not every child with an ASD diagnosis will benefit from the same course of treatment. There will soon be a wider variety of treatment options available, all of which will need thorough research among the diverse group of kids with ASD (Roane et. al., 2016).

- **Sensory Integration Therapy**

Sensory Integration Therapy is being used for children with developmental and behavioural disorders. It is a form of therapy designed to help individuals, particularly children, better process and respond to sensory information from their environment. It is based on the Ayres Sensory Integration (ASI) theory developed by A. Jean Ayres, an occupational therapist. Pfeiffer et. al. (2013) completed a pilot study to establish a model for randomized controlled trial research, identify appropriate outcome measures, and address the effectiveness of sensory integration (SI) interventions in children with autism spectrum disorder. The result findings identified significant positive changes occurred in the SI group and a significant decrease in autistic mannerisms occurred in the SI group.

- **Discrete Trial Training**

Discrete Trial Training is one of the structured teaching method used in Applied Behaviour Analysis therapy for children with autism which involves breaking down complex skills into smaller, manageable steps and teaching them individually, using repetition and reinforcement to promote learning. According to Smith, (2001), Discrete Trial Training (DTT) is a method for individualizing and simplifying instruction to enhance children's learning. For children with autism, DTT is especially useful for teaching new forms of behaviour (e.g speech sounds or motor movements that the child previously could not make) and new discriminations (e.g., responding correctly to different requests). DTT can also be used to teach more

advanced skills and manage disruptive behaviour. DTT is one of the most important instructional methods for children with autism.

- **COMDEAL Intervention Model**

The Communication DEALL (Developmental Eclectic Approach to Language Learning) Program is a comprehensive, multidisciplinary early intervention model for children up to the age of 6 years. The program involves teams from several disciplines such as occupational therapists, physiotherapists, speech-language pathologists, developmental psychologists, and educators to address the sensory-motor, communication, cognitive and psycho-social development of the child.

- **Complementary and Alternative Medicine**

Conventional medicine has been directed at the goals of diagnosis, treatment and when possible, cure of diseases states. Complementary and Alternative medical treatments are commonly used for children autism spectrum disorders. A review completed by Levy & Hyman (2009) discusses the evidence supporting the most frequently used treatments including categories of mind-body medicine, energy medicine, biologically based, manipulative and body based practices with the latter two the most commonly selected by families. The author also suggests that it is important for clinical providers to understand the evidence for efficacy and potential side effects and that, most treatments however have not been adequately studied and do not have evidence to support their use.

According to Doherty et. al. (2024), complementary and alternative medicine is a therapeutic option currently used by autistic people with continued interest and uptake. The evidence is quite limited regarding the efficacy of CAM use in autism. The result of the systematic review suggested that for autistic people, vitamin and mineral supplements may only be of benefit if there is a deficiency. The results also found that the main interventions used were dietary interventions and nutraceuticals, including targeted supplements, vitamins and minerals, omega 3 and probiotics, probiotics and digestive enzymes. The evidence does not support some of the most utilised dietary interventions such as Gluten Free diet and the use of targeted

nutraceutical supplements may be of benefit, but more conclusive research is still required to direct safe and effective treatment.

- **Family Psychoeducational Service**

When someone receives a diagnosis, they may need support with information and emotional needs. These are called psychoeducational needs. Beresford & Mukherjee (2025) concluded that their findings support the case for diagnostic services to have the resources to address psychoeducational needs across the diagnostic pathway, including the offer of a debrief appointment and group delivered psychoeducational program (with the option for 1:1 delivery) post-diagnosis. “Experts by experience” should be integral to the development and delivery of psychoeducational care.

Zhou et. al. (2019) studied on the effect of family- focused psychoeducational therapy for autism spectrum disorder children’s parents on parenting self-efficacy and emotion suggests that the family focused psychoeducational therapy improve parenting self-efficacy and emotion for autism spectrum disorder family.

Ivanov (2023) concluded that completing a psychoeducational course makes it possible to fill the lack of information regarding the disease and treatment tactics, increases compliance and harmonizes parent-child relationships.

- **Play Therapy**

Play Therapy can be an effective intervention strategy for children with autism spectrum disorder to reduce behavioural problems and improve social skills. Elbeltegi et. al. (2023) have stated that play therapy is an effective tool in the management of children with ASD however it depends on many factors. Play therapy should be continuous as the effect may wane with discontinuation. They have added that despite the weak evidence, play therapy still has a lot of potential benefits for patients and their families. It helps improve the child’s social skills and communication in a relaxed environment, integrates the parents, strengthens the child-parent bond and decreases the tension over the shoulder of the parents.

The findings completed by Yasmine & Benseghir (2023) provide evidence for the effectiveness of play therapy in reducing behavioural problems in children with autism spectrum disorder. The study also supports play therapy as an intervention strategy to address the behavioural challenges faced by children with autism spectrum disorder.

1.5 Screening and Diagnosis

There is an increase in the prevalence of Autism spectrum disorder worldwide which emphasises on the importance of identifying children with clinical manifestations of Autism Spectrum Disorder as early as possible. The earlier autism is identified; the sooner interventions can begin (Isaac et. al.,2025). Early therapy especially behavioural, speech, and occupational therapy has been shown to significantly improve communication, social skills, learning and adaptive behaviour. Early childhood is a period of rapid brain development and intervening during this critical window helps shape neural pathways in ways that can reduce the severity of symptoms and improve long-term developmental trajectories. Early screening for autism spectrum disorder is crucial for initiating timely interventions that can significantly improve developmental outcomes.

Uke et. al. (2024) has highlighted common screening tools_Autism spectrum disorder used in India as indicated in the table below.

Table 1: Screening Tools

Sl. No.	Name of Screening Tool	Age Group for Application	References
1	Modified Checklist for Autism in Toddlers	16-30 months	1
2	Trivandrum Autism Behavioural Checklist	2 to 6 years	2
3	Social Communication Questionnaire	4 years and above	3

4	Autism Behaviour Checklist	18 to 35 months	4
5	Ages and Stages Questionnaire	6 months to 5 years	5
6	Screening Tool for Autism in Toddlers	24 to 35 months	6
7	Communication and Symbolic Behaviour Scales Developmental Profile	6 to 24 months	7
8	Parents' Evaluation of Developmental Status	Birth to 7 years and 11 months	8
9	Indian Autism Screening Questionnaire	3 to 18 years	9
10	Chandigarh Autism Screening Instrument	1.5 to 10 years	10

According to the American Psychiatric Association (2013), there are two classifications guideline for the diagnosis of autism spectrum disorder. They are Diagnostic and Statistical Manual (American Psychiatric Association) and World Health Organization. The current versions are DSM V and ICD 10. The DSM-V criteria for diagnosing autism spectrum disorder are as follows:

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history.

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take the same route or eat the same food every day).

3. Highly restricted, fixated interests that is abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or preservatives interests).

4. Hyper- or hypo reactivity to sensory or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make co morbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Uke et.al. (2024) has constructed common diagnostic tools used in diagnosing Autism spectrum disorder in India as indicated in the table below.

Table 2: Diagnostic Tools

Sl.No.	Name of Diagnostic Tools	Age group for Application	References
1	Diagnostic and Statistical Manual of Mental Disorders	Above 1 year	1
2	Autism Diagnostic Observation Schedule	Above 1 year	2
3	Indian Scale for the Assessment of Autism	3-9 yrs	3
4	INCLIN Diagnostic Tool for Autism Spectrum Disorder (NDT-ASD)	2-9 years	4
5	Childhood Autism Rating Scale (CARS)	2 years and above	5
6	Autism Diagnostic Interview – Revised (ADI-R)	2 years and above	6

7	Gilliam Autism Rating Scale (GARS)	3-22 years	7
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According to Uke et. al. (2024), the diagnosis and management of autism is quite complex. As such the assessment and management should be done with the help of a multidisciplinary team which consists of the a development paediatrician, psychiatrist, psychologist, audiologist, occupational therapist, speech therapist, special educator and social worker.

1.6 Social Work and Autism Spectrum Disorders

The social work profession has not yet taken a leadership role in addressing the myriad of challenges that individuals on the Autism spectrum encounter across the lifespan. In this essay, we argue that social workers are well equipped to engage in research and practice aimed at promoting full and meaningful inclusion in society, as well as social and economic justice, for individuals on the autism spectrum. Short- and long-term goals that provide the social work profession with a framework to engage in research, practice, education, and advocacy aimed at supporting individuals on the Autism spectrum and their families were highlighted (Bishop-Fitzpatrick et al, 2018).

A study conducted by the Minnesota School Social Workers Association examined the role of school social workers in supporting parents of children with autism spectrum disorder (ASD). The survey revealed that the most common support provided by social workers was connecting parents to community resources, acting as a liaison between school and home, and providing emotional support. The study also highlighted the need for further research to understand the stressors faced by parents and develop effective interventions (Marnie et. al., 2012).

There is limited information in the literature that discusses the role of school social workers who work with children with autism spectrum disorders. Therefore, literature on the general role of social workers will be applied to understand the role

of a school social worker. There are many roles a social worker has when working with children with an autism spectrum disorder and their families. Literature on this topic discusses social workers' roles from an ecological perspective including collaboration with a multidisciplinary team, involvement in the assessment process, supporting and involving family members, providing support to the school, and advocating for policy changes. School social workers have an important role when working with children who have Autism spectrum disorders. One role is providing interventions for students. There is a paucity of literature on the interventions that school social workers use for children with Autism spectrum disorders. The only intervention found in the literature was the use of group therapy (VanBergeijk & Shtayermman, 2006; Dababnah et. al., 2010).

When working with children with an autism spectrum disorder, one important role is collaborating with other individuals in the child's life including parents, paediatricians, psychiatrists, physical therapists, psychologists, teachers, speech therapists, neurologists, occupational therapists, and other service providers (VanBergeijk & Shtayermman, 2006).

Social worker encounter children with Autism spectrum disorders in a range of areas, including child welfare settings, schools and day cares, social service organizations, governmental benefit offices, hospitals, clinics, and mental health treatment centres (Dababnah et. al., 2010).

The role of a school social worker involved with special education students includes identifying their needs, participation in assessment process, providing services and advocating for their needs. When working with children with autism spectrum disorders the social worker has the role of educating classmates, parents, and the community about the disorders because they are often misunderstood (Wood, 2011).

Collaborating with a multidisciplinary team, school social workers are involved in the assessment process for special education services (MSSWA, 2011; Levy, Mandell, & Schultz, 2009, Johnson et al, 2005). The assessment should take an

ecological perspective, focusing on the student as well as their interaction with the school environment, home, and community (NASW, 2002).

The social worker should include parents, siblings, and teachers in the assessment process because they are a valuable source of information about the child's development (VanBergeijk & Shtayermman, 2005).

Social workers should be comfortable identifying the early signs of autism spectrum disorders and using screening tools to determine if a child is at-risk for an autism spectrum disorder or other delays (Dababnah et al., 2011). Examples of these screening tools include the Checklist for Autism in Toddlers, Modified Checklist for Autism in Toddlers, Autism Behavior Checklist, and the Pervasive Developmental Disorders Screening Test-II – Developmental Disorders Screener (Baird & Charman, 2000; Robins, Fein, Barton, & Green, 2001; Krug et al., 1980; Siegel, 2004). Screening tools are not diagnostic instruments; they are used as an aid in assessing for risks of autism spectrum disorder (Dababnah et al., 2011).

Direct service with children, the school social worker provides support to other members of the child's ecosystem including parents, siblings, teachers and classmates. Families of children with autism spectrum disorders may need education and support after learning about the diagnosis (Dababnah et al., 2011).

Despite the important roles social workers serve, many are not trained to recognize or advocate for children with autism spectrum disorders and their families (Dababnah et al., 2010). A study including 23 social workers who work with children with disabilities in a British county reported inaccuracies in their understanding of characteristics associated with autism spectrum disorders (Peerce & Jordan, 2007). Almost 60 per cent of the 23 social workers believed Autism spectrum disorders were not fully developed until after three years of age. In fact, onset is found earlier and generally occurring before three years of age (American Psychiatric Association, 2000; Dababnah et al., 2010; Volkmar & Pauls, 2003). This suggests the need to educate and train social workers in early screening for autism spectrum disorders.

1.7 Policies and Programmes

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was adopted in 2006 which is the most important international treaty in protecting the rights of persons with disabilities including autism. Article 12 of the United Nations Convention on the Rights of Persons with Disabilities reaffirms equal recognition before the law for all people with disabilities and underlines that they have an inalienable right to exercise their legal capacity on an equal basis with others. UNCRPD emphasises non-discrimination, equal opportunities, accessibility and full participation in society. UNCRPD also requires signatory countries to adopt laws and policies that support people with disabilities. India also signed the UN convention on the 30th March 2007 (UNCRPD, 2006).

The Constitution of India also highlights various provisions securing the right to justice and equality of status in the community.

- Article 14- They like every citizens of India are equal before the law.
- Article 15(1) - The Government cannot discriminate any Indian including the person with autism on the ground of religion, caste of sex.
- Article 15(2)- Every citizens including the people with disability cannot be discriminated on any grounds for the access of any public places.
- Article 17- Autistic people cannot be treated as untouchable which is a punishable offence.
- Article 21- Every person has a right to life and liberty. It also includes right to education for the children with autism in the age group of 6 to 14.
- Article 23- Prohibition of forced labour.
- Article 24- Prohibition of employment of children under the age of 14 years.
- Article 32- Right to seek constitutional remedy and can move to the Supreme Court by filing Writ Petition.
- Article 300A- No person shall be deprived of the right to property. (Government of India. (1950). Constitution of India)

Under Sections 80DD and 80U of the Income Tax Act 1961 states that people with disability have the right to enjoy earnings of tax concession.

The First Legislation in India pertaining to Autism was passed in the National Trust Bill- National Trust for Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act 1999 which resulted in the establishment of the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation, Multiple Disability and other related conditions.

The Rights or Persons with Disabilities Act which was reviewed in 2016 which considers Autism as one of the 21 recognised disabilities. It gives certain rights and facilities to the autistic people so that they can live their lives in a better way and not be deprived because of their disorder. Under the Act, 4 per cent of the people with disabilities can be given employment in Government establishment. And the person who has the disability benchmark of 40 per cent is entitled to certain benefits.

The Rehabilitation Council of India (1992) is another initiative of the Indian Government that was formulated to train and guide special educators in India. It also plays a pivotal role in setting and upholding the minimum standards for the education and training of diverse professionals in this field. This initiative also introduced special diploma courses for educators in this field.

The Scheme for Implementation of the Persons with Disabilities (PwD) Act, 1995 (SIPDA) in Mizoram is a government initiative that is designed to enhance the rights and welfare of persons with disabilities (PwDs). This initiative is a component of India's dedication to the United Nations Convention on the Rights of Persons with Disabilities. SIPDA advocates for the establishment of accessible infrastructure in public structures. A variety of government offices and public spaces in Mizoram have been retrofitted with ramps, railings, adapted toilets, and elevators to ensure physical accessibility for PwDs as part of this initiative. The Directorate of Social Welfare Department, District Commissioner offices, and the Secretariat Complex in Aizawl are among the most notable examples. Through a variety of initiatives, SIPDA enables individuals with disabilities to achieve economic recovery. The National Handicapped Finance Development Corporation (NHFDC) scheme provides loans to persons with disabilities (PwDs) through the Mizoram Rural Bank. Training centres in Aizawl and Lunglei provide one-year courses in shoemaking,

needlework, and tailoring, as well as hostel accommodations. Stipends for pupils: Financial assistance is offered to pupils with disabilities at various educational levels. A monthly allowance is provided to persons with disabilities who have been registered with the Employment Exchange for a period exceeding two years without a placement.

The Rights of Persons with Disabilities Act, 2016, is overseen by the Office of the State Commissioner for Persons with Disabilities, Mizoram which was established in 2012. This office ensures the redress of grievances, promotes public awareness of the rights of Persons with Disabilities, and monitors compliance with accessibility standards.

The Samagra Shiksha- Inclusive Education_aims to integrate children with disabilities, including those with autism spectrum disorder into mainstream school from cl 1- X11. The key features include provisions of aids and appliances, learning materials and allowances. It also includes barrier free access in schools to ensure accessibility to classrooms, laboratories, libraries and toilets. Teachers are also being trained through Samagra Shiksha in special education to support children with disabilities.

Deendayal Disability Rehabilitation Scheme is a Central Scheme under the Ministry of Social Justice and Empowerment that provides financial assistance to voluntary organizations working for the education and rehabilitation of persons with disabilities including Autism. Examples of such institution in Mizoram are : Samaritan Society for the blind, Spastic Society of Mizoram etc. Spastic Society of Mizoram is one of the first NGO that supports parents with Autistic Children in Mizoram and started the only Centre for Autism in Aizawl, Mizoram through Gilead Special School.

The Mizoram State Legal Services Authority implements the NALSA Scheme, 2015 to provide legal aid to individuals with mental disabilities including autism through free legal assistance and sensitization programs for legal and medical professionals to better support with individuals with disabilities.

Though programmes and policies exist, the situational analysis and scenario in India in the field of Autism Spectrum Disorder is found to be quite deplorable, especially in northeast and particularly in Mizoram. Cases of Autism spectrum disorder is increasing year after year with some improvement in awareness and diagnosis. These increasing cases has to be met with an atmosphere where provisions not only exist but are made used of in the fullest capacity. This research therefore intends to be a window that helps open up research discourses in the area of Autism spectrum disorder.

1.8 Statement of the Problem

Social work as a profession deal with autism and its related disorders, however not much work has been done in working directly with the individual itself but continuously work with the caregivers in terms of rendering social work services at home and deals with emotional burden and coping strategy. Social work specialist working with an autistic child and their caregsivers are very much needed especially in an area where there is shortage of mental health professionals especially in a remote area like Mizoram where there is less opportunity for receiving in depth training. The role of a Social Worker is to understand and adapt their ways of working to accommodate the complexities and challenges a life with autism presents. The challenge of social worker involves working with care givers, family, and friends and moreover the individual itself, giving awareness and home-based intervention in this area is crucial as our society view autism as a disease and sever disability whereas in fact if given proper intervention can result in better prognosis and improvement in functionality.

Since there is a dearth of literature about knowledge and intervention practices of caregivers of children having autism spectrum disorder and Social Work as a profession must explore the possible best practices to respond to their needs, and explore what social work can do grounded on its own theories and practices and inculcate in its own community.

Children with disabilities are the most vulnerable population in a society. They face challenges such as poverty, poor health, stigmatization, and discrimination. Among the persons with disabilities, children suffering from autism spectrum disorder face more challenges with respect to the disability itself and even in research and society at large. The complexity of this type of disability is such there are very few people who understand the nature of the problem and once identified; it is too late for the child to be rehabilitated.

It can also be noted that among children with disabilities, children with Autism spectrum disorder are misunderstood most and even care givers have little knowledge and understanding about the issue and how it can be identified early and on how intervention can be taken for rehabilitation. Besides this, though western literature exists, there is very little research undertaken at the national and local level that can give a concrete understanding about the knowledge, attitude and caregiving and practices undertaken by caregivers of Children with Autism Spectrum Disorder. Keeping this in view, the research intends to fill this gap and come up with the reliable data in understanding the same.

1.9 Rationale of the Study

Autism Spectrum Disorder is still relatively unknown in Mizoram, as it is in many other parts of India, particularly among carers. Research can support in identifying the knowledge gaps and misunderstandings that hinders early diagnosis and action.

It is also important to understand that cultural attitudes and traditions can influence how people interpret and view the diagnosis of autism spectrum disorder. This research will also help in understanding how our cultural beliefs, stigma and family dynamics affect the caregiving and access to services.

Children with autism spectrum disorders rely heavily on both primary (parents, grandparents etc) and secondary caregivers (professionals). The researchers can analyse the carers challenges and how they are coping effectively which can suggest suggestive measures for intervention. Caring for someone with ASD can be

difficult on an emotional, physical, and economical level. This research will explore and analyse the lived experiences of primary and secondary caregivers in Mizoram and help in understanding the gaps and filling the same to enrich knowledge and academic discourse in the area of Children with Autism Spectrum Disorder.

1.10 Objectives of the Study

The objectives of the study are as follows:

1. To profile the demographic characteristics of primary and secondary caregivers of children with autism spectrum disorders in Mizoram.
2. To assess the knowledge on autism spectrum disorders among primary and secondary caregivers of children with autism spectrum disorder in Mizoram.
3. To assess the attitude of primary and secondary caregivers towards children with autism spectrum disorder.
4. To explore the practices of primary and secondary caregivers of children with autism spectrum disorder in Mizoram.
5. To find out the differences in knowledge, attitude and practices between primary and secondary caregivers of children with autism spectrum disorder in Mizoram.
6. To find out the relationship between knowledge, attitude and practices of primary and secondary caregivers of children with autism spectrum disorder in Mizoram.
7. To find out the challenges faced by primary and secondary caregivers of children with autism spectrum disorder in Mizoram
8. To find out the coping strategies of primary caregivers of children with autism spectrum disorder

9. To suggest measure for social work intervention and social policy in the field of autism spectrum disorder.

1.11 Chapter Scheme

The Chapter Scheme has been arranged as follows:

Chapter I: Introduction

Chapter II: Review of Literature

Chapter III: Methodology

Chapter IV: Results and Discussion

Chapter V: Conclusion

CHAPTER II

REVIEW OF LITERATURE

Many social workers look for adequate guidance, assessment, and intervention methods and use research and evaluation methods to support their theories and practices. A review of the literature is essential, and it helps the researcher understand the theoretical background and findings of different scholars in various aspects. For any type of scientific research work, theoretical knowledge is the basis for understanding the concepts, theories, models, methods, and different perspectives thoroughly. However, secondary data is the only source that helps the researcher get the information as well as analyses the present situation of the problem in the theoretical context. The purpose of this chapter is to find and review the existing literature related to the prevalence, the knowledge, attitudes, intervention practices, challenges and coping mechanisms of primary and secondary caregivers of children with Autism spectrum disorders and identify the research gaps.

2. 1 International Literature

Research on caregivers with autism spectrum disorders are mostly conducted in western countries. In recent years, there has been increasing awareness about autism spectrum disorders around the world, including in low- and middle-income countries. Unlike countries in Western Europe and North America where infrastructure and capacity are available to help meet some of the needs of individuals with ASD, little expertise or capacity exists in most of the developing world. (Wallace et al, 2012).

Hall et. al., (2012), studied the diagnosis of autism for children (from birth to age 21) continues to increase, with the current rate being 1 in 110 children in the US. Besides financial strain, families often experience reduced quality of life due to disruptive behaviours related to autism. Results also suggest the levels of disruptive behaviours associated with autism vary, community support can be but is not always helpful, and that the family's ability to cope with the challenges of autism is important to the family.

Pang et. al. (2018) revealed that the predicted incidence of autism spectrum disorder in China has continuously been lower than that seen in most Western research. The underestimated prevalence could be attributable to a number of factors including irregularities in monitoring and diagnostic procedures, variances in translated instruments, and conflicts between diagnostic criteria. This review gives insight into autism spectrum disorder evaluation and diagnosis in the Chinese population and explores methods for the continued advancement of ASD detection and intervention in mainland China.

Literature on parents' experiences in obtaining an autism diagnosis for their children is limited. A pilot research was done involving four parents of children with autism in North Wales to explore this matter. Semi-structured interviews were performed to gather parents' experiences, and the responses were evaluated utilising a grounded theory methodology. Six fundamental types emerged. These encompassed parents' challenges in comprehending their child's behaviours, the resultant perplexity from their failure to interpret these behaviours, and difficulty in securing a diagnosis. The results also indicate parents' sense of relief following the accurate diagnosis. This facilitated their comprehension and acceptance of autism and its constraints on their child; enhanced adaptation to the condition within family dynamics; and cultivated more pragmatic expectations regarding their child's future (Midance & O'Neill, 1999).

Parents of children with ASD face significant challenges in obtaining a diagnosis, often waiting until 5-6 years old. This long and stressful process involves multiple professionals and assessing the child's development. Delaying treatment can lead to higher functioning in individuals with ASD, emphasizing the importance of early intervention. A study conducted by the Autism Society of British Columbia in British Columbia found that parents of children with autism typically become concerned about their child's language and social development around 23 months of age. The majority of parents wait 5-6 months before consulting a professional about their concerns. The average age of the child was 5 years, with boys diagnosed at 4.5 years and girls at 6 years (Siklos & Kerns, 2007).

There is a constant paucity of knowledge on autism spectrum disorders everywhere in the world. According to a study by Liu et. al. (2016), most participants firmly felt that more services should be provided for kids with autism spectrum disorder and were ignorant of organizations that specialize in ASD as well as scientifically validated intervention techniques.

Alshaigi et. al. (2023) also found that parents experienced stigmatization and that family requires psychiatric attention to help them cope with their new predicament. A greater amount of enacted stigma indicates a need for their rights (as individuals with ASD) and improved societal awareness.

The diagnosis and treatment of Autism in Pakistan occurs in multiple settings and is provided by variety of health professionals. Unfortunately, knowledge and awareness about Autism is low among Pakistani healthcare professionals & the presence of inaccurate and outdated beliefs regarding this disorder may compromise early detection and timely referral for interventions. A study assessing the knowledge and misconceptions of healthcare professionals in Pakistan regarding autism found that there is a lack of understanding and awareness about the disorder. The study involved 154 physicians and 93 non-physicians, assessing their knowledge of DSM-IV TR criteria, beliefs about social, emotional, cognitive, treatment, and prognosis. The results suggest that current professionals have an unbalanced understanding of Autism due to misconceptions about developmental, cognitive, and emotional features. The study calls for continued education for healthcare professionals across disciplines regarding Autism in Pakistan (Divan et. al., 2011)

Studies conducted in Saudi Arabia by Alyami et. al. in 2022 on attitudes and knowledge regarding autistic spectrum disorder revealed that participants had a low degree of understanding of the condition. Additionally, they suggest that government funding should be made accessible to support educational assistance for kids with ASD. The government should devote more funds and resources to helping children with autism spectrum disorders, and public spaces need to be modified to

accommodate the requirements of individuals with ASD. Various media channels should help to improve the community's understanding of ASD and its attitude toward ASD sufferers through well-informed educational efforts. The goal of educational efforts should be to increase public awareness of the causes and treatments of ASD.

There is little information on the attitudes of the general adult populations towards individuals with autism. There are studies that look at knowledge of autism as a representation for attitude towards people with autism (Tipton & Blacher, 2014; Campbell & Barger, 2011). Nonetheless, these studies are limited due to the lack of established connection between knowledge and attitude in the area of autism spectrum disorders. This limitation, could be because while knowledge about autism may influence attitudes, other factors such as personal experiences, cultural perceptions, and media representations may also play significant roles. It is essential to acknowledge that perceptions of individuals with autism are influenced by a multitude of intricate circumstances, beyond mere comprehension of the illness. Knowledge gaps, misconceptions, or preconceptions regarding autism may adversely affect views. Conversely, pleasant personal interactions with individuals with autism can foster more favourable attitudes, regardless of one's inadequate knowledge about the illness. The absence of a definitive correlation between knowledge and attitude in autism research may also arise from the methods of measuring knowledge (e.g., theoretical versus experiential knowledge) or the evaluation of attitudes (e.g., implicit versus explicit attitudes). It indicates the necessity for more sophisticated study that considers various aspects of both knowledge and attitudes, along with wider social and cultural influences (Jacoby, 2015).

According to research, children may become more socially isolated if developmental disorder indicators are not identified early, which can make subsequent interventions more challenging. After receiving a diagnosis, parents' expectations for family life drastically change, which can cause mental anguish (Volkmar & Wiesner, 2009; McConachie & Diggle, 2007). The parent will become more isolated from the outer world and the therapeutic intervention will be more

challenging, resulting in the child beginning the recovery program later. This is especially true if the parent is unaware of the symptoms the child is exhibiting. Parents start to form particular sentiments and attitudes towards their problematic child at the moment of diagnosis or earlier, when they first observe the signs.

Tipton & Blacher (2014) conducted research entitled "*Autism Awareness: News from a Campus Community*," published in the Journal of Autism and Developmental Disorders in 2014. The research examined the knowledge and attitudes of autism spectrum diseases among more than 1,000 university students, faculty, and staff. The results demonstrated that those with firsthand experience of autism possessed more precise information, while demographic factors including age, education, and university role affected degrees of autism knowledge.

Campbell & Barger (2011) in their study, "*Peers' Knowledge About and Attitudes Towards Students with Autism Spectrum Disorders*," was included in the Comprehensive Guide to Autism (2014). This chapter analyses the impact of middle school students' comprehension of autism on their attitudes towards classmates with autism, emphasizing the significance of educational interventions in fostering positive opinions.

Studies shows that negative attitudes and stigmas are correlated with a person displaying autistic behaviours; the more extreme the behaviours, the less willing the person is to interact with the disabled individual (Butler, 2011).

A study completed by Gillian et. al. (2009) stated that families embraced attitudes of optimism, acceptance, and gratitude, while endeavouring to modify their surroundings or fulfil their children's needs to the best of their ability with their children of autism spectrum disorder and down syndrome. These viewpoints afforded families a sense of optimism, significance, and agency regarding their circumstances. Their results demonstrate the fortitude and perseverance of families when confronted with life's challenges. Myers et. al. (2009) found that parents' experience with autism also made them understand the world of disability and advocating for other parents who are going through same sort of difficulties.

Anwar et. al. (2018) completed a study to determine the awareness and understanding of autism among parents in Karachi, Pakistan. They observed that the Karachi population has a lack of knowledge and understanding about autism. Their study further suggested that awareness initiatives be implemented to increase parents' knowledge of autism, allowing for early assessments and proper treatment plans/therapy.

A study findings indicated that video-assisted instruction effectively improved knowledge, fostered a positive attitude, and promoted best practices among primary carers in the care of children with ASD. The findings also will assist mental health nurses, psychologists, intellectual disability nurses, educators, public health professionals, social workers, and others in recognising the significance of video-assisted teaching programs concerning the care of children with ASD, as well as in encouraging primary carers to engage in such programs. The community mental health nurse can develop a video-assisted educational program in the community focused on the care of children with ASD. The outcome of the study demonstrate that video-assisted instruction is successful in improving the knowledge, attitudes, and practices of primary carers concerning the care of children with ASD. Continuous awareness in primary health centres and community areas is essential to enhance the knowledge, attitudes, and practices of primary carers (Chandran et. al., 2019).

A study in Pakistan found that 44.6 per cent of General Practitioners (GPs) have knowledge about autism, with those under 30 and those with a medical degree in the last 5 years reporting more knowledge. However, many General Practitioners still hold misconceptions about autism's signs, symptoms, and etiology (Rahbar et. al., 2010).

There is a paucity of research about preservice teachers' knowledge and beliefs about children with autism spectrum disorder and their integration into general education classrooms, particularly in early childhood education. A study was undertaken by Barning et. al. (2011) regarding the knowledge and attitudes of pre-

service teachers in early childhood education. The research findings revealed that preservice teachers possessed insufficient knowledge and maintained fundamental misconceptions regarding autism spectrum disorder and the requirements of children with autism spectrum disorder in inclusive classrooms. Participants expressed a need for further knowledge in this domain and generally endorsed inclusion; nevertheless, they had ambivalent opinions regarding the inclusion of children with more severe disabilities and their prospective responsibilities in an inclusive classroom. The discussion also encompassed the implications for both collegiate and non-collegiate preparation, as well as in-service training for early childhood educators.

According to Wang et. al. (2019) a study on autism awareness and attitude towards treatment in caregivers of children aged 3- 6 years in Harbin, China, a total of 2,786 respondents, representing 57.8 per cent, were able to identify ASD. The acknowledgement of autism was influenced by gender, geographic location, age, and educational attainment. Regarding attitudes towards mental health service use for ASD, 4,007 respondents (84.6%) opted to seek therapy from a health organization; 2,470 (68.2%) selected consultation with a psychotherapist. There exists significant potential for enhancement in awareness of ASD and its treatment among Chinese communities. Lack of understanding regarding ASD and negative perceptions of mental health services may hinder early identification and intervention attempts. Health education and promotion are essential to enhance individuals' understanding of autism spectrum disorder (ASD) and the mental health treatments accessible to them. There is a large room for improvement in awareness about ASD and treatment in the Chinese communities. Insufficient knowledge about ASD and inappropriate attitudes towards mental health service use may impede the efforts of early identification and intervention. Health education and promotion are needed to improve people's knowledge about ASD and available mental health services

Hayat et. al. (2019) measured health care providers' understanding of the increasingly common autism spectrum disorder, as well as their opinions of its prognosis, management, and parallels with other specialties. They concluded that

Saudi Arabian healthcare practitioners don not know enough about autism spectrum disorders.

Early signs of autism appear during the initial two years of life, with a credible diagnosis available by 24 months of age. Caregivers' awareness of autism is critical for early diagnosis. However, research on caregivers' understanding of autism in countries with low or middle incomes is limited. A study completed by Rena et. al. (2020) concluded that the severe lack of information of autism among Nepalese caregivers highlights the need to improve awareness among caregivers of all ages, educational levels, and caste/ethnic groups to facilitate early detection of autism.

A child who has been diagnosed with autism causes ongoing stress in the family unit, affecting not only the caregivers but also siblings and family connections (Higgins et al., 2005). The child with autism often requires a significant amount of parental attention and effort (Tarakeshwar & Pargament, 2001). Mothers of autistic children have been observed to be more stressed and have difficulty adjusting than mothers of children with various physical and intellectual disabilities (Pakenham et al., 2005). According to research, the burden of caring falls primarily on the mother, with husbands assisting with monitoring rather than providing healthcare or domestic activities.

The diagnosis of ASD is a significant challenge for the family, leading to a shift in perspective and a profound sense of the necessity for assistance and adjustment to the new circumstances (Critchley et al., 2021). Parents initially anticipate the birth of a healthy kid who will mature into an autonomous adult; when this expectation is unmet, they must recalibrate their aspirations and future plans for both themselves and their child (Baña, 2015; Cuevas et al., 2018). This suggests highlighting the necessary environmental modifications for the family to attain happiness and well-being (Hsiao, Higgins, Pierce, Whitby, & Tandy, 2017). Stress reduction is a variable that enhances the quality of life for families with children diagnosed with ASD (Hsiao et al., 2017; Wang et al., 2020). Parents of children with Autism spectrum disorder (ASD) exhibit significant psychological discomfort, notably anxiety (Shepherd, Landon, Goedeke, & Meads, 2021), and mothers of children with ASD

experience elevated stress levels compared to mothers of children with other disabilities (McStay, Trembath, & Dissanayake, 2014).

Compared to other forms of challenges, parents of children with autism seem to be more likely to experience sadness, anxiety, social isolation, exhaustion, and difficulty in receiving proper diagnosis and treatments. Bouma & Schweitzer (1990) discovered that Autism causes more family stress than cystic fibrosis (CF).

Primary carers of children with autism spectrum disorder (ASD) encounter numerous problems that may affect their mental health and overall well-being. Due to their responsibilities in childcare, it is imperative that primary carers are acknowledged as healthcare consumers deserving of interventions aimed at enhancing health, well-being, and quality of life (QOL). Interventions predominantly address the needs of the child, leaving deficiencies in meeting the requirements of the primary carer. The mental health and welfare of the primary carer is crucial for the child with ASD to thrive and reach their full potential. Consequently, the incorporation of the social, emotional, and health requirements of the primary carer must be explicit, with defined objectives aimed at enhancing quality of life within treatments (Fewster et. al., 2020).

A study completed by Hoefman et. al. (2014) examines the effects of caring on parents of children with autism spectrum disorders. They also examine the concept validation of the care-related quality of life instrument, which assesses the impact of caregiving. Primary carers of children with autism spectrum disorders were included. Numerous parents encountered significant challenges in balancing daily activities with caregiving, faced financial difficulties, or experienced negative moods. Validity assessments indicated that a greater influence of caregiving on the care related quality of life correlated positively with increased subjective load and diminished family quality of life. The study also concluded that while many parents derived fulfilment from providing care for their child with an ASD, this caregiving affected their own lives considerably and in a variety of ways.

Grey (1993), Sharpley, Bitsika & Efremidis (1997), and Kaminsky & Dewey (2002) emphasize the critical components of parenting a kid with autism spectrum disorders. These include: The protracted and arduous procedure of obtaining a diagnosis, a) The enduring characteristics of autism spectrum disorder, b) autism spectrum disorder is not widespread in the general population, although this is gradually changing, c) The lack of social and, at times, familial acceptance of autistic behavior, d) Minimal social support e) Highly disruptive or antisocial behavior.

Stuart & Grew (2009) assessed demand in three domains: the family, the married couple, and the individual caregiver. Most families expressed significant distress after learning of their child's condition. Increased burden was strongly and consistently predicted by the severity of symptoms, increased accumulation expectations, peer support, and the adoption of inactive avoidant coping techniques.

Hall & Graff (2010) completed a pilot study that focused on conducting focus group discussions with parents of children with autism to allow parents to express their concerns about parenting a child with autism and to address techniques parents can use to cope with these challenges. Parents clearly want and need knowledge about autism. Parents indicated services and resources that need to be expanded and developed to better meet their child's needs. These findings corroborate prior studies in which families expressed a need for collaboration with healthcare practitioners. Nurses are frequently the initial point of contact for autistic children and their families, and they can help parents and healthcare providers collaborate more effectively.

Compared to parents of usually developing children, caregivers of children with autism spectrum disorder (ASD) face higher levels of stress and more serious adverse effects from their role. 20.84 (4.72) was the average overall felt stress score. This was seen as being above average. Caretakers of ASD children with learning disabilities, those who reside far from the medical facility, and those who lack the means of transportation to the treatment facility were all found to have higher levels of perceived stress. They are more likely to experience sadness, anxiety, social isolation, exhaustion, and difficulty in receiving proper diagnosis and treatments. In

summary, parents of children with ASD experienced a great deal of stress when caring for their kids. For the benefit of children and ASD families overall, institutions should reduce the variables that were anticipated to raise the caregivers' perceived stress (Adib et al, 2019).

Papadopoulos et. al. (2021) revealed three interrelated themes associated with challenges faced by parents' emotional load (a), family stress (b), and social weight (c). The mothers' sense of vulnerability, anguish, and load. The results offer important insight into the experiences of women in one of the medium-income countries of Europe who are raising children with ASD.

Minhas et. al., (2015) found that in in South Asia: thoughts from Pakistan and India, In South Asia, the mothers bear nearly all the care giving responsibilities, which elevate their stress levels. A child who has been diagnosed with autism causes ongoing stress in the family unit, affecting not only the caregivers but also siblings and family connections (Higgins et. al., 2005). Mothers of autistic children have been observed to be more stressed and have difficulty adjusting than mothers of children with various physical and intellectual disabilities (Pakenham et al., 2006). According to research, the burden of caring including depression falls primarily on the mother, with husbands assisting with monitoring rather than providing healthcare or domestic activities (Dogra et. al.,2017).

Children diagnosed with autism spectrum disorder (ASD) need thorough therapy and well-rounded care. Because of the emphasis on training for the children, mothers of children with ASD frequently fail to recognise their mental health issues. Mothers who experience stress and depression may find it difficult to provide their children with the kind of care and therapy they need. According to a study by Selvakumar et al. (2020), the mothers' quality of life was reduced and they had signs of worry and depression. They nevertheless shown constructive coping mechanisms. Addressing mothers' psychological anguish and coping mechanisms is also necessary as part of an all-encompassing intervention for kids with ASD.

Parents of children with ASD reported higher objective and subjective burden, more frequent psychological distress, lower social support. Mothers reported greater subjective burden than fathers. Structural equation modelling showed that the most consistent positive and negative predictors of objective and subjective burden were ASD symptom severity and social support, respectively. Other positive predictors were engagement, distraction and disengagement coping, intellectual disability, and adaptive functioning. Other negative predictors were spiritual wellbeing and hardiness. Some effects were indirect through social support and coping strategies. Parents of children with ASD carry a huge caregiving burden, and added to the understanding of the factors associated with burden (Picardi et. al., 2018).

A study completed by Sheri et. al., (2017) analysed maternal stress, coping strategies, and support needs among mothers of children with Autism Spectrum Disorder. Results showed that 77 per cent of mothers experienced significant stress, and 62.4 per cent identified unmet needs. The most common unmet needs were financial support, break from responsibilities, understanding other children, rest/sleep, and hope. Most coping strategies were helpful, and both coping strategies and support needs predicted maternal stress.

The study completed in Saudi Arabia in light of the Covid 19 found that mother's opinions toward caring for their children with ASD were more impacted by the age of the kid and the parents. In addition, parents' concern during the COVID-19 pandemic was noticeably more than it was prior to the pandemic. It was discovered that the relationship between stress and the perception of mental health care was mediated by the mental health of parents during COVID-19. Lastly, the open-ended questions revealed that throughout the pandemic spread, parents sought assistance from therapists, teachers, and family members to deal with children who had ASD. In addition to financial and psychological support, other methods such as online courses and training sessions were suggested in regard to perceived mental health care. The study's conclusions emphasized how crucial it is for the government and local health authorities to promote the introduction of interventions for parents and kids with ASD in order to enhance mental health in general (Youssef et. al., 2021).

Rivard et. al. (2014) study showed that fathers felt higher levels of anxiety than mothers. Correlations revealed that both parents' stress levels were related to their child's age, cognitive quotient, severity of autism symptoms, and adaptive behaviour. The degree of severity of autistic symptoms and the gender of the child predicted paternal anxiety, and but not maternal stress.

Bonis (2016) study on Autism spectrum disorder parents found higher stress levels, impacting their mental health and ability to care for the child. Understanding these challenges can guide research, intervention development, and practice. Recommendations include early diagnosis, addressing disparities, availability of therapy, and stress management for parents.

Kourkoutas et. al. (2012) shed light on how autism affects a child's development at various phases and how parents manage their family's schedule and finances, as well as how to include their impaired child in the community and attend school. The results also point to the need of creating family-cantered programs that improve parenting abilities and assist parents in managing intensely upsetting feelings and challenges.

Tathkur & Kang (2021) investigated the worries that parents of ASD children have. The findings indicated that raising a kid with ASD presents a number of difficulties for caregivers, which can have a detrimental effect on their physical and mental health as well as how society views them and their ability to manage their finances. There are numerous challenges faced by caregivers of children with ASD. Health care providers need to be aware of these issues and offer the knowledge and training necessary for improved management. Moreover, the results of this research hold policy implications for health authorities in terms of bettering health services for children with ASD diagnoses.

Ting et. al. (2018) conducted a study on affiliate stigma and depression among caregivers of children with Autism Spectrum Disorders in China. The findings indicated that affiliate stigma was frequent and severe among caregivers of autistic children; their depressed symptoms were much more significant than the

national average for the same age group. A lack of self-worth, high shame proneness, and low family flexibility were linked to affiliate stigma and increased depressive symptoms. Affiliate stigmatized partially mediated the relationship between self-esteem, shame proneness, family adaptation, and depression levels. This was the first quantitative study to assess affiliate stigma among caregivers of children with ASD in mainland China. The findings emphasize the importance of de-stigmatization for caregivers of autistic children and suggest that interventions that boost self-esteem, reduce feelings of shame, and improve family functioning may be successful.

Bakracevic et. al. (2021) conducted a study to assess the levels of anxiety, depression, and stress among Slovenian parents of children with autism spectrum disorder, as well as their coping techniques. The respondents did not indicate any clinically significant levels of stress, depression, or anxiety. However, mother's experienced more stress and anxiety-related symptoms than fathers. The findings revealed that positive interpretation and growth coping methods were positively connected to increase felt social support and life satisfaction, while being adversely related to despair and anxiety. Perceived social support has a strong negative correlation with anxiety. Individuals with higher levels of education utilized acceptance strategies substantially more often.

According to Hall et. al. (2012), the number of children in the US receiving an autism diagnosis (from birth to age 21) is currently 1 in 110. Families frequently endure a lower quality of life in addition to financial hardship as a result of disruptive behaviours associated with autism. The findings also imply that the degree of disruptive behaviours linked to autism varies, that community assistance can be beneficial but is not always so, and that the family's capacity to manage the difficulties caused by autism is crucial.

Illias et. al. (2018) conducted a study on factors related to stress and resiliency among the parents of children with autism spectrum disorder (ASD) in Southeast Asia (SEA). The study revealed six primary characteristics as being linked to parenting stress such as financial hardship, social support, the severity of autism symptoms, parents' perceptions and comprehension of ASD, parents' anxiety and

concerns about their child's future, and religious views. These six elements could potentially be classified as coping mechanisms or resilience strategies that may lessen the stress associated with parenting, or as a cause of parenting stress.

According to the literature, one of the biggest problems that families, especially mothers, face is parental emotional overload. Delays in receiving a diagnosis, managing the diagnosis and accompanying symptoms, and having limited access to social and medical resources were the primary sources of stress. Information sharing between impacted families and the use of an integrated healthcare network to support patients and their families were the most common coping mechanisms identified. Strong effects of ASD on family relations lead to caregiver overload, particularly in mothers. Health system faced challenges in caring for children with autism spectrum disorder (ASD), including parental emotional overload, diagnostic postponement, and poor access to health services. Strengthening the patient-family dyad and promoting full development are crucial for these families. To support the complete development and social inclusion of children with ASD, health systems must offer comprehensive, ongoing, and coordinated care. Coping strategies include information exchange and integrated healthcare networks. (Gomes et. al., 2015). Studies also indicate that parental coping tactics included problem-focused techniques like nutrition control and childcare, as well as emotion-focused techniques like faith in spirits, prayer, and spiritual healing. (Gona et. al. 2016).

Caregiver of those with autism spectrum disorder is constantly subjected to high stress levels. As a result, such stress is linked to an increased risk of poor health outcomes. However, few researches have examined the effectiveness of psychotherapy therapies to enhance wellbeing in this population. A study completed by Nicolas et. al. (2015) concluded that caregivers reported decreased levels of stress immediately following the intervention compared to baseline, as well as less physical complaints, lower levels of depressive disorders, and higher mood states at one month. Their findings also support the effectiveness of the cognitive-behavioural therapy designed to reduce stress and health problems in persistently stressed caregivers. Furthermore, the training may be beneficial in the early phases of the

caregiving process, providing caregivers with helpful methods for avoiding future health concerns. The program's integration into broader psychosocial interventions would be extremely useful to this population.

Providing care for individuals with Autism spectrum disorder can be emotionally and physically taxing. Studies indicate that carers of individuals with ASD frequently endure elevated levels of stress, anxiety, and despair. The perpetual requirement for oversight, addressing behavioural issues, and implementing suitable interventions may result in carer burnout and emotional exhaustion. Furthermore, the erratic nature of autistic symptoms, encompassing social and communication challenges, repetitive behaviours, and sensory sensitivity, exacerbates the complexities of caregiving (Karst & Hecke, 2012).

Parents of children with autism spectrum disorder (ASD) encounter conflicting obligations when attending to their child's needs and managing familial responsibilities. The impact of family commitments and parental stress on the utilisation of intervention programs for young children with ASD remains uncertain. Twenty-five percent of children were not receiving any intervention services; 26 per cent were receiving one service; and 49 per cent were receiving two or more interventions. Perceived developmental delay and the absence of a sibling in the household were correlated with increased likelihood of seeking intervention services. Children were more inclined to receive several services if their parents possessed at least a college degree and exhibited low stress levels. The study determined that elements such as perceived developmental stage, parental stress, and sibling caregiving may influence access to resources for children with ASD. The study findings indicate that conflicting family demands may hinder service utilisation. Mothers of children with ASD who have many children, possess poor educational attainment, and have elevated stress levels may require supplementary assistance or alternate service delivery models (Elizabeth et. al., 2018).

A study by Herring et. al. (2006) indicates that carers of children with ASD experience elevated stress levels relative to carers of children with other developmental impairments. The emotional well-being of carers is exacerbated by cultural and financial demands, including expenses related to special schooling, therapy, and medical care (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005).

The lifetime characteristic of autism in a child has significant ramifications for parents, who encounter a variety of obstacles and emotional costs in parenting the child. Parents who have a child with autism face numerous obstacles in all parts of care, which affects their stress and adaptability. To ensure the family's well-being and quality of life, health treatment should be family-centred, addressing and supporting the needs of the entire family rather than just the affected child (Lynn et. al., 2016).

Li et al. (2023) investigated the societal support and distress of autistic children's caretakers. Their findings point to a strong mediation influence of self-esteem on the relationship between social support and depression, implying that obtaining greater social support reduces depression levels by enhancing ASD caregivers' self-esteem. Shilubane & Mazibuko (2020) found that coping strategies were associated with additional ASD awareness initiatives to improve parents' understanding of the illness, understanding parents' cultural attitudes about ASD to improve parents' coping skills, caregivers' awareness and preconceptions of ASD, lack of understanding, cultural beliefs, prayer, a strong support system, and acceptance.

Lopez et. al. (2015) indicated that emotional support networks, such as family and peer groups, play a significant role in helping caregivers manage the emotional strain associated with caregiving.

According to Giallo et. al. (2014) carers with robust social support networks experienced reduced carer stress and enhanced overall quality of life. Support groups for parents of children with ASD offer carers a sense of community and comprehension, which is crucial in alleviating feelings of loneliness and powerlessness.

A study completed by Sumbane (2024) on the coping strategies adopted by caregivers of children with autism in the Limpopo Province, South Africa reveals that caregivers of autistic children often use emotion- and problem-focused coping strategies to manage their emotions and cope with the stress of raising their child. The research, which involved 28 caregivers from public special schools, found that positive coping strategies like positive reappraisal and acceptance, negative coping strategies like denial and overprotection, and problem-focused coping strategies like active coping, peer group support, and professional support. These strategies can be integrated into intervention programs and guide specialized institutions.

Parents and carers of children with ASD have reported considerable stress and difficulties in caregiving. Nonetheless, research on stress coping mechanisms among parents and carers of children is still insufficient. The methodological constraints of previous studies were examined. The review completed highlighted the necessity for additional investigation on the coping strategies of parents and carers of children with ASD (Lai et al, 2010).

Research shows that moderate cohesion and adaptability in a family are linked to higher positive coping strategies. Parents of autistic spectrum disorder children with enmeshed families implemented more positive coping strategies, suggesting that this style may be more adaptive. However, mothers perceived more social support from family and friends (Altieri et. al., 2008).

Four mediators were identified by an exploratory factor analysis in a study by Sartor et. al. (2023). These mediators were dysfunctional coping, functional coping, social support, and self-efficacy. Parental stress and everyday demands were found to be significantly mediated by the use of dysfunctional conduct and parental self-efficacy. It was discovered that demands had a direct impact on parental stress, suggesting some partial mediation. It was also discovered that cognitive functioning and assistance were not important mediators. Key findings show that dysfunctional coping increases parental stress and strong parental self-efficacy decreases parental

stress brought on by the daily difficulties of parenting children with ASD. It follows that in order to lessen the stress brought on by the many demands of daily life, parents of children with ASD should reduce the dysfunctional coping mechanisms they use and increase their sense of self-efficacy.

The severity of the child's symptoms and the specific challenges associated with the disorder (e.g., behaviour problems, communication issues) have a significant impact on caregivers' stress levels and the coping strategies they employ. Caregivers of children with more severe symptoms tend to use more emotion-focused coping and report higher levels of stress and burden (Meyer et. al., 2011).

According to Twoy et al. (2007), as coping strategies, the parents looked to friends for support and encouragement, to other families who were going through similar issues for informal assistance, and to organizations and programs for official support.

According to studies conducted by Chin et. al. (2023), they found that coping mechanisms of parents of children with autism spectrum disorder included acceptance and adaptability, management, support, and communication. Additionally, referrals to specialized consultation with social workers or therapists, textbooks, web-based services, and parent support groups are examples of help and resources that should be considered.

Shilubane & Mazibuko (2020) found themes associated with coping strategies of parents such as lack of understanding, cultural beliefs, prayer, a strong support network, and acceptance. According to their findings, additional awareness initiatives about ASD should be conducted to raise parents' comprehension of the illness. Understanding parents' cultural attitudes about ASD may improve parents' coping skills. Further, Hall & Graff (2010) found that knowledge about autism and expanded and developed services and resources help parents cope better with their challenges.

Ismael et. al. (2018) completed a study on the coping strategies among caregivers with autism spectrum disorder through a cluster analysis using secondary data from 273 survey responses. Four distinct groups were identified: Social-Supported/Planning, Spontaneous/Reactive, Self-Supporting/Reappraisal, and Religious/Expressive. The Social-Supported/Planning group used planning, instrumental social support, and emotional social support more than the other three groups. The Spontaneous/Reactive group used less restraint and suppression of competing activities. The Religious/Expressive group used religious coping and venting of emotions more. They also suggest that future research should investigate differences between groups of caregivers based subjective strain.

Caregivers who use a combination of adaptive coping strategies—such as seeking professional help, engaging in self-care practices, and utilizing social support—tend to report better mental health and a higher quality of life. Furthermore, caregivers who experience lower levels of stress are better able to provide support and care for their children with ASD, which contributes to more positive outcomes for the child (Lee et. al., 2018).

Catalona et. al. (2018) identified the key qualities of interventions supporting the mental health of parent carers and proposed practitioner and suggest that practitioner guidelines for supporting the mental health and well-being of parents and carers should involve addressing the parent's self-perspective taking and ability to solve real-time problems.

Depape & Lindsay (2015) found that parents' experiences of raising a child with Autism spectrum disorder influenced the creation of family-focused programs and services, offered guidance to medical professionals advocating on behalf of parents, and supplied parents—especially those whose children have just received an ASD diagnosis—with useful information.

A study conducted by Samadi (2020) on parental views and emotions about autism spectrum disorder in Iran concluded that Iranian parents had their own unique justification for their experiences with ASD, and that early childhood development

and strategies must be understood within a cultural context. Culturally informed research on ASD is critical for raising awareness of the necessity of recognizing parental concerns and the need for educational and psychiatric supports in countries where autism is under diagnosed, misunderstood, or even ostracized. Understanding the differences in ASD meaning across cultures encourages stakeholders including service providers and legislators to understand and value cultural and individual differences in the twenty-first century.

The intervention landscape for Autism spectrum disorder (ASD) is complex, incorporating several therapeutic methods designed to meet the unique requirements of persons with ASD. The interventions related to autism spectrum disorder seek to augment communication, social competencies, cognitive functions, and adaptive behaviours, ultimately elevating the quality of life for individuals with ASD and their family. There is a lot of discussion about the therapeutic usefulness of behavioural and developmental therapies for addressing the basic signs and symptoms of autism spectrum disorder. Because no single behavioural or developmental intervention helps all symptoms in all people with autism spectrum disorder, clinical therapy should be based on individual requirements and resource availability (Ospina et. al., 2008).

Treatment of Autism spectrum disorders (ASD) is challenging. The perspective of parents/caregivers on the success of therapies and supports provided to their children is crucial but often overlooked in ASD literature. Conclusion of this study: Better education and awareness are required to assist ASD youngsters and their families. Pharmacists should look on ways to give better services (Breik et. al., 2018).

There is a constant paucity of knowledge on autism spectrum disorders everywhere in the world. According to a study by Liu et. al. (2016), most participants firmly felt that more services should be provided for children with Autism spectrum disorder and were ignorant of organizations that specialize in ASD as well as scientifically validated intervention techniques.

Children with Autism spectrum disorder needed intense behavioral training. Intervention practices may differ. Children with autism spectrum disorder need early intervention. Best practices guidelines must be developed for early assessment and diagnosis at a young age. The well-researched programs use applied behavioral analysis principles to provide treatment. (Odom et al., 2003; Dunlap, 1999; Merlin & Simpson, 1998; National Research Council, 2001; Rogers, 1998).

Horany et. al. (2011) investigated the efficacy of group cognitive behavioral treatment on depression among Muslim parents of autistic children in Jordan. The results showed that the participants' depression decreased with time; 50 per cent of the variability in depression among the participants may be attributed to the group counselling 55 therapies. This suggested that the experimental group outperformed the control group in terms of depression by 56 per cent among conclusion; this study suggested that group cognitive behavioural therapy is an efficient therapy for depression among parents of autistic children.

Tylor (1998) examined the behavioural family intervention as a means of enhancing parenting techniques. The use of behavioural family interventions and other scientifically proven approaches should be combined. Additionally, behavioural family interventions should be used more widely. Finally, a public health approach on family functioning should be adopted, involving researchers, clinicians, and policymakers working together.

The US National Research Council (NRC) Committee on Educational Interventions for Children with Autism (2001), based on a comprehensive, evidence-based report, suggested that early therapy for children with ASD makes a clinically significant difference for many children in terms of better-than-expected gains in IQ scores, language, autistic symptoms, future school placements, and several measures of social behaviour. It is therefore recommended that EI be delivered to children up to the age of eight years for a least of 25 hours per week year round (both one-on-one and in small groups). The significance of a goal-oriented, evidence-based, tailored

program that satisfies the requirements of both children with Autism and their families was emphasized.

Cridland et al. (2013) published a comprehensive review of family-focused research on autism spectrum disorder. Family Systems Approaches are suggested as an accepted theoretical framework for upcoming family-focused autism spectrum disease research by taking into account theoretical notions like boundaries, ambiguous loss, resilience, and traumatic growth, according to an evaluation of their usefulness. They added that there are restrictions on the body of current literature and that family-focused research on autism spectrum disorder might still be view as relatively new.

A study on educational and therapeutic treatments for families of autistic children was carried out by Jocelyn et. al. in 1998. They contrasted day care services only with an enhanced intervention. Compared to the day-care along group, parents participating in the group obtaining support and education services reported higher levels of satisfaction, enhanced feelings of control and more understanding towards autism.

Zhou et. al. (2018) found that challenges of primary caregivers included stigma, lack of self-worth, high shame proneness, and low family. Affiliate stigma partially mediated the relationship between self-esteem, shame proneness, family adaptation, and depression levels. The findings emphasize the importance of de-stigmatization for caregivers of autistic children and suggest that interventions that boost self-esteem, reduce feelings of shame, and improve family functioning may be successful.

According to Pakenham, Sofronoff & Samios (2004), it is important to strengthen the interventions for caregivers by policy making. There is a need for more studies to understand the effectiveness of the coping strategies provided to the parents. Effective and sustainable psycho-social programs are needed to provide for supporting the parents (Malhotra, Khan & Bhatia, 2012). To further facilitate this

process, future interventions could employ cognitive restructuring techniques to enhance benefit finding and sense making.

Jocelyn et. al. (1998) conducted a study on educational and support interventions for families of children with autism. They compared an enriched intervention with day care services alone. The parents in the group receiving education and support services had gains in knowledge about autism, increased perceptions of control, and improved satisfaction in comparison to the day care only group.

Studies related to psychological management of parental stress Koegel et al (1972) studied the consistent stress profiles in mothers of children with autism. Results suggested the importance of developing treatment programs aimed at reducing stress in specific areas in families with autistic children.

Various parent training interventions have been shown to have some effect on the symptoms of children with autism. There is an urgent need for experts in various international centres to jointly standardise a parent training intervention for children with autism and carry out a large scale study to assess its clinical and economic effectiveness. (Shoumitro et al, 2020)

Children with Autism spectrum disorder required intensive behavioural training. The intervention practices may vary. Children with Autism spectrum disorder require specific intervention at an early age. The development of best practices guidelines is required with early assessment and screening at a very young age. The well-researched programs are treatment based on the principles of applied behavioural analysis. (Odom et al.2003; Dunlap 1999; Merlin and Simpson, 1998; National Research Council, 2001; Rogers, 1998) which represents a wide range of Early Intervention strategies for children with Autism Spectrum Disorder.

2.2 National Literature

There are few studies carried out in India on the population with Autism spectrum disorders. Currently the needs of the children with autism in India are not being met in either the regular or special education systems. Children with autism are frequently refused admission in special schools because officials protest that they are not equipped to handle these children. Children with autism going to typical schools helps to develop better social interaction and communication skills among them. Parents whose children were attending school were found to be using more of problem focused coping when compared to parents whose children were not going to school. Children with autism has difficulty to fully understand and comprehend what is happening in the environment, which make interventions with them more intensive, systematic and long term process. Short periods of hospitalization may not work with them (Uthaman, 2008).

While Autism spectrum disorder is globally recognized, studies related to it has expanded significantly only within the last two decades. A study completed by Raina et al (2017) in Himachal Pradesh have estimated that a prevalence of 0.9 per cent among children aged 1-10 years. Another study by Arora et. al. (2018) in Chandigarh estimated 0.87 per cent among children aged 1.5-10 years using the INCLIN Diagnostic Tool for Autism Spectrum Disorder. A study on “*A Narrative Review of Autism Spectrum Disorder in the Indian Context*” completed by Srivastava et. al. (2024) explored the current state of knowledge about autism spectrum disorder in the Indian context. The findings indicated that the prevalence of autism differed among various research conducted in India. The research identified advanced paternal age, foetal distress, gestational respiratory infections, labour complications, preterm birth, neonatal jaundice, delayed birth cry, birth asphyxia, late initiation of breastfeeding, neonatal seizures, maternal hormonal intervention, and consanguinity as risk factors for Autism spectrum disorder. Parents and families of children with autism endure a multifaceted adverse experience, both within the family unit and outside the community. This adverse experience is exacerbated by the deficiency of awareness and accessibility to suitable professional assistance and resources. There is an urgent

necessity for services that assist parents in managing the stress associated with raising a child with autism.

Assessment and management of children with Autism spectrum disorders (ASDs) in the developing countries such as India fall far behind in child psychiatry, much alone autism spectrum disorders. Bhat et. al. (2019) provides valuable insights into the socio-demographic profiles of families with children diagnosed with Autism spectrum disorder (ASD) in Bangalore, India. The research highlighted that a significant portion of children with ASD in rural areas (70%) do not receive any intervention or schooling, indicating a gap in access to services. Furthermore, the study notes that most children who do receive therapy attend private clinics, as government healthcare services for ASD are still in the early stages and primarily focus on diagnosis and research rather than comprehensive intervention.

India is the world's second-most populous nation. Even though this nation has a sizable population under the age of twenty, little is known regarding the frequency and prevalence of many developmental diseases. The study completed by Raina et. al., (2015) determined the rate of Autism spectrum disorders in the tribal, rural, and urban areas of Himachal Pradesh. The prevalence rate, according to the data, is 0.9/1000. In the rural area, the highest rate of prevalence was noted. According to the study's conclusion, socioeconomic status (SES) may be a key marker for autism spectrum disorders in India.

There is a lack of evidence-based estimate of the population prevalence of Autism spectrum disorder (ASD) in India. A study conducted in Kolkata by Chauhan et. al. (2019) involving 11,849 school children, aimed to estimate the prevalence of Autism. The weighted prevalence estimate of Autism spectrum disorder was found to be 0.23 per cent, suggesting that the true prevalence might be higher, especially considering that approximately 20 per cent of children in the state are not enrolled in the school system. The scarcity of high-quality population-based epidemiological studies on ASD in India highlights an urgent need to study the burden of ASD in India.

A study conducted by the Institute for Communicative and Cognitive Neurosciences (ICCONS) in Kerala, India, found that there are an estimated 23.3/10,000 individuals with Autism spectrum disorder (ASD) in a semiurban community. The survey, conducted in Shoranur, found that 43 individuals were diagnosed with ASD during phase I screening, with a male-to-female ratio of 2.1:1. The prevalence of ASD is higher in the age group of 6-10 and 16-20 years (Poovathinal et. al., 2016).

Arun & Chavan (2021) completed a survey of Autism spectrum disorder in Chandigarh, India. The study was planned to assess the community based prevalence of autism spectrum disorder in Chandigarh, India. The study employed a sufficient sample size, utilised a screening tool with elevated sensitivity and specificity, and the final diagnosis was determined by a conventional diagnostic instrument and clinical interview conducted by a seasoned physician. The study suggested that the prevalence among boys and girls was nearly identical, contradicting the existing data. This suggests that certain males may have been overlooked. Notwithstanding these constraints, this study contributes significant evidence to the current literature and the little data regarding the incidence of autism in India. This studies also suggest that the prevalence of suggest that of ASD in Chandigarh was in tandem with other reports from across India and was lower than western countries.

According to Chauhan et al, (2019), autism spectrum disorder (ASD) is a developmental disorder that has significant implications for public health. Not just children and their parents are impacted. The nation's expenses related to health care, education support, and rehabilitation services are also affected, both directly and indirectly. An evidence-based assessment of the incidence of ASD in India's population is lacking. To ascertain the incidence of ASD in the Indian community, a systematic review was conducted. The studies' findings were incorporated into the systematic review. One of the four included research that examined populations in both urban and rural areas, whereas the other three focused solely on urban populations. Four investigations carried out in an urban setting indicated a pooled percentage prevalence of 0.09 (95% confidence interval (CI) 0.02–0.16) in children

aged 0–15 years, whereas the study from the rural setting revealed a pooled percent frequency of 0.11 (95% confidence interval (CI) 0.01–0.20) in children aged 1–18 years. There is a pressing need to investigate the prevalence of ASD in India due to the dearth of excellent population-based epidemiological research on the disorder in that country. Better data collection regarding the prevalence of ASD in India would improve the development of rehabilitative programs in our nation.

Although the prevalence of Autism spectrum disorder (ASD) is similar in many social, ethnic, and geographic groupings, developing nations such as India have substantially lower both the quantity and quality of ASD-related services and resources. Furthermore, societal influences have a significant impact on the lives of individuals with ASD. Harman (2014) offers valuable insights into the challenges faced by individuals with autism and their families in India. This study, conducted as part of the SIT Graduate Institute's India: Public Health, Policy Advocacy, and Community program, involved interviews with 17 parents of children with ASD and observations of ASD-related organizations in Jaipur and New Delhi. The findings highlighted significant influences of socioeconomic and cultural factors on the experiences of individuals with ASD. The study noted a scarcity of appropriate ASD-related resources in India, compounded by stigma and lack of awareness, which hindered access to quality treatment and intervention. Efforts by non-governmental organizations to address these issues were often limited by insufficient governmental support and funding. Moreover, stigma and lack of awareness further hindered quality and accessibility of treatment and intervention.

Many children with Autism spectrum disorder continue to lack timely and adequate treatment due to persistent shortcomings in early diagnosis and intervention. A significant barrier is that parents often do not have sufficient information or understanding about autism, its potential impact, or the intervention and support strategies available. Early identification is critical for children with ASD to lead fulfilling lives. Research by Aluri & Karanth (2002) highlights that most parents initially discussed their concerns with pediatricians, with specialists such as speech-language pathologists, psychologists, and special educators being consulted

later. Parents reported that they initially consulted pediatricians regarding their child's problem. Professionals such as psychologists, speech language pathologists and special educators were often consulted later. Parents reported that early referrals to these professionals for appropriate intervention would have helped and stressed the need for this information being made available to medical practitioners. Parents emphasized the need for medical professionals to be better informed about autism and underscored that earlier referrals to appropriate specialists could have significantly improved outcomes (Singhal & Gupta, 2005).

Inadequate awareness of the illness among family members and primary care professionals causes a delay in diagnosis and proper treatment. Children with autism as well as their parents face a great deal of stigma and discrimination. Specialized services are hard to come by, mostly found in cities, and out of reach for most people. Creating networks of family and community support might be one of the intervention strategies used to provide the primary caregiver a break. Community members, including health professionals in the community, traditional practitioners, and even determined family members, could be trained to identify, and offer evidence-based interventions in their absence of specialists. To attain more inclusivity, efforts to raise awareness should be implemented alongside task-shifting measures. Research indicates that raising an autistic child or a child with neurodevelopmental disorders can be more arduous than parenting a child who achieves developmental milestones, particularly in the absence of adequate support systems, as shown in low- and middle-income countries. According to the findings on the perspectives of autism and developmental disorders among carers of children in an urban environment in New Delhi, India, there was a need for an essential necessity for enhanced community awareness and acknowledgement of autism in India, such as through community and healthcare training, which could mitigate stigma and promote broader familial support (Estrin et. al., 2023).

A study in Goa demonstrated the feasibility of using the WHO-CST program with children with social communication challenges. The program, which included group sessions and home visits, was found to be acceptable and feasible, with parents

reporting reduced stress and gains in their own skills and knowledge (Brian et. al,2024).

Parents of children with Autism spectrum disorder may experience significant stress associated with obtaining an ASD diagnosis and managing the therapeutic options. Parent education programs provide a method for delivering support, information, and resources to families after a child's diagnosis. Due to the diversity of these programs, research has advocated for enhanced characterization and systematic assessment of this parent-focused intervention. The study completed by Milgramm et. al. (2022) delineates the framework and substance of a community-oriented, group-format parental education initiative for families of children recently diagnosed with ASD. Post-program participation, parents indicated less parenting stress, enhanced knowledge and empowerment, and elevated satisfaction levels.

The knowledge of parents on the topic of Autism Spectrum Disorder is increasingly high, but however it needs to be systematic and structured. It was also found that parents are too overprotective in caring for their child, when the child was unable to sleep or sleep too much, parents were constantly alarmed and more stress when the child is not acting normally as the day before. Parents and other close relatives must make significant adjustments because of their child's developmental handicap. There is a huge need for competent service providers who are willing to work with individuals, families, and society as entirety (Gupta & Singhal 2005). Because of the scarcity of skilled specialists in India, parents must act as co-therapists in their children's therapy (Uthaman, 2008).

Raju et. al. (2023) conducted a study on the quality of life of Indian parents of children with Autism spectrum disorder and how socio-demographic factors relate to it. The results highlight the need for intervention techniques focused on enhancing support services, helping family's function, and helping parents create healthy coping mechanisms.

The diagnosis of Autism spectrum disorders (ASD) is growing in emerging nations like India. On the other hand, nothing is known about the lives of parents who have an ASD child. In order to better understand the unfulfilled requirements of families raising a child with ASD, Divan et. al. (2012) completed to explore the perspective of families in Goa, India. The research results indicated that parenting a child with ASD places a great deal of stress on families because of conflicting obligations, which frequently results in early social disengagement followed by reintegration into social networks. Second, the effects are multifaceted, affecting not only the individual but also the larger community through adverse experiences with prejudice. Third, parents proactively address these issues using a variety of strategies with assistance from both new and established social support networks as well as medical professionals. Fourth, there is a significant financial and emotional strain placed on families by professionals in the health, education, and religion fields who are not well-versed in the special needs of families with ASD. Ultimately, a number of unmet requirements can be found as a result of these experiences, most notably those for assisting more solitary families and the restricted availability of interdisciplinary based on evidence services for ASD. There are also findings where caring a child with ASD influenced the quality of relationships with other family members, sometimes resulting in marital conflicts between spouses, increasing difficulties between parents and other children, and tense relationships between the usually supportive extended family networks

Patra and Kumar (2020) conducted an extensive scoping assessment of research on Autism spectrum disorder in India with the goal of gaining a general understanding, identifying gaps, and developing evidence- based suggestions for more research. Numerous study themes, including biomarkers, clinical profiles, treatments, psychological in nature community, epidemiological and risks factors were found. The state of the art indicates to encompass evidence-based intervention studies, the adaptation and translation of standard diagnostic tools and qualitative research on the lived experience of autism. Studies on biomarkers, risk assessment, and epidemiology, however were of poor quality. The findings also indicate that for a thorough assessment of the true burden and biology of autism in India, national

research on epidemiology, biomarkers, and risk factors with representative sampling are required. Designing implementation research is also necessary in order to assess the efficacy of evidence-based therapies in everyday health care settings. They suggest that in order to better understand autism and its outcomes in India, future research should close these gaps.

Autism is a neurodevelopmental disease necessitating ongoing preventive, therapeutic, and rehabilitative management for the kid. Parenting children with autism spectrum disorder has numerous obstacles. The absence of awareness, accompanying stigma, misdiagnosis, and inadequate management affect parents' life in multiple dimensions. Islam et. al. (2024) conducted a study on “*Quality of life, treatment-seeking pathways, and out-of-pocket expenditures of parents with children diagnosed with autism spectrum disorder (ASD) in South Delhi*”. Their findings reveal that the quality of life of parents was harmed across multiple domains, with the psychological domain being the most significantly impacted. The age of parents influenced the social domain. Delays in symptom identification, diagnostic confirmation, inadequate treatment service availability, and the lack of integration of rehabilitative programs were significant deficiencies in the treatment-seeking process. The median out-of-pocket spending constituted 16 per cent of monthly familial income. The study recommended that community awareness, sensitization of the medical community, and the integration of all services for management and rehabilitation are essential for enhancing the quality of life for parents. Financial assistance via health programs, NGOs, or insurance is an essential change to mitigate catastrophic health expenditures.

Autism spectrum disorders (ASD) are increasingly recognized in developing countries like India. However, little is known about the experiences of parents raising a child with ASD. A qualitative study completed by Divan et. al. (2012) on the “*Challenges, coping strategies and unmet needs of families with a child with autism spectrum disorder in Goa, India*” aimed to describe the experiences of families in Goa, India with a view to understanding the unmet needs of families raising a child with ASD. Twenty in-depth interviews and nine focus group discussions were carried

out with families of children with ASD and key community stakeholders such as special educators, teachers, and parents of typically developing children. This qualitative data was triangulated to explore the experiences, life impact, and unmet needs of raising a child with ASD. Key findings suggest that raising a child with ASD puts a tremendous strain on families due to competing commitments, often leading to initial social withdrawal with later reintegration into social networks. Second, the impact is multidimensional, involving the personal sphere but also extending into the wider community with negative experiences of discrimination. Third, parents actively respond to these challenges through a range of approaches with help from existing and new social support networks and health care providers. Fourth, professionals from the health, education, and religious sectors have a low awareness of the unique needs of families living with ASD which leads to a considerable economic and emotional burden on families. Finally, as a consequence of these experiences, several unmet needs can be identified, notably for supporting increasingly isolated families and the limited access to multidisciplinary evidence-based services for ASD.

A study conducted by Manohar et. al. (2019) titled *"Brief Parent-Mediated Intervention for Children with Autism Spectrum Disorder: A Feasibility Study from South India"* assessed the acceptability and feasibility of a succinct parent-mediated home intervention for children with Autism spectrum disorder (ASD), designed for resource-limited settings, with an emphasis on mitigating parental stress from a socio-cultural perspective. Fifty children aged 2 to 6 years, diagnosed with Autism Spectrum Disorder per DSM-5 criteria, were randomised into an intervention group (n = 26) or an active control group (n = 24). The intervention, employing a naturalistic developmental behavioural approach and focussing on joint attention, imitation, social, and adaptive skills, was scheduled to take place during five outpatient sessions within a 12-week timeframe. All children were observed at 4, 8, and 12 weeks. Parents of children in the intervention group indicated more significant enhancements in parental stress and child outcome measures than those in the control group. The intervention was considered acceptable and feasible, exhibiting strong fidelity metrics and retention rates.

The COVID-19 pandemic has induced anxiety and mental health issues in the general populace. Parents of children with Autism spectrum disorder (ASD) have a higher prevalence of anxiety and overall bad health compared to parents of children without ASD. During COVID-19, parents of children with ASD are likely to endure heightened symptoms of anxiety, despair, and deteriorating mental health. This may be attributed to the emergency measures that encompassed school closures, the suspension of essential services, the implementation of a work-from-home policy, and insufficient professional support, among other factors. A study conducted by Choudhury & Chandel (2022) aimed to examine the psychological well-being and the effects of perceived pressure on parents during the COVID-19 epidemic in eastern India. Parents of 290 children engaged in an online survey that investigated demographics, views and utilisation of tele-rehabilitation, routine home care therapy, parental discomfort, and psychological well-being. Data analysis revealed the prevalence of symptoms associated with depression, anxiety, and stress at 65.5 per cent, 20.6 per cent, and 37.4 per cent, respectively. A significant difference was observed in perceived strain across parents ($p < 0.001$, effect size = 0.92). Parents in remote regions lack awareness of tele-rehabilitation, resulting in its inefficient use for rehabilitation, which is associated with heightened risks for mental health issues. A negative perception of homecare therapy is substantially associated with increased psychological symptoms and mental distress. The current study revealed an increased prevalence of depression and a significant change in parental stress during the sudden COVID-19 pandemic.

Research indicates that a poor prognosis of Autism spectrum disorder may be exacerbated by familial stress. Family system indicators include things like inadequate support networks, inadequate financial resources, and stress within the family that can lead to a bad prognosis. Negative attitudes and a lack of assistance are examples of environmental risk factors that might negatively impact a kid with autism's prognosis. One particularly significant study finding is that prior to intervention parental levels of stress may be one of the most powerful indicators of

initial intervention program performance. However, adaptive coping mechanisms, informal social support sources, and views about the efficiency of interventions were linked to decreased stress levels. Thus, the combined impact of individual, familial, and systemic risk factors impacts the child's development. Further, finding of particular importance is that pre-intervention parental stress levels may be one of the strongest predictors of the success of early intervention programmes. However, adaptive coping strategies, informal social support sources and beliefs about the efficacy of the interventions were associated with lower levels of stress. Thus, the combined effects of individual, family, and systems risk factors influence the development of the child. (Gupta & Singhal, 2005).

Caregiving for individuals with Autism spectrum disorder presents significant challenges, but caregivers employ a range of coping strategies to manage these demand. A Qualitative Study from South India completed Ray et al (2024) on the lived-in experiences of caregivers of autistic children was executed in a tertiary care hospital located in Bangalore, India The lived experiences illuminate the various emotional, social, psychological, and physical distress that carers endure daily. The everyday challenges faced by each carer are distinct and formidable. Five themes and their respective subthemes were identified: emotional breakdown, alteration in family dynamics, spiritual transformation, felt social burden, and outlook on a child's future. The study concluded that carers of children with autism have numerous problems, including physical and mental distress, financial limitations, and the loss of a fulfilling social life on a daily basis. Interventional strategies, including nurse-led clinics, counselling initiatives, and training sessions for carers to address the diverse challenges encountered by carers, could be implemented to mitigate the escalating concerns of carers of children with autism.

The stress experienced by caregivers can affect family relationships. In Chennai, India, research indicated that aggressive behaviours in children with ASD contributed significantly to parenting stress. However, families that accepted the diagnosis early and sought professional help reported better family relationships (Karupannan et al, 2022).

According to Uthaman (2008), given that autistic children struggle to fully absorb and appreciate what is going on in their surroundings, interventions with them must be more thorough, methodical, and prolonged. Brief hospital stays might not be effective for them.

A study completed by Dalwai (2017) on the effect of multidisciplinary intervention on clinical outcomes of children with autism spectrum disorder in Mumbai, India analysed the functional changes in children with Autism spectrum disorder (ASD) before and after a multidisciplinary developmental intervention program in Mumbai, India. The intervention included occupational therapy, speech therapy, and parental counselling. The results showed significant positive changes in functional ability in most sub-scales, except socialization. The intervention was individualized to each child and was compared to the Childhood Autism Rating Scale (CARS) and Vineland Social Maturity Scale (VSMS).

In India, various interventions exist for children with Autism spectrum disorder (ASD), although they frequently encounter obstacles in mainstream education. They are frequently assigned to specialized institutions and regarded as having intellectual disability. The government provides multiple programs but necessitates a disability certificate. A study conducted by Bharat et. al. (2022) on the current interventions for autism spectrum disorder in India, involving 20 organizations, found that just two employed mainstream diagnostic instruments, while the remainder utilized screening tools. The inconsistent application of fully established and translated autism diagnostic instruments complicates the accurate estimation of autism prevalence in India. The primary issue encountered by these organizations is their tendency to address only symptoms temporarily, while parents frequently transition between therapy facilities, so constraining the long-term efficacy of their therapies. Among the data provided by the seven organizations, only one presented a five-year longitudinal study, demonstrating a 90 per cent success rate in integrating into mainstream or independent living. Of the remaining six organizations, only two reported their short-term results, and one of them offered a case study involving three youngsters utilizing sensory integration. Most organizations concurred that their

primary challenge lies in the fact that, despite employing various interventions, they could only manage symptoms temporarily. Additionally, another issue encountered is that the parents of these children frequently transition between therapy centers, hindering the observation of long-term outcomes from the interventions administered. The study's findings indicate that, despite the availability of numerous treatments in India, 90 per cent of organizations are unable to publish their short- or long-term results. There exists minimal hope for these youngsters, necessitating a program with clearly defined outcome-based interventions. The program must be located close to their residence, as they are long-term issues. Like the western nations, the school should spend in accommodating the needs of these children and offer early help. Certain children possess innate talents, necessitating governmental adaptation of the curriculum to ensure these gifted individuals do not remain unutilized in society.

According to Aluri (2000) and Karanth (2002), based on personal interviews of parents with Autism Spectrum Disorder in Bangalore City 1999-2000 based on personal interviews of parents with open ended questions indicated that while behavioural, communication and special education services were the most sought after by families, all these services were not available at any one centre, necessitating that the families travel miles together with their little child on a daily basis in order to avail these services. It was concluded that multidisciplinary intervention through a team approach under one roof was urgently needed to support children with autism spectrum disorder.

2.3 Regional and Local Literature

Autism Spectrum Disorder is not known commonly in India let alone in Mizoram. The more people are aware of the disorder the more it is easier for caregivers to give out their interventions. A lot of stigma and discrimination is associated with children with disabilities.

Autism spectrum disorder (ASD) in Northeast India is inadequately studied, with scarce information regarding its prevalence and awareness. There is a paucity of literature concerning studies on Autism spectrum disorder in North-East India, particularly in Mizoram.

A study completed by Das et. al. (2017) evaluated the parental stress levels, social support, coping strategies employed by families and resilience in addressing caregiving problems in North -East India. Their results indicated that majority of parents exhibited personal time constraints, which negatively impacted their professional lives. Caregivers often experience heightened levels of stress, anxiety, and depression due to the demanding nature of supporting a child with ASD. Despite these challenges, families demonstrated resilience and effective coping mechanisms.

Despite a multitude of stressors, family members have effective coping mechanisms to function cohesively in challenging situations. Responses concerning secondary social support from family, friends, and neighbors were varied; religious and spiritual outlets were frequently utilized. Although social desirability, weariness, and the limitation of a single-center sample were constraints, this study also illuminates significant difficulties concerning families with children with autism in a location where specialized center are few. The future implications may center on Children with Autism's (CWA) prospects, rehabilitation, care, and parental issues, which are significantly overlooked in North -East India.

Khanal & Misra (2017) completed a study on the, *"Intervention strategies for the learners with Autism Spectrum Disorder: A case study of Sikkim Spastic Society"*. The study highlighted that the Special Education Centre of the Sikkim Spastic society focuses on addressing the needs of autistic learners, including communication and social deficits. Intervention strategies focus on developing functional skills, such as task-breaking, eye contact, and relationship building, to help autistic learners perform daily tasks independently. Social skills development, such as peer interaction and imitation activities, is also crucial. However, awareness among parents, teacher training, and clinical and medication shortages are needed for effective implementation of these strategies.

2.4 Research Gap

There is still a substantial lack of comprehensive, region-specific literature that addresses the many facets of autism spectrum disorder in India let alone Mizoram, despite the fact that there is a growing amount of research on autism spectrum diseases in India. Through the synthesis of previously conducted research and the provision of an in-depth analysis of autism spectrum disorder (ASD) prevalence, diagnostic methods, intervention techniques, and social impact within the setting of India, the purpose of this literature review is to fulfil the aforementioned need.

The research literature also reveals a gap in research among secondary caregivers at the international and national level. There is ample research on impact but very few of knowledge, attitude and practices.

By concentrating on Mizoram and India, the purpose of this review is to bring attention to the difficulties and opportunities that are specific to the treatment of autism spectrum disorder in a growing nation that has a diverse cultural fabric. The findings are intended to provide important information to policymakers, healthcare professionals, educators, and researchers in India and Mizoram with the goal of encouraging an approach to autism spectrum disorder management that is more inclusive and effective.

CHAPTER III

METHODOLOGY

This chapter serves as the foundation for the research study, detailing the systematic approach used to collect, analyse and evaluate the data. In this chapter, the setting of the present study and methodology are presented with description of the research process and designs that were used.

3.1 Field of the study

The field of study was Mizoram covering 8 Districts out of 11 Districts namely Aizawl, Lunglei, Champhai, Serchhip, Khawzawl, Kolasib, Mamit and Lawngtlai

Mizoram is a state in north-eastern India, with Aizawl as its capital and largest city. It shares 722-kilometres (449 miles) of international borders with Bangladesh to the west, and Myanmar to the east and south, with domestic borders with the Indian states of Assam, Manipur, and Tripura. It covers an area of 21,087 square kilometres (8,139 sq mi). Ninety-One per cent of the area is covered by forests, making it the most heavily forested state in India. With an estimated population of 1.25 million in 2023, it is the second least populated state in India. With an urbanisation rate of 51.5 per cent, it is the most urbanised state in northeast India, ranking fifth in urbanisation nationwide. One of the two official languages and most widely spoken tongue is Mizo. Mizoram is home to the highest percentage of scheduled tribes and literate persons in India with Mizos forming the majority.

Figure 1: Map of Mizoram



Source: exploremizroam.com

Aizawl is the largest city as well as the capital of the state of Mizoram in India. The city is located north of the Tropic of Cancer in the northern part of Mizoram. The district occupies an area of 3577 Sq. kms. According to the 2011 census Aizawl district has a population of 400,309. Aizawl has a sex ratio of 1009 females for every 1000 males, and a literacy rate of 98.5 per cent.

According to the 2011 census Lunglei district has a population of 161,428. As of 2011 it is the second most populous district in the state, after Aizawl. It covers an area of 4536 Sq.kms. Lunglei has a sex ratio of 947 females for every 1000 males, and a literacy rate of 88.86 per cent.

Champhai is one of the eleven districts of Mizoram. The district is bounded on the north by Churachandpur district of Manipur state, on the west by Saitual and Serchhip districts, and on the south and east by Myanmar. The district occupies an area of 3,185.83 Sq.kms. According to the 2011 census Champhai district has a

population of 125,745. Champhai has a sex ratio of 984 females for every 1000 males, and a literacy rate of 95.91 per cent.

Serchhip is another district of Mizoram. The District has a population of 64,937 according to the 2011 census. The District area covers 1421 Sq. kms. The average literacy rate of Serchhip in 2011 was 98.76 per cent. Male and Female literacy in 2011 were 99.24 per cent and 98.28 per cent respectively. The district is located right in the central part of the State. The district is bounded on the north and northwest by Aizawl District, on the west and south by Lunglei district, on the southeast by Myanmar (Burma), and on the east by Champhai District.

Khawzawl is one of the new designated districts of Mizoram created in 2019. Khawzawl is 152 km away from Aizawl. It covers an area of 78 Sq.kms. The total population of the district is 42,355 as on 2023. The district has a high literacy rate of 96.64 per cent where male literacy is 97.39 per cent while female literacy rate is 95.86 per cent. It shares borders with Saitual to the north, Champhai district to the north-east and east, Serchhip district to the north west, west and south.

Kolasib district is in the northern part of Mizoram. Situated along the border with the state of Assam, Kolasib is an important transit point connecting Mizoram with the rest of India. The town is known for its strategic location and serves as a gateway to Mizoram from the neighboring states. As of the 2011 census, Kolasib district had a population of 83,955. The district covers an area of 1,382 Sq. Kms. The district is flanked by Hailakandi and Cachar Districts of Assam in the north, Aizawl District in the south and east and Mamit District in the west. The literacy rate in Kolasib district is 94.54 per cent.

Mamit district is bounded on the north by Hailakandi district of Assam state, on the west by North Tripura district of Tripura state and Bangladesh, on the south by Lunglei district and on the east by Kolasib and Aizawl districts. The district occupies an area of 3,025.75 Sq. kms. According to the 2011 census, Mamit district has a population of 86,364. Mamit has a sex ratio of 927 females for every 1,000 males, and a literacy rate of 84.93 per cent. India has set up several Border Haats

(markets) and ICP (Integrated Check Posts) in Mizoram to boost the border trade and Look-East connectivity to Trans-Asian Railway and Asian Highway Network (via AH1). Marpara and Tuipuibari on Bangladesh–India border are two ICP in Mamit district.

Lawngtlai district is located in the southern part of Mizoram. It shares borders with Lunglei district to the north, Bangladesh to the west, Myanmar to the south, and Saiha district to the east. According to 2011 census, the district has a population of 20,830 of which 10,659 are males while 10,171 are females. The population of children between the ages of 0-6 is 3122 which is 14.99 per cent of the total population of Lawngtlai. The literacy rate of Lawngtlai is 95.66 per cent where male literacy is 96.97 per cent while female literacy rate is 94.28 per cent. It has its distinct feature for housing one of the highest minority population concentrated areas in India in the western belt of the district. It occupies an area of 2557.10 Sq. kms.

3.2 Research Design

The study is exploratory in nature and adopted mixed method using both quantitative and qualitative techniques.

3.3 Population and Unit of the Study

The population of the study includes all primary and secondary caregivers in Mizoram. Caregivers of children with Autism spectrum disorder and professionals who are working with children with Autism spectrum disorder represent the unit of study.

3.4 Source of Data Collection

Data were collected from both primary and secondary sources. Primary source included data collected from both the primary and secondary caregivers of children with Autism Spectrum Disorders. Secondary sources were collected from books, literature and Government and Non- Governmental published and unpublished records.

3.5 Sampling Procedure

A purposive sampling procedure was utilized for the identification of both primary and secondary caregivers. The primary caregivers were identified from registered and diagnosed cases of children with Autism spectrum disorder from recognised health settings across the districts in Mizoram. Additionally, to cover more sample, a snowball sampling procedure was also utilized to identify primary caregivers whose children were officially diagnosed with Autism spectrum disorder from other parts of India. Primary caregivers were identified from 11 districts altogether namely Aizawl, Lunglei, Champhai, Serchhip, Khawzawl, Kolasib, Mamit and Lawngtlai. There were 138 primary caregivers who were identified to form the final sample from the quantitative study and 13 primary caregivers (5 for case study and 8 for focus group discussion) who were identified to form the final sample for qualitative study. The total sample size for primary caregivers were 151.

Likewise, the secondary caregivers were also purposively selected from government and non-government settings working in the area of disability and particularly prioritizing on professionals working with children with Autism spectrum disorder. The secondary caregivers were identified from 6 districts altogether namely Aizawl, Lunglei, Champhai, Serchhip, Kolasib and Mamit. The total sample size for secondary caregivers were 35.

Overall, the sample size of the study covered 186 respondents.

3.6 Tools of Data Collection

A semi-structured interview schedule formed the tool for data collection. The tool included information related to the profile of the respondents, the knowledge on Autism spectrum disorder, their attitude towards children with Autism spectrum disorder and their intervention practices in the care and rehabilitation of children with Autism spectrum disorder. It also included information regarding the challenges

faced by the respondents, coping strategies of the primary caregivers in particular and suggestions to reduce the challenges of the caregivers.

To measure, the knowledge, attitude and intervention practices, standardized tools were constructed and to assess them, different items, categories and models were taken from various studies and literature related to Autism spectrum disorder. (Liu et al, 2016; Uthaman, 2018; COMDEAL, Bangalore, DSM 5 & ICD 10).

To assess the knowledge on Autism spectrum disorder, 28 factual items about Autism spectrum disorder were developed for respondents to answer Yes (1) and No (0). The tool was statistically tested for reliability. Guttman Split –half coefficient reliability value for the Knowledge scale was .659 respectively.

To assess the attitude towards children with Autism spectrum disorder, 20 negative items against children with Autism spectrum disorder were developed. A 5-point scale was constructed to assess the attitude where 0 indicated Strongly Agree, 1 indicated Agree, 2 indicated Neither Agree nor Disagree, 3 indicated Disagree and 4 indicated Strongly Disagree. The tool was statistically tested for reliability. The Cronbach Alpha reliability value for attitude scale was .837.

And finally, to assess the caregiving and intervention practices, 19 items with scope for adding additional items by respondents were developed. The items included various models and skill related caregiving and intervention practices related to Autism spectrum disorder. A 5-point scale to assess the frequency of caregiving and intervention practices was constructed where 0 indicated Never, 1 indicated Seldom, 2 indicated Sometimes, 3 indicated Often and 4 indicated Always. The tool was statistically tested for reliability. The Cronbach Alpha reliability value for attitude scale was .901.

Qualitative techniques such as in-depth interview and focus group discussion were also conducted to gather additional information.

3.7 Data Analysis

The quantitative data was analysed using Microsoft Excel and SPSS package. Simple frequency, descriptive statistics and means were used to present the quantitative data. Pearson Correlation Coefficient was used to find out the relationship of knowledge, attitude and practices of the caregivers. To find out the differences in knowledge, attitude and practices between the primary and secondary caregivers, t-Test was also analysed. In-depth Interviews were analysed to form case studies and focus group discussions were presented accordingly to find out the objectives of the study.

3.8 Ethical Consideration

Written informed consents were obtained from the respondents. The participants in the study were explained in detail about the nature and objectives of the study and they were informed that their participation was purely voluntary. Confidentiality was strictly maintained as part of the research process. Only those who were willing to give their consent were interviewed and studied. The methodology used in this study was designed to rigorously meet the research objectives. A pilot study was conducted to ensure the validity and reliability of the tool. Items that were found irrelevant and invalid were omitted. The approach adopted was meticulously planned to ensure dependability, validity, and relevance to the study.

3.9 Limitation of the Study

The Limitations of the study were as follows:

- The Covid-19 Pandemic hindered the research activity.
- Diagnosed cases were limited
- Many professionals were not available for interview.

- Due to the geographical terrain, there was difficulty in accessing the respondents.
- District Mental Health Programmes was not developed and were absent in some districts.

3.10 Operational Definition

3.10.1 Primary and Secondary Caregivers

Primary Caregivers in this study refers to parents or any family members involved in the direct care and rehabilitation of children with Autism spectrum disorder. Secondary Caregivers in this study refers to professionals such as paediatrician, psychiatrists, clinical psychologists, social workers, counsellors, special educators, trained teachers, occupational therapists, speech therapists and rehabilitation therapists etc. involved in the care and rehabilitation of children with disabilities and particularly children with Autism spectrum disorder.

3.10.2 Caregiving and Intervention Practices

In this study caregiving and intervention practices refers to any practices undertaken by the primary and the secondary caregivers in the care and rehabilitation of children with Autism spectrum disorder in Mizoram.

CHAPTER IV

RESULTS AND DISCUSSIONS

4.1 Socio-Demographic Profile

The demographic characteristics of the respondents are important indicators in understanding the background of the respondents. In this section, the demographic characteristics include category of respondents, age group, gender, marital status, religious denomination, type of family, form of family, educational qualification, family primary occupation, monthly income of family, socio-economic category, relationship of primary caregivers with children, history of disability in family, designation of secondary caregivers, working experience of secondary caregivers and diagnosticians of children with Autism spectrum disorder.

Table 4.1.1: Category of Respondent

Sl. No.	Category	Frequency	Percent
1	Primary Caregiver	138	79.8
2	Secondary Caregiver	35	20.2
	Total	173	100.0

Source: Computed

Table 4.1.1 shows the distribution of respondents according to the category of caregivers. The table shows that more than three fourth (79.8 %) of the respondents are primary caregivers and the remaining two fifth (20.2%) of the respondents are secondary caregivers.

Table 4.1.2: Age Group

Sl.No.	Age Group	Category		Total N=173
		Primary Caregiver n=138	Secondary Caregiver n=35	
1	25-39 Years	82 (59.4)	26 (74.3)	108 (62.4)
2	40-59 Years	43 (31.2)	8 (22.9)	51 (29.5)
3	60 Years and above	7 (5.1)	0 (0.0)	7 (4.0)
4	18-24 Years	6 (4.3)	1 (2.8)	7 (4.0)

Source: Computed

Figures in parenthesis indicate percentages

Table 4.1.2 highlights the distribution of respondents according to their age group. From the table, among the primary care givers, more than half (59.4%) of them belong to the age-group of 25-39 years of age, followed by 31.2 per cent who belong to the age-group of 40-59 years of age. A few (5.1%) belongs to the age-group 60 Years and above while fewer (4.3%) belongs to the age-group of 18-24 years.

Among the secondary caregivers, more than two third (74.3%) of the respondents belong to the age group of 25-39 years of age, while more than a fifth (22.9%) belongs to the age group of 40-59 years of age. A few (2.8%) of the respondents from the secondary caregivers belong to the age group of 18-24 years of age and there are no respondents above the age of 60 from the secondary care givers.

Overall, less than two third (62.4%) are from the 25-39 years age group followed by more than a fourth (29.5%) who belong to the 40-59 years age group. Less than a tenth (4.0% each) are from the age groups 60 years and above and 18-24 years respectively.

Table 4.1.3: Gender

Sl.No.	Gender	Category		Total N=173
		Primary Caregiver n=138	Secondary Caregiver n=35	
1	Female	79 (57.2)	28 (80.0)	107 (61.8)
2	Male	59 (42.8)	7 (20.0)	66 (38.2)

Source: Computed

Figures in parenthesis indicate percentages

Table 4.1.3 shows the gender distribution of the respondents. From the table, among the primary caregivers, more than half of the respondents (57.2%) are females while less than half (42.8%) of the respondents are males.

From the secondary caregivers, majority (80%) of the respondents are females and a fifth (20%) of the respondents are males.

Overall, less than two third (61.8%) are females and more than a third (38.2%) are males.

Table 4.1.4: Marital Status

Sl.No.	Status	Category		Total N=173
		Primary Caregiver n=138	Secondary Caregiver n=35	
1	Married	107 (77.5)	10 (28.6)	117 (67.6)
2	Unmarried	23	22	45

Table 4.1.5: Religious Denomination

Sl.No.	Denomination	Category		Total N=173
		Primary Caregiver n=138	Secondary Caregiver n=35	
1	Presbyterian	103 (74.6)	29 (82.9)	132 (76.4)
2	Baptist	21 (15.2)	3 (8.6)	24 (13.9)
3	United Pentecostal Church	6 (4.4)	0 (0.0)	6 (3.5)
4	The Salvation Army	3 (2.2)	1 (2.8)	4 (2.3)
5	Catholic	1 (0.7)	2 (5.7)	3 (1.7)
6	Local Christian Denomination	3 (2.2)	0 (0.0)	3 (1.7)
7	Seventh Day Adventist	1 (0.7)	0 (0.0)	1 (0.5)

Source: Computed

Figures in parenthesis indicate percentages

Table 4.1.5 highlights the distribution of respondents according to their religious denomination. The table shows that all the respondents belong to Christianity and among the primary caregivers, majority (74.6%) of the respondents belong to the Presbyterian denomination while more than a tenth (15.2 %) of them are Baptists. Less than a tenth (4.3%) of the respondents belong to the United Pentecostal Church while the Salvation Army and the Local Christian Denomination constitute a few (2.7 % each) of respondents respectively. Very few (0.7% each) belong to the Catholic church and Seventh Day Adventist respectively.

Among the secondary caregivers, majority (82.8%) of the respondents belong to the Presbyterian denomination while less than a tenth (8.6%) are from the Baptist denomination. The table also shows that there are few (5.7%) Catholics and fewer (2.8%) respondents from the Salvation Army. There are no respondents who belong to the United Pentecostal Church, Local Christian Denomination and Seventh Day Adventist among the secondary caregivers.

Overall, the table shows that majority (76.4%) of the respondents belong to the Presbyterian denomination followed by more than a tenth (13.9%) who belong to the Baptist church. A few of the respondents were distributed among the United Pentecostal Church (3.5%), The Salvation Army (2.3%), Catholic (1.7%), Local Christian Denomination (1.7%) and Seventh Day Adventist (0.5%) respectively.

Table 4.1.6: Type of Family

Sl. No.	Type	Category		Total N=173
		Primary Caregiver n=138	Secondary Caregiver n=35	
1	Nuclear	97 (70.3)	27 (77.1)	124 (71.7)
2	Joint	41	3	44

		(29.7)	(8.6)	(25.4)
3	No Response	0 (0.0)	5 (14.3)	5 (2.9)

Source: Computed

Figures in parenthesis indicate percentages

Table 4.1.6 represents the respondents according to the type of family. From the table, among the primary caregivers, majority (70.3%) live in a nuclear type of family more than a fourth (29.7%) of the respondents live in a joint family.

Among the secondary caregivers, majority (77.1 %) live in nuclear type of family while the remaining (8.5%) live in a joint family. Among the respondents, more than a tenth (14.3%) of them do not have any response.

The overall findings indicate that majority (71.7%) of the respondents belong to nuclear family while a fourth (25.4%) are from a joint family.

Table 4.1.7: Form of Family

Sl. No	Form	Category		Total N=173
		Primary Caregiver n=138	Secondary Caregiver n=35	
1	Stable	130 (94.2)	30 (85.7)	160 (92.5)
2	No Response	1 (0.7)	4 (11.4)	5 (2.9)
3	Reconstituted	4	1	5

		(2.9)	(2.9)	(2.9)
4	Broken	3 (2.2)	0 (0.0)	3 (1.7)

Source: Computed

Figures in parenthesis indicate percentages

Table 4.1.7 indicates the distribution of respondents according to the form of family. The table highlights that among the primary caregivers, a vast majority (94.2%) of the respondents are from a stable family followed by a few (2.9%) who come from a reconstituted family and another few (2.2%) of the respondents who belong to a broken family. A fewer (0.7%) of the respondents do not have any response.

Further, among the secondary caregivers, the table also shows that majority (85%) of the respondents comes from a stable family while a few (2.9%) are from a reconstituted family. Fewer (1.7%) of the respondents belong to broken families. There were 2.9 per cent of the respondent who did not give any response.

Table 4.1.8: Educational Qualification

Sl.No.	Qualification	Category		Total N=173
		Primary Caregiver n=138	Secondary Caregiver n=35	
1	Graduate	51 (36.9)	4 (11.4)	55 (31.8)
2	Post -Graduate	16 (11.6)	17 (48.6)	33 (19.1)

3	High School	29 (21.0)	0 (0.0)	29 (16.8)
4	Higher Secondary	25 (18.1)	2 (5.7)	27 (15.6)
5	Master of Philosophy (M.Phil.)	4 (2.9)	6 (17.1)	10 (5.8)
6	Middle School	7 (5.1)	0 (0.0)	7 (4.0)
7	Doctor of Medicine (MD)	0 (0.0)	6 (17.1)	6 (3.5)
8	Literate	3 (2.2)	0 (0.0)	3 (1.7)
9	Doctor of Philosophy (Ph.D.)	3 (2.2)	0 (0.0)	3 (1.7)

Source: Computed

Figures in parenthesis indicate percentages

Table 4.1.8 shows the distribution of respondents according to the educational qualification. From the table, among the primary caregivers more than a third (36.9%) of the respondents are graduates while a little more than a fifth (21%) studied till high school level. Less than a fifth (18.1 %) studied up to Higher Secondary level and more than a tenth (11.6%) are post graduates. The rest are distributed among those who studied till Middle school (5.1%), Master of Philosophy

(2.9%) and Doctor of Philosophy (2.2%). There are a few (2.2%) who had no education but are Literate.

From the secondary caregivers, almost half (48.6%) of the respondents attained education up to Post Graduation while more than a sixth (17.1% each) had their degrees in Master of Philosophy and Doctor of Medicine respectively. More than a tenth (11.4%) of the respondents are graduates while a few (5.7%) of them studied till Higher Secondary level.

Overall, less than a third (31.8%) of the respondents are graduates followed by less than a fifth (19.1%) who are post graduates. A sixth (16.8%) of the respondents studied till the high school level while those who studied till the higher secondary level comprised of more than a tenth (15.6%) of the respondents. The rest are distributed among those who studied till Master of Philosophy (5.8%), Middle school level (4%), Doctor of Medicine (3.5%) and Doctor of Philosophy (1.7%). There are very few (1.7%) respondents who had no education but are literate.

Table 4.1.9: Family Primary Occupation

Sl.No.	Occupation	Category		Total N=173
		Primary Caregiver n=138	Secondary Caregiver n=35	
1	Government Service	60 (43.5)	30 (85.7)	90 (52.0)
2	Self-Employment	46 (33.3)	3 (8.5)	49 (28.3)
3	Others	27 (19.6)	1 (2.9)	28 (16.2)
4	Agriculture	2 (1.4)	1 (2.9)	3 (1.7)
5	Petty Business	2 (1.4)	0 (0.0)	2 (1.2)
6	Large Business	1 (0.7)	0 (0.0)	1 (0.5)

Source: Computed

Figures in parenthesis indicate percentages

Table 4.1.9 shows the distribution of respondents according to the primary occupation of family. From the primary caregivers, we see from the table that less than half of the respondents (43.5%) have government jobs as their primary occupation followed by a third (33.3%) of the respondents who are self-employed. Almost a fifth (19.6%) of the respondents reported as being from the ‘Other’ category while a few (1.4% each) have agriculture and petty business as their primary occupation of the family respectively. Very few (0.72%) of the respondents are engaged in large business as their primary occupation.

The table also shows that among the respondents from the secondary caregivers, majority (85.7%) of them reported as having government jobs as their primary occupation while less than tenth (8.5%) of the respondents’ primary occupation is family is self-employment. A few (2.9%) of the respondent’s primary occupation of family is agriculture while another 2.9 per cent of the respondents reported as having ‘Other’ occupation as their main family occupation.

Overall, more than half (52%) of all the respondents’ primary occupation of family is government service followed by more than a fourth (28.3%) whose primary occupation is self-employment. A sixth (16.2%) reported as having ‘Other’ as their primary occupation and very few reported agriculture, petty business and large business as the primary occupation of their family.

Table 4.1.10: Monthly Income of Family

Sl. No.	Income	Category		Total N=173
		Primary Caregiver n=138	Secondary Caregiver n=35	
1	Rs.20000-Rs.50000	66 (47.8)	11 (31.4)	77 (44.5)
2	Rs 60000-Rs. 1 lakh	48 (34.7)	9 (25.7)	57 (32.9)
3	Rs 1 lakh above	20 (14.5)	14 (40.0)	34 (19.7)
4	Less than Rs.10000	4 (2.9)	1 (2.9)	5 (2.9)

Source: Computed

Figures in parenthesis indicate percentages

Table 4.1.10 demonstrates the distribution of respondents according to their family income. The table indicates that from the primary caregivers, less than half (47.8 %) of the respondents have a family monthly income of Rs.20000-Rs.50000 followed by more than a third (34.7%) of them whose family income is Rs.60000-Rs.1 Lakh. More than a tenth (14.5%) has a family monthly income of Rs.1 Lakh and above while only a few (2.9%) have a family income of less than Rs.10000.

From the secondary caregivers, the table shows that more than more than a third (40.0 %) has a family monthly income of Rs.1 Lakh and above followed by less than a third (31.4%) of respondents whose family has a monthly income of Rs.20000-Rs.50000. A fourth (25.7%) of the respondents reported as having a family monthly income of Rs.60000-Rs.1 Lakh while very few (2.9%) of the respondents' family earn a monthly income of less than Rs.10000.

The table shows that from the overall data, less than half (44.5%) of all the respondents has a family monthly income of Rs.20000-Rs.50000 followed by less than a third (32.9%) of the respondent whose family monthly income is Rs.60000-Rs.1 Lakh. Less than a fifth (19.7%) of all the respondents have families with a monthly income of Rs.1 Lakh and above while only a few (2.9%) of the respondents have families who earn less than Rs.10000.

Table 4.1.11: Socio-Economic Category

Sl.No.	Category	Category		Total N=173
		Primary Caregiver n=138	Secondary Caregiver n=35	
1	Above Poverty Line (APL)	73 (52.9)	17 (48.6)	90 (52.0)
2	Below Poverty Line (BPL)	30	2	32

		(21.7)	(5.7)	(18.5)
3	No Category	17 (12.3)	6 (17.1)	23 (13.3)
4	Do not know	12 (8.7)	8 (22.9)	20 (11.6)
5	Antyodaya Anna Yojana (AAY)	6 (4.4)	2 (5.7)	8 (4.6)

Source: Computed

Figures in parenthesis indicate percentages

Table 4.1.11 shows the respondents according to their socio-economic status. The table shows that among the primary caregivers, more than half (52%) belongs to the APL category followed by a little more than a fifth (21.7%) of the respondents who are from the BPL category. More than a tenth (12.3%) of the respondents have no category while less than a tenth (8.7%) of the respondents do not know their socio-economic category. A few (4.4%) of the respondents belong to AAY category.

Further, the table also shows that among the secondary caregivers, less than half (48.6%) of the respondents belongs to the APL category while more than a fifth (22.9%) of the respondents do not know their socio-economic category. There were more than a tenth (17.1%) of the respondents who fall under the no category while less than a tenth (5.7% each) belong to BPL and AAY category respectively.

From the table, the overall findings reveal that more than half (52%) of the respondents belong to the APL category followed by less than a fifth (18.5%) who belong to the BPL category. There were more than a tenth (13.3%) who had no category while a little more than a tenth (11.6%) do not know their category. Lastly but not the least, only a few (4.6%) belong to the AAY category.

Table 4.1.12: Relationship of Primary Caregivers to children

Sl. No.	Relationship	Frequency	Percent
1	Mother	67	48.5
2	Father	52	37.7
3	Others	19	13.8
	Total	138	100.0

Source: Computed

Table 4.1.12 shows the relationship of primary caregivers to the children with Autism spectrum disorder. From the table, almost half (48.5 %) of the respondents are mothers, while more than a third (37.7 %) of the respondents are fathers. The remaining who were a little more than a tenth (13.8%) of the respondents are the ‘Other’ primary caregivers such as aunts, siblings and grandparents.

Table 4.1.13: History of Disability in Family

Sl.No	Category	Frequency	Percent
1	No Disability	130	94.2
2	Disability	8	5.8
	Total	138	100.0

Source: Compute

Table 4.1.13 shows the distribution of respondents according to the history of disability in the family. The table indicates that among the primary caregivers, majority (94.2 %) of the respondents reported that there is no history of disability in

the family while a few (5.8%) of the respondents reported that there is history of disability in their family.

Table 4.1.14: Designation of Secondary Caregivers

Sl. No.	Designation	Frequency	Percent
1	Clinical Psychologist	8	22.9
2	Social Worker	7	20.0
3	Special Educator	7	20.0
4	Doctor	3	8.6
5	Psychiatrist	3	8.6
6	Teacher	3	8.6
7	Psychologist	2	5.7
8	Counsellor	1	2.8
9	Speech Therapist	1	2.8
	Total	35	100.0

Source: Computed

Table 4.1.14 represents the designation of the secondary caregivers. The table shows that Clinical Psychologist comprises of more than a fifth (22.9%) of the total respondents. Social Worker and Special educators also comprises of a fifth (20.0% each) of the respondents respectively. Less than a tenth (8.6%) are doctors, psychiatrists, and teachers while fewer (5.7%) are psychologist. The least (2.8% each) are counsellors and speech therapist respectively.

Table 4.1.15: Working experience of Secondary Caregivers

Sl.No.	Years of experience	Frequency	Percent
1	0-5 Years	20	57.1
2	6-10 Years	9	25.7
3	16-20 Years	4	11.4
4	More than 20 years	1	2.9
5	11-15 Years	1	2.9
	Total	35	100.0

Source: Computed

Table 4.1.15 shows the distribution of secondary caregivers according to their working experience. The table shows that more than half (57.1%) of the respondents has a working experience of 0-5 years followed by a fourth (25.7%) whose working experience ranged from 6-10 years. More than a tenth (11.4%) of the respondents has a working experience of 16-20 years while a few (2.9% each) of the respondents has a working experience of more than 20 years and 11-15 years respectively.

Table 4.1.16: Diagnosticians of Children

Sl.No	Diagnosticians	Frequency	Percent
1	Clinical Psychologist	76	55.1
2	Psychiatrist	38	27.5
3	Medical Doctor	24	17.4
	Total	138	100.0

Source: Computed

Table 4.1.16 highlights the distribution of respondents according to diagnosticians of children with Autism spectrum disorder. The table shows that more than half (55.1%) of the respondents reported that the children were diagnosed by Clinical Psychologist while more than a fourth (27.5%) of the respondents reported that the children were diagnosed by Psychiatrist. More than a tenth (17.4%) of the respondents stated that the children were diagnosed by Medical doctors.

4.2 Knowledge on Autism Spectrum Disorder

This section will cover the level of knowledge primary and secondary care givers have on Autism spectrum disorder. It will also cover aspects of differences in knowledge between the primary and secondary caregivers. The knowledge is measured based on 2-point scale i.e. 1 for 'Yes' and 0 for 'No' where 1 indicates that they have knowledge and 2 indicates that they don't have knowledge. The knowledge was assessed based on 28 items about factual information on Autism spectrum disorder.

Table 4.2.1: Knowledge on Autism Spectrum Disorder

Items	Statements	PC*	SC**	Total (N=173)
		Mean (n=138)	Mean (n=35)	
1	ASD is a developmental disorder	1	1	1
2	ASD is being diagnosed at the age range of between 2-3 Years	1	1	1
3	ASD rate of co-morbidity is high with other genetic disorders and psychiatric disorders	1	0	1

4	ASD affects people differently	1	1	1
5	ASD is a mental disorder	1	1	1
6	ASD is a lifelong disorder	1	1	1
7	ASD is not caused by vaccinations during childhood	1	1	1
8	ASD involves delays and impairment in social skills	1	1	1
9	Children with ASD find it hard to understand other people's feelings	1	1	1
10	ASD involves delays and impairment in behavioral skills	1	1	1
11	ASD involves delays and impairments in language skills	1	1	1
12	ASD cannot be diagnosed in adulthood	0	1	1
13	The prevalence of ASD is greater in children than adults	1	1	1
14	ASD involves sensory impairments	1	1	1
15	ASD is caused by abnormalities in brain structures or functions	1	1	1
16	ASD is not curable	1	1	1
17	ASD does not involve physical illness	1	1	1
18	Environmental factors contribute to difficulties faced by children with ASD	1	1	1
19	Children with ASD do not show affectionate behavior	1	1	1

20	ASD has different levels of impairment	1	1	1
21	All children with ASD do not have intellectual disability	1	1	1
22	ASD is not caused by poor parenting skills or poor home care	1	0	1
23	ASD does not only occur in children	1	1	1
24	Children with ASD do not eventually overgrow autism	1	1	1
25	Children with ASD find it hard to communicate and participate in social interaction	1	1	1
26	Right to Person with Disability Act 2016 protects and promote the rights of Children with ASD	1	1	1
27	There are services for intervention for children with ASD in Mizoram	1	1	1
28	The level of support required by children with autism does not change with age	0	0	0
	Total Mean Average	1	1	1

Source: Computed

*Primary caregivers; ** Secondary caregivers

Table 4.2.1 shows the mean distribution of respondents according to their knowledge on Autism Spectrum Disorder. The table shows that among the primary caregivers, knowledge is high (1) in 26 items except in 2 items which is low (0) such as *ASD cannot be diagnosed in adulthood* and *on the level of support required by children with autism does not change with age*. Overall, the knowledge of primary care givers was high (1).

Further, among the secondary caregivers, the table shows that the knowledge is high (1) in 25 items and low (0) in 3 items such as *ASD rate of co-morbidity is high with other genetic disorders and psychiatric disorders, ASD is not caused by poor parenting skills or poor home care and the level of support required by children with autism does not change with age*. Overall, the knowledge of secondary caregivers is high (1).

Overall, among the primary and secondary caregivers, then table shows that the average mean knowledge is high (1) in 27 items and low (0) in 1 item which is on *the level of support required by children with autism does not change with age*.

Table 4.2.2 Differences on Knowledge

Category	N	Mean	Std. Deviation
Primary Caregiver	138	0.98	0.15
Secondary Caregiver	35	0.94	0.24
Mean Difference		0.04	
Std. Error Difference		0.03	
t		1.11	
df		171.00	
Sig. (2-tailed)		0.27	

Source: Computed

Table 4.2.2 shows the t-Test to find out the significant differences in knowledge on Autism spectrum disorder between the primary and secondary caregivers. The table shows that shows that there is no difference (1.11) in the knowledge on Autism spectrum disorder between the primary and secondary caregivers.

4.3 Attitude towards children with Autism Spectrum Disorder

This section will cover the attitude primary and secondary caregivers have towards children with Autism spectrum disorder. It will also cover aspects of differences in attitude between the two categories of respondents. The attitude was measured based on a 5-point scale where 0 indicates strongly agree, 1 indicates agree, 2 indicates neither agree nor disagree, 3 indicates disagree and 4 indicates strongly disagree. The attitude was assessed based on 20 negative items related to children with Autism spectrum disorder. Therefore, lower the scale, the attitude is being perceived as negative (bad), likewise, higher the scale, the attitude is being perceived as positive (good).

Table 4.3.1: Attitude towards children with Autism Spectrum Disorder

Items	Statement	PC*	SC**	Total (N=173)
		Mean (n=138)	Mean (n=35)	
1	Children with ASD do not need professional interventions	3	3	3
2	Children with ASD cannot be improved	3	3	3
3	Training is not important in managing a child with ASD	3	3	3
4	Children with ASD should not have children after they grow up	3	2	3
5	Having a child with ASD is embarrassing	3	3	3
6	I am not comfortable in helping a child with Autism Spectrum Disorder	3	2	3

7	Children with ASD should not marry after they grow up	3	3	3
8	Children with ASD are not able to have emotional attainment	3	3	3
9	Having a child with ASD causes Depression	2	1	2
10	Having a child with ASD causes anger	2	1	2
11	Having a child with ASD is irritating	2	2	2
12	Having a child with ASD is fearful	2	2	2
13	Having a child with ASD is not acceptable	2	2	2
14	Having a child with ASD is an emotional burden	2	2	2
15	Having a child with ASD is expensive	2	1	2
16	Children with ASD lack empathy	2	2	2
17	There is no time for self-care if you have a child with ASD	2	2	2
18	Children with ASD are incapable of forming relationship and expressing emotions	2	2	2
19	it is hard to manage the behavior of children with autism spectrum disorder	2	2	2
20	Attitude Having a child with ASD is stressful	1	1	1
	Total Average	2	2	2

Source: Computed

*Primary

caregivers; ** Secondary caregivers

Table 4.3.1 shows the mean distribution of respondents according to the attitude on children with Autism spectrum disorder. The table shows that among the primary caregivers, the attitude is good (3) in 8 items moderate (2) in 11 items and bad in 1 item (1). The total mean average in the attitude of primary caregivers shows a moderate (2) attitude towards children with Autism spectrum disorder.

The above table also indicates that among the secondary caregivers, the attitude is good (3) in 6 items, moderate (2) in 10 items and bad in 4 items (1). The total mean average of secondary caregivers shows a moderate (2) attitude towards children with Autism spectrum disorder.

Overall, the attitude of the respondents towards children with Autism spectrum disorder is good (3) in 8 items, moderate (2) in 11 items and bad in 1 item (1). The mean average of the overall assessment among the primary and secondary caregivers shows a moderate (2) attitude towards children with Autism spectrum disorder.

Table 4.3.2: Differences in Attitude

Category	N	Mean	Std. Deviation
Primary Caregiver	138	2.22	0.601
Secondary Caregiver	35	2.17	0.568
Mean Difference		0.046	
Std. Error Difference		0.113	
T		0.408	
Df		171	
Sig. (2-tailed)		0.683	

Source: Computed

Table 4.3.2 shows the t-Test to find out the significant differences in attitude towards children with Autism spectrum disorder between the primary and secondary caregivers. The table shows that there is no difference (0.408) in the attitude towards children with Autism spectrum disorder between the primary caregivers and secondary caregivers.

4.4 Caregiving and Interventions Practices on children with Autism Spectrum Disorder

This section will cover the caregiving and intervention practices of primary and secondary caregivers on children with Autism spectrum disorder. It will also cover findings related to the differences in practices between the primary and secondary caregivers. The intervention practices were measured based on frequency of practices. A 5-point scale was developed where 0 indicates never, 1 seldom, 2 indicates sometimes, 3 indicates often and 4 always. The caregiving and intervention practices were assessed based on 20 items that covered various modules related to the care and intervention practices on children with Autism spectrum disorder.

Table 4.4.1: Caregiving and Interventions Practices on Children with Autism Spectrum Disorder

Items	Practices	PC*	SC**	Total (N=173)
		Mean (n=138)	Mean (n=35)	
1	Educational Intervention	3	3	3
2	Improving Self- Care Skills	3	3	3
3	Improving communication Skills	2	3	3

4	Improving Social Skills	3	3	3
5	Improving Cognitive Skills	3	3	3
6	Improving Behavioural Skills	3	3	3
7	Improving Sensory Skills	2	3	3
8	Improving Emotional Management Skills	2	3	3
9	Improving Analytical Skills	2	3	3
10	Counselling	2	3	3
11	Occupational Therapy	2	2	2
12	Early intervention	2	2	2
13	Applied Behavioural Analysis	1	2	2
14	Sensory Integration Therapy	1	2	2
15	Family Psycho Educational Service	1	3	2
16	Play Therapy	1	2	2
17	Discrete Trial Training	0	1	1
18	COMDEALL Intervention Model	0	1	1
19	Complementary and Alternative Model	1	1	1
20	Supportive Psychotherapy	0	0	0
	Total Average	2	2	2

Source: Computed

*Primary caregivers; ** Secondary caregivers

Table 4.4.1 shows the mean distribution of respondents according to the caregiving and intervention practices applied and used by primary and secondary caregivers on children with Autism spectrum disorder. The table shows that among the primary caregivers, caregiving and intervention practices such as education intervention, improving self-care skills, social skills, cognitive skills and behavioral skills are often (3) used by the respondents while items such as improving sensory skills, emotional management skills, improving analytical skills, counselling, occupational therapy and early intervention are sometimes (2) used by the respondents. The table also indicates that items such as applied behavioral analysis, sensory integration therapy, family psycho educational service, play therapy and complementary and alternative model are seldom (1) used by the respondents. Further, items such as discrete trial training, COMDEALL intervention model and supportive psychotherapy are never (0) used by the primary caregivers. Overall, the mean average on the frequency of usages on the caregiving and intervention practices by the primary caregivers are found to be average (2) in the scale measurement.

The table also shows that among the secondary caregivers, items such as education intervention, improving self-care skills, communication skills, social skills, cognitive skills, behavioral skills, sensory skills, emotional management skills and analytical skills, counseling and family psycho-educational service are often (3) used while items such as occupational therapy, early intervention, applied behavioral, sensory integration therapy and play therapy are sometimes (2) used. The table also indicates that items such as discrete trial training, COMDEALL intervention model and complementary and alternative model are seldom (1) used. Other items such as supportive psychotherapy is never (0) used. Overall, the mean average on the frequency of usages on the caregiving and intervention practices by the secondary caregivers are found to be average (2) in the scale measurement.

From the overall assessment, the study found that the use of caregiving and intervention practices are high (3) in items such as educational intervention, improving self-care skills, improving communication skills, improving social skills, improving cognitive skills, improving behavioural skills, improving sensory skills, improving emotional management skills, counselling, and improving sensory skills. Further, the use of items such as occupational therapy, early intervention, applied behavioural analysis, sensory integration therapy, family psycho educational service and play therapy are found to be average (2) while the use of items such as discrete trial training, COMDEALL intervention model and complementary and alternative medicine are found to be low (1). Lastly but not the least, the use of supportive psychotherapy is very low (0) in the scale assessment.

Table 4.4.2: Differences in Caregiving and Intervention Practices

Category	N	Mean	Std. Deviation
Primary Caregiver	138	1.74	0.757
Secondary Caregiver	35	2.37	0.843
Mean Difference		-0.632	
Std. Error Difference		0.147	
t		-4.309	
df		171	
Sig. (2-tailed)		0.000	

Source: Computed

Table 4.4.2 indicates the t-Test to find out the significant differences in caregiving and intervention practices on children with Autism spectrum disorder between the primary and secondary caregivers. The table shows that there is a significant difference (-4.309) in the caregiving and intervention practices between

the primary and secondary caregivers. This finding shows that the frequency in the usages of caregiving and intervention practice is higher among the secondary caregivers than the primary caregivers.

4.5 Relationship between Knowledge, Attitude and Practices among Caregivers

This section will cover the findings related to the relationship between knowledge, attitude and practices among the primary and secondary caregivers of children with Autism spectrum disorder. The relationship shall be analysed through Pearson's Coefficient Correlation where significant level of relationship is at 0.05.

Table 4.5.1 Relationship between Knowledge, Attitude and Practice of Primary Caregivers

Sl.No.	Category		Knowledge	Attitude	Practice
1	Knowledge	Pearson Correlation	1	.220^{**}	0.146
2	Attitude	Pearson Correlation	.220^{**}	1	0.109
3	Practice	Pearson Correlation	0.146	0.109	1

****Correlation is significant at the 0.05 level (2-tailed)**

Table 4.5.1 highlights the relationship between the knowledge on Autism spectrum disorder, attitude towards children with Autism spectrum disorder and the caregiving and intervention practices on children with Autism spectrum disorder among primary caregivers, through Pearson's Coefficient correlation analysis. The table shows that there is a significant positive relationship (**.220**) between knowledge and attitude among the primary caregivers. This finding indicates that among the primary caregivers, higher the knowledge on Autism spectrum disorder, better the attitude towards children with Autism spectrum disorder.

The table also shows that there is no relationship between knowledge and practices (0.146) and attitude and practices (0.109). This indicates that knowledge and practices have nothing to do with each other among the primary caregivers. And further, attitude and practices also have nothing to do with each other among the secondary caregivers.

Table 4. 5.2 Relationship between Knowledge, Attitude and Practices of Secondary Caregivers

Sl.No.	Categories		Knowledge	Attitude	Practices
1	Knowledge	Pearson Correlation	1	0.075	0.110
2	Attitude	Pearson Correlation	0.075	1	.416^{**}
3	Practices	Pearson Correlation	0.110	.416^{**}	1

****Correlation is significant at the 0.05 level (2-tailed)**

Table 4.5.2 shows the relationship between the knowledge on Autism spectrum disorder, attitude towards children with Autism spectrum disorder and the caregiving and intervention practices on children with Autism spectrum disorder among secondary caregivers, through Pearson's Coefficient correlation analysis. The table shows that there is a significant positive relationship (**.416**) between attitude and practices among secondary caregivers. This finding highlights that better the attitude towards children with Autism spectrum disorder, higher the frequency in the usages of caregiving and intervention practices on children with Autism spectrum disorder among secondary caregivers.

The table also shows that there is no relationship (0.075) between knowledge on Autism spectrum disorder and attitude towards children with Autism spectrum disorder among the secondary care givers. Further, the finding also shows that among the secondary caregivers, there is no relationship (0.110) between knowledge on Autism spectrum disorder and caregiving and intervention practices. This

indicates that knowledge has nothing to with attitude and also, knowledge has nothing to do with practices among secondary caregivers.

4.6 Challenges, Coping Strategies and Suggestions

This section will include the findings related to the challenges faced by primary and secondary caregivers of children with Autism spectrum disorder, the coping strategies of the primary caregivers and the suggestions to solve the challenges faced by primary and secondary caregivers.

Table 4.6.1: Challenges of Primary Caregivers

Sl.No.	Challenges	Frequency N=138	Percent
1	Nature of disability of children	92	66.6
2	Effects mental health (depression, stress, low self-esteem, sleeping disorders, anger, hopelessness)	81	58.6
3	Lack of socialization and leisure time	25	18.1
4	Non- Acceptance	13	9.4
5	Lack of family support	10	7.2
6	Discrimination	9	6.5
7	Lack of Services	8	5.7
8	Joblessness	6	4.3
9	Lack of awareness about ASD	6	4.3
10	Expensive services	3	2.1
11	Effects work	3	2.1
12	Disruption in family functioning	2	1.4
13	Unrealistic advice by others	1	0.7

Source: Computed

Table 4.6.1 shows the distribution of respondents according to the challenges faced by the primary caregivers of children with Autism spectrum disorder. The table shows that two third (66.6 %) of the respondents face challenges related to the nature of disability followed by more than half (58.6%) of the respondents who reported as having challenge relating to mental health such as depression, stress, low self-esteem, sleeping disorders, anger and hopelessness. Less than a fifth (18.1%) of the respondents reported that they have no time to socialize and no leisure time and less than a tenth of them reported as having challenges that included non-acceptance, lack of family support, discrimination, lack of services, joblessness, and lack of awareness about Autism spectrum disorder respectively. Very few of them face challenges related to services being expensive, work being affected, family functioning being disrupted and unrealistic advice given by others.

Table 4.6.2: Challenges of Secondary Caregivers

Sl.No.	Challenges	Frequency N=35	Percent
1	Nature of Disability of Children	14	40.0
2	Lack of awareness	5	14.2
3	Non- acceptance by parents	3	8.5
4	Lack of services	3	8.5
5	Stress	2	5.7
6	Expensive services	2	5.7
7	Overthinking	1	2.8
8	Lack of family support	1	2.8
9	No space and time	1	2.8
10	Low follow up rates	1	2.8

Source: Computed

Table 4.6.2 highlights the distribution of respondents according to the challenges faced by the secondary caregivers of children with Autism spectrum disorder. The table shows that less than half (40%) of the respondents have challenges related to the nature of disability of the child followed by more than a tenth (14.2%) of the respondents who reported lack of awareness as a challenge. Less than a tenth of them reported as having challenges that included non-acceptance by parents, lack of services, stress, expensive services, over thinking, lack of support from family members, no space and time and low follow up rates respectively.

Table 4.6.3: Coping Strategies of Primary Caregivers

Sl.No.	Strategies	Frequency N=138	Percent
1	Religious Faith and Prayer	55	39.8
2	Acceptance	29	21.0
3	Seeking social support	27	19.5
4	Hard work	15	10.8
5	Patience	11	7.9
6	Seeking professional support	11	7.9
7	Positive thinking	11	7.9
8	Following a therapy schedule	10	7.2
9	Venting out to others	9	6.5
10	Positive family support	8	5.7

11	Homebased practice	8	5.7
12	Seeking individual counselling	6	4.3
13	Self- learning	4	2.8
14	Attending parent's training programme	3	2.1
15	Teaching social skills to children	3	2.1
16	Giving phone	2	1.4
17	Pharmacological treatment of children	2	1.4
18	Providing recreational resources to children	2	1.4
19	Being alert	2	1.4
20	Setting up a surveillance camera	1	0.7

Source: Computed

Table 4.6.3 highlights the distribution of respondents according to the coping strategies of primary caregivers. From the table, we find more than a third (39.8%) cope through religious faith and prayer followed by a little more than a fifth (21.0%) of the respondents who use acceptance as a strategy to cope with their problems. Less than a fifth (19.5%) reported that seeking social support is one coping mechanism and a tenth (10.8%) of them cope by working hard. Less than a tenth reported strategies such as patience, seeking professional support, positive thinking, following a therapy schedule, venting out to others, positive family support and home-based practice. Very few of them also resort to seeking individual counselling, self-learning, attending parents training programmes, teaching social skills to children, giving phone to children, pharmacological treatment to children, providing recreational resources to children, being alert and setting up surveillance camera as coping strategies respectively.

Table 4.6.4: Suggestions of Primary Caregivers

Sl.No.	Suggestions	Frequency N=138	Percent
1	More awareness on ASD	74	53.6
2	More government provisions	31	22.4
3	More human resources	24	17.3
4	Accessible Services	21	15.2
5	More family support	17	12.3
6	Availability of institutional care	16	11.5
7	Affordable services	14	10.1
8	Continuing education services from government	10	7.2
9	Disciplining children	6	4.3
10	Early intervention	5	3.6
11	Seeking professional help	4	2.8
12	Receiving adequate training for parents	3	2.1
13	Playground for children	2	1.4

Source: Computed

Table 4.6.4 indicates the distribution of respondents according to the suggestions of the primary caregivers to reduce the challenges faced by them. From the table, more than half (53.6%) of the respondents suggested for more awareness on Autism spectrum disorder while more than a fifth (22.4%) of them reported for

more government provisions to reduce their challenges. More than a sixth (17.3%) of the respondents suggested for more human resources in the field of Autism spectrum disorder while more than a tenth (15.2%) of them reported as needing accessible services to reduce their challenges. Further, more than a tenth (12.3%) of them suggested for more family support and more than a tenth (11.5%) suggested for availability of institutional care for children with Autism spectrum disorder. There are a tenth (10.1%) of them who also suggested for affordable services while less than tenth of them suggested for continuation of education services from the government, disciplining the children, early intervention, seeking professional help, receiving adequate training for parents and playground for children respectively.

Table 4.6.5: Suggestions of Secondary Caregivers

Sl. No.	Suggestions	Frequency N=35	Percent
1	More awareness on Autism spectrum disorder	16	45.7
2	Adequate training for skill enhancement	6	17.1
3	Accessible services	4	11.4
4	Early Intervention	3	8.5
5	More Human Resources	3	8.5
6	Proper care and support	3	8.5
7	Availability of institutional care	2	5.7
8	Disciplining children	2	5.7
9	Family support	2	5.7
10	Structured play intervention	2	5.7
11	Acceptance	1	2.8

Source: Computed

Table 4.6.5 shows the distribution of respondents according to the suggestions of the secondary caregivers to solve their problems. The table shows that less than half (45.7%) of the respondents suggested for more awareness on Autism spectrum disorder to solve their challenges while more than a sixth (17.1%) of the respondents reported for more adequate training for skill enhancement. There were more than a tenth (11.4%) of the respondents who suggested for accessible services for children with Autism spectrum disorder and less than tenth of them suggested for early intervention, more human resources, proper care and support, availability of institutional care, disciplining children, family support, structured play intervention and acceptance respectively.

4.7 Case Studies

This section shall highlight the qualitative findings that are presented as case studies. Altogether, five (5) in-depth interviews were conducted to understand the lived experience of the primary caregivers and their children.

4.7.1 Case I

Biaki (Fictitious) is a mother of three children. Her first son was born in 2013 and is presently studying in Class IV. He was born healthy. She reported as having a miscarriage in her second and third pregnancy in 2015 and 2017. After her third miscarriage, she was diagnosed with asthma.

In 2020, she conceived another child and during her pregnancy her asthma worsened and was under medical care and attention through therapeutic inhalers and nebulizers. Considering her past experiences, she was filled with anxiety and as her child was born, she was filled with fear.

After the birth of her boy child, the baby has a rare skin rash on his face and right arm that looked like burns. After proper medical tests and attention, the doctors found no evidences of fatality. However, in the next three months of her child's birth, the rash had spread in his head, calves, stomach and back. As her child grew, he

eventually got well much to Biaki's relief and soon after, he could walk in his 11th month and even started to run steadily.

When the boy turned one, Biaki was cautious to see that her child could not utter simple words like 'mom' or 'dad'. She did not worry at first thinking that it might have been just a mile delay. But as the child reached one-and-a-half-year-old, he was very unresponsive and Biaki started being more curious and even afraid. With a hope that he will eventually catch up, Biaki and her husband decided to consult a psychiatrist when the child was two and half years old. They were told by the doctor to return when the child turned three. When they did return, much to their dismay and shock, they found that their child had been diagnosed with Autism spectrum disorder.

It was a very difficult news for Biaki and her husband, however, they coped as best as they could and tried not to stress and overthink. In 2024, Biaki and her husband enrolled their child to Gilead Special School, a day school for children with special needs. Biaki was happy to know that her child progressed. He could communicate with them if he wants to use the toilet and bathroom. As Biaki talked about her son, with a sense of pride she reported that her child could also eat by himself, but of course, with a little help. She also informed that her son was very particular and selective about the food he eats.

. In her own words, she stated, *'We do our best to support him, but because of my job as a nurse, I am not always available. That is why a supportive family is so important. As a mother of a child with Autism spectrum disorder, I have learned that the small things that make us happy may seem unimportant to others; but for us, every little progress is something to celebrate'*.

4.7.1.1 Analysis of Case 1

The above case illustrates the ordeal a mother goes through from childbirth. Past experiences can trigger stress and anxiety and even conditions of health of children can easily post as a threat to future development of a child. From this case, we see the alertness of caregivers and the proactive role played by Biaki, the mother

of the child in observing any delays in development. This has paved way for early intervention and quick diagnoses that led to the early rehabilitation the child in a professional setting. This case clearly shows the importance of early intervention and the responsibility of caregivers in this regard. Because of these interventions, the child has developed skills in communication as well as other daily living activities. These positive outcome of the child even in her child's disability has improved the mental health of Biaki and her acceptance has helped her see things positively.

4.7.2 Case II

Fela (Fictitious) is an 8-year-old boy and the younger of two siblings. He has a 10-year-old sister who also has been identified with learning needs. According to Fela's mother, there was no concerns during the pre or postnatal periods. However, with time, developmental differences in Fela's behaviour became noticeable when he was three years of age. At that time, he had not yet begun to speak and exhibited significantly limited social interaction skills.

Given these concerns, his mother, who is known to be proactive and informed, sought for developmental assessment at NIMHANS (National Institute of Mental Health and Neurosciences). Following the assessment, much to the sorrow of his mother, Fela was diagnosed with Autism spectrum disorder.

Fela's father is a government servant and is currently posted outside Aizawl. As a result, Fela is primarily cared for by his mother, who is a full-time caregiver to both Fela and his elder sister who also have additional learning and developmental needs.

Fela's mother shared her emotional and practical challenges she faced while living in a joint family system with her in-laws. Although she is deeply committed and motivated to care for her children, she expressed that a lack of understanding and support from her in-laws—particularly with regard to the nature of Autism Spectrum Disorder (ASD)—has made her caregiving role more difficult. She reported that while she applies appropriate parenting strategies and maintains boundaries with Fela, her in-laws often hold unrealistic expectations of him. This mismatch in

understanding has created additional emotional strain on her as both a mother and a daughter-in-law.

Fela's mother also disclosed her own mental health journey. She was diagnosed with clinical depression during the early period of Fela's diagnosis with ASD. While she has undergone treatment in the past, she is currently not receiving any professional mental health support. Despite these personal challenges, she describes herself as a "fighter" and a "warrior" for her son. She takes great pride in Fela's current progress, both at home and in school, and attributes this to her perseverance and advocacy.

Fela's mother had a strong bond with her son and Fela also exerted this relationship. Her mother's pride in son and her acceptance of his diagnosis were evident. She also shared her role in supporting other parents of children with ASD by offering encouragement, emotional support, and connecting them with relevant professionals and resources.

At present, Fela attends a special school but no separate therapy has been sought in the school. Fela's mother provides for a structured routine and boundaries for her son. Fela is thriving and meeting his potential under the care of his mother

4.7.2.1 Analysis of Case II

Case II also shows the importance of a caregiver in early diagnosis and intervention. Again, we also see the proactive role of a mother who is responsible for not only Fela but also her daughter who needs special care and attention. The load has indeed created enough stress and mental health problems to cause clinical depression on the mother. On top of the challenges associated Fela, the mother also receives little support from her family that has caused much distress to her. However, her reliance and love for her children has helped her accept the challenges she faces and this has helped her to be productive not only to her children but also to other caregivers of children with Autism spectrum disorder.

The case illustrates that apart from the professional services sought by caregivers, caregivers can also take initiative to teach their children with the necessary skills for their daily activities.

4.7.3 Case III

Hruaia (Fictitious) is a 7-year-old boy from Khawzawl district. He comes from a household marked by low socio-economic status. He is the middle child among three siblings Hruaia has one half elder brother who is 14 years old and a half baby sister who is 8 months old. His father passed away when Hruaia was around 4 years old due to substance misuse.

Hruaia lives with his mother, half-sister, and maternal grandmother. The mother is engaged in small-scale business activity, which limits her availability. Her involvement in unhealthy relationships with multiple men further disrupts the family's stability. Hruaia's mother appears unable to prioritize the needs of her son and his siblings adequately. His maternal grandmother is the primary caregiver. She is an elderly and takes primary responsibility for Hruaia's care. She is burdened because of the extra effort needed to take care of Hruaia and due to her old age, she is unable to respond effectively to her grandson's needs.

Hruaia's was taken to a clinical psychologist at Champhai by her grandmother when he was three and a half years old due to the concerns of his developmental delays. It was at that time that he was diagnosed with Autism spectrum disorder.

The emotional and psychological development of Hruaia may be at risk due to his loss of a father at a young age and inconsistent caregiving from his mother. The maternal grandmother, though loving, faces limitations due to age and financial constraints. As a result of this, there are evidences of neglect in educational, health and emotional needs of the child.

At present, Hruaia is not accessing any rehabilitative services. However, he is enrolled in a school that he does not enjoy or feel comfortable because he is not toilet

trained. This has caused difficulty to adapt in his social environment. Because of this he seldom attends the school. His lack of interest and refusal to participate in school activities are few reasons for his absences.

4.7.3.1 Analysis of Case III

The case illustrates how lack of responsibility of parents adds fuel to the fire. Hruaia's father passed away because of drug abuse, and the irresponsibility and absence of his mother has only led to the burden of his grandmother who is the primary caretaker of Hruaia. This case also shows that, even though there is early diagnosis, financial constraints and lack of proper care and attention constraints the child in his rehabilitation process to learn skills that can improve his daily functioning. Lack of support from the family has only led Hruaia to worsen his disability.

4.7.4 Case IV

Rina (Fictitious) is a 9-year-old boy from Champhai district. He is the second youngest among his siblings. His mother took him to a clinical psychologist when he was four years old and was eventually diagnosed with Autism spectrum disorder.

He is currently enrolled in school but his attendance is very irregular. His educational level is significantly below the expected standard for his age group. This suggests possible developmental delays. Rina is only partially toilet trained, indicating delays in achieving basic self-care milestones. He also has a history of going missing from home. On one notable occasion, he was lost for more than 15 hours, prompting a community-wide search effort. This raises concerns around his safety, supervision, and possible behavioural challenges.

Another concern about Rina is the absence of professional service in his village. Therefore, he does not receive any therapeutic interventions at present. He is non-verbal and does not use functional communication methods effectively.

His parents have limited understanding of Autism spectrum disorder, which impact their ability to support the child's developmental needs and access appropriate services.

4.7.4.1 Analysis of Case IV

The above case illustrates how lack of awareness and understanding on the part of parents can lead or even worsen the disability of the child. These lacunae are also burdened with the lack of attention towards the child's needs and even existence from the caregivers.

Apart from this, lack of services has also created more challenges and leads to the child's inability to function well if there are intervention programmes or initiatives undertaken by the caregivers.

4.7.5 Case V

Mama (Fictitious) is a 6-year-old boy diagnosed with Autism spectrum disorder at the age of 3 by a clinical psychologist in Aizawl. His developmental challenges were first noted when he began occupational therapy when he was 2.5 years of age. Mama is an only child and lives with his parents in Aizawl. His father serves in the Assam Regiment and is frequently posted outside the city, which results in his mother being the primary caregiver.

Mama exhibits behaviours commonly associated with autism, including hand-flapping, erratic behaviour and sometimes aggressive outbursts, and self-harming tendencies. These behaviours present significant challenges for his mother, who has had to forego employment to provide full-time care for him.

Initially, Mama's mother struggled to come to terms with his diagnosis. However, over time, and particularly as she witnessed gradual improvement in Mama's behaviour, she became more hopeful and optimistic. A vital source of emotional and informational support for her has been connecting with other parents of autistic children.

In pursuit of better educational and therapeutic support for Mama, the family has temporarily relocated from another district to Aizawl district. Currently, Mama is enrolled in a school and undergoes speech and occupational therapy accessed through private professionals. Despite her resilience, Mama's mother expresses a strong need for more government-supported services in their hometown. Currently, the lack of accessible local services places a heavy financial and emotional burden on the family due to the private services undertaken by them. The parents spend approximately Rs. 30,000.00 per month on Mama's care and since his father is the only bread winner, this adds further financial difficulties.

4.7.5.1 Analysis of Case V

This case also shows a mother as a sole primary caregiver of a child with Autism spectrum disorder. The nature of disability has also posed great threat and difficulties in management of the problem. This has also led to the mother to quit her job. This case also highlights the difficulties in accepting the child's disability and how time gradually helps in coping with this problem. Intervention has helped improve the child's functioning and this has also created positive thinking and hopefulness in the part of the caregiver. This shows the importance of early intervention that eases stress of caregivers. Another important finding is the support system and coping mechanisms through support groups from parents with autistic children.

The case also illustrates inaccessibility of services in certain regions underscoring the urgent need for improved and accessible local infrastructure for children with special needs. Another challenge is the financial logistics needed for interventions which has caused great burden to the family. Lastly but not the least the case also shows what parents go through to serve the needs of their children in this case a relocation from home to another District where services are available. This highlights the ordeal and resilience caregivers go through to find better services for their children.

4.8 Focus Group Discussion

A focus group discussion was conducted to gain a deeper understanding on the knowledge attitude, practices, challenges and coping strategies of primary caregivers of children with Autism spectrum disorders. Eight (8) group members (all primary caregivers) were identified to discuss the topics on *'knowledge attitude, practices, challenges and coping strategies related to Autism spectrum disorder'*.

Table 4.8.1: Participants Particulars

Age	Particular	Relationship with Child	Educational Qualification	Marital Status	Occupation
40	Parent 1	Mother	Graduate	Married	Petty Business
30	Parent 2	Mother	Higher Secondary	Married	Home Maker
40	Parent 3	Mother	Post -Graduate	Married	Government Service
34	Parent 4	Mother	Graduate	Single Mother	Petty Business
42	Parent 5	Mother	Post -Graduate	Single Mother	Government Service
40	Parent 6	Mother	Higher Secondary	Married	Home Maker
45	Parent 7	Mother	Graduate	Married	Church Service
43	Parent 8	Mother	Graduate	Single Mother	Government Service

The findings based on the discussions are as follows:

- Most of the parents have a good understanding about Autism spectrum disorders as they get more information about the diagnosis and symptoms from various sources and are accessing support from school.
- Most parents express initial denial and confusion about their child's diagnosis and find it hard to accept.
- Empathetic and sympathetic feeling towards their children are common. One parent expressed that she felt bad when people stare at her child's behaviour, and she would like to protect him from community stigma at all costs.
- Participants reported significant difficulties in accessing services whether it is inside Aizawl city or outside Aizawl. Even if their children can access the services in Aizawl, the cost is high for a parent with middle income as their children need to access not only special need school but also speech therapy, occupational therapy, and behavioural skills training.
- There are no specialised provision nor professionals who specialise in children with Autism spectrum disorder in other districts apart from Aizawl. One participant of the group from Champhai district stated that she had to request for a transfer of job in Aizawl so that she can enrol her son at Gilead Special School in Aizawl. Another parent from Champhai district also stated that as her son's needs are quite high and since there are no school in their district to manage his behaviour, they are planning to relocate to Aizawl in the near future.
- One of the main challenges is the support needed from family members. Many parents have stated that it is not possible for both the parents to earn a living. Either one parent had to leave their employment for the sake of their children.
- Parents expressed a need for more awareness to reduce stigma and increase public understanding of Autism spectrum disorder.
- Parents also shared various coping strategies including spiritual/religious practices, counselling, support from family members and participating in special needs support programmes.

- Parents shared that they want more provisions from the Government in accessing services in all Districts and not only in Aizawl.
- Parents also suggested for awareness activities that can reach everyone and not only the community but within their family network as well.

The focus group discussion illuminated complex challenges faced by parents of children with Autism spectrum disorder, including emotional struggles, social stigma, financial strain, and lack of services. Despite these difficulties, parents demonstrated remarkable resilience and a strong desire to advocate for systemic improvements. They appreciated the opportunity to share their experiences and expressed hope for a paradigm shift in awareness, care, education, and support services for children with ASD and their families.

CHAPTER V

CONCLUSION

The diagnosis of Autism can be heart-breaking for parents since the presence of an autistic child may have a profound effect on the functioning of his or her family life. The present study was an attempt to assess the knowledge, attitude, practices, challenges and coping strategies of primary and secondary caregivers. Further, it also intends to suggest measures for social work intervention in the area of Autism spectrum disorder.

Autism Spectrum Disorder (ASD) is a type of disability that has gained attention in the field of mental health in the latter part of the 20th century. Its dynamic nature in symptoms and characteristics has created various challenges in diagnosis, care and intervention. Although there are literature and data across the globe, there are still very few research on ASD in India and no research in Northeast and Mizoram. No official data exist at the State level, however, with the development of Mental Health Programme, there has been few diagnosed cases registered after 2022.

Autism Spectrum Disorders (ASD) are the most common developmental disability in the world, and their incidence is rising daily. According to WHO estimates from April 2017, 1 in 160 children globally suffers from autism spectrum disorders. Studies using epidemiological methods have shown a consistent rise in the number of autism diagnoses (Fombonne, 1999; London & Etzel, 2000). According to early studies, 4 to 6 people out of 10,000 could have autism (strictly confined to youngsters who meet all criteria for the illness) (Wing & Gould, 1979).

Based on prevalence estimates, there could be up to 2 million autistic individuals in India. However, research on autism is still in its early stages in the Indian subcontinent. In India, the frequency of autism has been rising significantly. In India, the estimated prevalence of autism is 1 in 68 children. The prevalence of autism is higher in boys than in girls, with a male-to-female ratio of roughly 3:1 (Malhi & Sankhyan, 2021; Krishnan et al., 2021).

Families play several roles in their children's lives, particularly if their child is diagnosed with Autistic Spectrum Disorder (Harris, 1994). They provide emotional support, serve as role models for behavior and social interaction, and advocate for services. Many children still lack adequate treatment at the appropriate time due to the continued inadequacy of early diagnosis and intervention. Having a child with autism can have a significant impact on the family, particularly on women, who are typically the primary caretakers for children with autism. It has also been said that having a child with autism can have a significant influence on the family, particularly on mothers, who are typically the primary caretakers for children with autism. Parents occasionally lack the essential information and understanding about autism, its possible effects, and the available intervention and support strategies, the reason for which they face several dynamic challenges.

There are various gaps that exist in India as a whole. Apart from sporadic studies related to demography, there is little or no research conducted on knowledge, attitudes and practices related to the care of children with autism spectrum disorders. As highlighted in literature, studies suggest the ever increasing cases of the problem and Mizoram is not immune to this. At present, there are no data available on children with autism spectrum disorder in Mizoram. Whatever cases that are officially registered are found to represent only a few with more than majority of the cases found to be unregistered.

This study will therefore bridge this gap to understand about the disability in particular and how knowledge, attitudes and practices can help in opening up avenues for improvement of services and solving challenges. With this in mind the objectives of the study include profiling the demographic characteristics of primary and secondary caregivers, assessing their knowledge on Autism spectrum disorders, assessing the attitude towards children with Autism spectrum disorder , explore the caregiving and intervention practices, finding out the differences in knowledge, attitude and caregiving and intervention practices, finding out the relationship between knowledge, attitude and caregiving and intervention practices, exploring the

challenges and coping strategies of primary and secondary caregivers and finally suggesting measures for social work intervention and social policy in the field of autism spectrum disorder.

The field of study was Mizoram covering 8 Districts out of 11 Districts namely Aizawl, Lunglei, Champhai, Serchhip, Khawzawl, Kolasib, Mamit and Lawngtlai. The study is exploratory in nature and adopted mixed method using both quantitative and qualitative techniques. The population of the study includes all primary and secondary caregivers in Mizoram. Caregivers of children with Autism spectrum disorder and professionals who are working with children with Autism spectrum disorder represent the unit of study.

Data were collected from both primary and secondary sources. Primary source included data collected from both the primary and secondary caregivers of children with Autism Spectrum Disorders. Secondary sources were collected from books, literature and Government and Non- Governmental published and unpublished records.

A purposive sampling procedure was utilized for the identification of both primary and secondary caregivers. There were 138 primary caregivers who were identified to form the final sample from the quantitative study and 13 primary caregivers (5 for case study and 8 for focus group discussion) who were identified to form the final sample for qualitative study. The total sample size for primary caregivers were 151.

Likewise, the secondary caregivers were also purposively selected from government and non-government settings working in the area of disability and particularly prioritizing on professionals working with children with Autism spectrum disorder. The total sample size for secondary caregivers were 35. Overall, the sample size of the study covered 186 respondents.

A semi-structured interview schedule formed the tool for data collection. The tool included information related to the profile of the respondents, the knowledge on Autism spectrum disorder, their attitude towards children with Autism spectrum

disorder and their intervention practices in the care and rehabilitation of children with Autism spectrum disorder. It also included information regarding the challenges faced by the respondents, coping strategies of the primary caregivers in particular and suggestions to reduce the challenges of the caregivers. In-depth interviews were conducted to form case studies and focus group discussions were also conducted to explore the qualitative aspects.

5.1 Major Findings from Quantitative Study

- The study shows that 79.8 per cent of the respondents were primary caregivers and the remaining 20.2 per cent were secondary caregivers.
- The result also indicated that 48.5 per cent of the primary caregivers were mothers and 37.7 per cent were fathers. This finding is similar to Hoefman et. al, (2015) where caregivers of children with ASDs predominantly were the biological parents (95%), and mostly mothers on average.
- Among the primary care givers, more than half (59.4%) of them belong to the age-group of 25-39 years of age while among the secondary caregivers, more than two third (74.3%) of the respondents belong to the age group of 25-39 years of age.
- Among the primary caregivers, more than half of the respondents (57.2%) are females and from the secondary caregivers, majority (80%) of the respondents are females.
- Majority (77.5%) of the primary caregivers are married while among the secondary caregivers, less than two third (62.9%) of the respondents are unmarried.
- All respondents are Christians and majority (76.4%) of the respondents belong to the Presbyterian denomination.
- Majority (71.7%) of the respondents belong to nuclear family.
- Majority (92.5%) of the respondents are from a stable family.

- Among the primary caregivers more than a third (36.9%) of the respondents are graduates while from the secondary caregivers, almost half (48.6%) of the respondents attained education up to Post Graduation.
- More than half (52%) of all the respondents' primary occupation of family is government service.
- From the primary caregivers, less than half (47.8 %) of the respondents have a family monthly income of Rs.20000-Rs.50000 and from the secondary caregivers, more than more than a third (40.0 %) has a family monthly income of Rs.1 Lakh and above.
- More than half (52%) of the respondents belong to the APL category.
- A few (4.6%) of the respondents reported that there is history of disability in their family.
- Secondary caregivers work as clinical psychologist, social worker, special educators, doctors, psychiatrists, teachers, psychologist, counsellors and speech therapist. More than half (57.1%) of them have a working experience of 0-5 years.
- The children are diagnosed by Clinical Psychologist, Psychiatrist and Medical doctors.
- Among the primary caregivers, knowledge is low (0) in items such as ASD cannot be diagnosed in adulthood and on the level of support required by children with autism does not change with age.
- Among the secondary caregivers, knowledge is low (0) in 3 items such as ASD rate of co-morbidity is high with other genetic disorders and psychiatric disorders, ASD is not caused by poor parenting skills or poor home care and the level of support required by children with autism does not change with age.

- Overall, among the primary and secondary caregivers, the table shows that the average mean knowledge is high (1) in 27 items and low (0) in 1 item which is on the level of support required by children with autism does not change with age. There is no difference (1.11) in the knowledge on Autism spectrum disorder between the primary and secondary caregivers.
- Among the primary caregivers, the is bad in 1 item (1) which is on having a child with ASD as being stressful. The total mean average in the attitude of primary caregivers shows a moderate (2) attitude towards children with Autism spectrum disorder. Among the secondary caregivers, the attitude is bad in 4 items (1) such as having a child with ASD causes depression, having a child with ASD causes anger, having a child with ASD is expensive and having a child with ASD is stressful. The mean average of the overall assessment among the primary and secondary caregivers shows a moderate (2) attitude towards children with Autism spectrum disorder. There is no difference (0.408) in the attitude towards children with Autism spectrum disorder between the primary caregivers and secondary caregivers.
- Caregiving and intervention practices such as applied behavioral analysis, sensory integration therapy, family psycho educational service, play therapy and complementary and alternative model are seldom (1) used by the respondents. Further, discrete trial training, COMDEALL intervention model and supportive psychotherapy are never (0) used by the primary caregivers. Overall, the mean average on the frequency of usages on the caregiving and intervention practices by the primary caregivers are found to be average (2) in the scale measurement. Among the secondary caregivers, practices such as discrete trial training, COMDEALL intervention model and complementary and alternative model are seldom (1) used. Supportive psychotherapy is never (0) used. Overall, the mean average on the frequency of usages on the caregiving and intervention practices by the secondary caregivers are found to be average (2) in the scale measurement. The overall mean score of caregiving and intervention practice among the respondents shows an average score in the assessment scale.

- There is a significant difference (-4.309) in the caregiving and intervention practices between the primary and secondary caregivers. This indicates that the frequency in the usages of caregiving and intervention practice is higher among the secondary caregivers than the primary caregivers.
- There is a significant positive relationship (.220) between knowledge and attitude among the primary caregivers. This finding indicates that among the primary caregivers, higher the knowledge on Autism spectrum disorder, better the attitude towards children with Autism spectrum disorder.
- There is a significant positive relationship (.416) between attitude and practices among secondary caregivers. This finding highlights that better the attitude towards children with Autism spectrum disorder, higher the frequency in the usages of caregiving and intervention practices on children with Autism spectrum disorder among secondary caregivers.
- Challenges faced by the primary caregivers of children with Autism spectrum disorder includes challenges related to the nature of disability, challenge relating to mental health such as depression, stress, low self-esteem, sleeping disorders, anger and hopelessness., no time to socialize and no leisure time, non-acceptance, lack of family support, discrimination, lack of services, joblessness, and lack of awareness about Autism spectrum disorder respectively, expensive services, work being affected, family functioning being disrupted and unrealistic advice given by others.
- Challenges faced by secondary caregivers include the nature of disability of the child, lack of awareness, non-acceptance by parents, lack of services, stress, expensive services, over thinking, lack of support from family members, no space and time and low follow up rates respectively.
- Coping strategies of primary caregivers include religious faith and prayer, acceptance, seeking social support, working hard, patience, seeking professional support, positive thinking, following a therapy schedule, venting out to others, positive family support, home-based practice, seeking individual counselling, self-learning, attending parents training programmes, teaching social skills to children, giving phone to children, pharmacological

treatment to children, providing recreational resources to children, being alert and setting up surveillance camera.

- Suggestions to solve the challenges of primary caregivers include more awareness on Autism spectrum disorder, government provisions, more human resources in the field of Autism spectrum disorder, accessible services, more family support, availability of institutional care for children with Autism spectrum disorder, affordable services, continuation of education services from the government, disciplining the children, early intervention, seeking professional help, receiving adequate training for parents and playground for children.
- Suggestions of secondary caregivers include more awareness on Autism spectrum disorder, adequate training for skill enhancement, accessible services for children with Autism spectrum disorder, early intervention, more human resources, proper care and support, availability of institutional care, disciplining children, family support, structured play intervention and acceptance.

5.2 Major Findings from Qualitative Study

- Effects on emotions and mental health: The case studies completed shows how hard it can be on parents to raise a child with ASD. Some common themes are: There was a lot of stress, worry, and depression, especially after diagnoses. Parents generally have a hard time not knowing what will happen with the child.
- Coping: Parents said they dealt with their emotional and physical problems in several ways, such as, seeking help from family, friends, and parent groups. Taking part in spiritual or religious activities to feel more in charge, setting up routines and learning about ASD is also a positive way of coping.
- Financial Constraints: The case studies also depicted the financial constraints on the parents for availing services for their children with Autism spectrum disorder. Families also need to relocate for the sake of their children to access better services for their children with autism

spectrum disorder. Accessing autism-related services is a major challenge, particularly outside Aizawl. Even within the city, the high cost of therapies (e.g., speech, occupational, behavioural) places a financial strain on middle-income families. Districts outside Aizawl lack specialized schools and professionals.

- **Caregiver Burden:** The challenges of caregivers include depression, stress, sleeping disorders, marital discord and divorce, denial, anger, self-blame, role conflicts, and socialization. Family Dynamics also plays an important role in understanding the family environment and how it can have an impact on the child. Findings also indicate the surmounting burden of the parents and also the need of intervention at the family level
- **Lack of Awareness:** The case studies also evident how the lack of awareness and knowledge can have an impact on the children's well-being and safety. There is a strong call from parents for greater public awareness and education about autism to reduce stigma and promote community understanding.
- **Early Diagnoses and Intervention:** Early diagnoses and intervention of children has helped children to develop skills for daily living. This in turn has reduced stress and burden on the part of the caregivers.
- **Mothers as primary caregivers:** The study reveals that mothers are the primary caregivers of children. Their grit and proactivism has helped their children acquire skills of daily living. Most mothers have developed a strong understanding of autism over time, primarily through various information sources and school support. However, initial reactions to the diagnosis often involved denial, confusion, and emotional distress. Mothers expressed feelings of sadness and pity, especially in response to public stigma. A strong desire to protect their children from judgment and discrimination was evident.
- **The need for constant care** often forces one parent—typically the mother—to leave their job, impacting household income and increasing caregiving pressure.

5.3 Suggestions

More and more study on autism spectrum disorder (ASD) in India has shown how important it is to help people on the spectrum and their families deal with the unique problems they face. Even though people in cities know more about and understand ASD, there is still a big gap in rural and remote places, like states like Mizoram. Based on the study's results, suggestions are given below on how to improve understanding, intervention methods, and support systems for people with ASD in India, with a focus on the social and cultural setting of Mizoram. The ideas are meant to raise awareness, improve professional training, change government policy, and fund more research so that people on the spectrum and their caretakers can get all the help they need.

- Autism Spectrum Disorder (ASD) needs to be better understood so that people can better understand and help people with ASD. As the link between families, healthcare systems, and communities, social workers are in a unique position to raise understanding and encourage more welcoming practices. Awareness campaigns need to be a part of both the small (one-on-one) and large (community and policy) parts of social work. The study also confirms that among the primary caregivers, more knowledge leads to better attitude towards children with ASD. Therefore, it is imperative that awareness become the key strategies to improve attitude.
- Further, the study also shows that among the secondary caregivers, positive attitude leads to more practices in the care and intervention of children with ASD. Therefore, efforts should be taken to bring about positive attitude towards children with ASD.
- From the study, caregiving and intervention practices among primary caregivers is lesser than the secondary caregivers. Therefore, more initiatives has to be undertaken to increase the knowledge of intervention practices among primary caregivers.

- At the local level, social workers need to work directly with families. For example, this means teaching parents, carers, and other family members about the symptoms of ASD, ways to cope, and the different ways it can show up. Social workers can give parents and other adults who care for children the tools they need to help the child grow and develop by offering personalised counselling and support programs.
- At the societal level, social workers can push for changes that make the community more aware of ASD and make it easier for people with ASD to get services. This includes setting up campaigns to raise knowledge about ASD in schools, neighbourhoods, and even workplaces so that people can better understand it. These efforts should stress how important it is to include people with ASD in all aspects of school life, help them fit in with their peers, and give them the chances to do well in society. Both types of intervention are important for lowering stigma, promoting acceptance, and making sure that people with ASD and their families get the help they need from both experts and the public.
- In India, most of the work to raise knowledge about ASD has been done to identify the diagnostic criteria and get medical help right away. But this knowledge needs to be expanded right away to include a wider view that includes not only the diagnosis but also the difficulties of parenting, the skills needed to live on one's own, and the rights of people with ASD. People from all walks of life, not just doctors or special educators, need to be involved in raising awareness. Parents and other adults who care for a child with ASD need to know more than just the diagnosis.
- It is also important for families to know what the legal rights of people with disabilities are, especially since India passed the Rights of Persons with Disabilities (RPwD) Act, 2016. States like Mizoram have limited resources and infrastructure, so the government needs to make sure that all areas get the same number of services and facilities. Government programs that help people with ASD should be made available in more areas, especially those that aren't getting enough help. Every area in

Mizoram should have resource centres, specialised schools, and rehabilitation centres for people with ASD so that they can get the services they need, no matter where they live.

- Community understanding is very important, but it's also very important that people who work with people who have ASD—from teachers to healthcare workers—get training in how to spot and deal with problems that are caused by ASD.
- Sensitisation programs for professionals at all levels should work to get rid of biases, make communication better, and raise the quality of care generally. Teachers and school counsellors need to know how to spot early signs of ASD so that help can be given right away.
- There should be courses in teacher training programs on ASD awareness, inclusive education, and how to handle the classroom for kids on the spectrum. These kinds of activities would also help stop the bullying and other problems that kids with ASD often face at school.
- People who work in health care, like paediatricians, general practitioners, and mental health experts, need to be taught how to spot ASD early and help families find the right services. This is very important in rural places where it's hard to get specialised care.
- Social workers are very important when it comes to helping families feel better. Making these workers more aware of the subtleties of ASD can help them provide better counselling, advocacy, and resource coordination.
- Skill enhancement initiatives designed for those on the autistic spectrum.
- Organised training sessions for carers, particularly in rural and underserved regions, can equip them with knowledge, coping methods, and behavioural tactics to assist children with ASD. Carers of individuals on the spectrum require emotional and psychological support to mitigate stress and prevent burnout.
- Social stigma continues to be a substantial obstacle to inclusion and acceptance. Awareness initiatives utilising local media, educational

institutions, and faith-based organisations can mitigate myths and prejudices around autism, fostering a more inclusive society.

- At present, access to government assistance for ASD is limited to several districts, including Aizawl. It is imperative to replicate and expand these programs across all eleven districts of Mizoram to guarantee fair access. Establishing district-level disability resource centres helps decentralise services and enhance outreach.
- The research identified elevated mental distress and a notable knowledge deficiency among primary carers. Systematic, evidence-based intervention programs that emphasise mental health, coping methods, and knowledge upgrading can substantially reduce carer load and promote family functioning.
- Training programs should be sensitive to different cultures, considering things like Mizoram's traditions, beliefs, and family structures. Content that is culturally relevant can help carers connect with it better and feel more comfortable using what they've learnt in their everyday lives. Including community leaders, local languages, and resources that are specific to the area in training programs can also make them easier to reach and more useful.
- Stigma and abuse against people with autism spectrum disorder make it hard for them to fit in with their peers. A lot of people in India, including people in Mizoram, still don't understand neurodevelopmental disorders. This leads to bad stereotypes and being left out of social groups. Campaigns to raise knowledge, community involvement, and practices that include everyone are all important ways to deal with these problems.
- For families who live in rural areas or places where specialised services are hard to get to, home-based treatments are essential for helping people with ASD all the time. Therapeutic strategies can be regularly used with home-based interventions, even when professional help is not easily accessible.

- The study shows dearth of data related to children with ASD in different districts of Mizoram. Government resources and services need to be strengthened to improve diagnosis as well as services related to ASD in Mizoram.
- Scope for future research: Some study can be replicated with both primary and secondary caregivers of children with Autism spectrum disorder and comparisons can be made on the knowledge, awareness, challenges and coping to get better understanding of gender roles and differences. More number of respondents, larger samples can be taken for the intervention. Specific groups for fathers and mothers could be conducted so that specific issues each one face can be discussed and dealt with, in detail. The caregivers of children with autism spectrum disorder can be supported with a specific systematically intervention programme. Indian research on autism spectrum disorder is still in its early stages, especially in rural areas that aren't well studied, like Mizoram. To learn more about the problems and needs of people with ASD, more study is needed with a lot of different kinds of people as samples. Also, methods used in future studies should be more open and sensitive to different cultures. To learn about the long-term outcomes of people with ASD, especially those who have gotten early intervention and support, longitudinal studies are needed. The results of these studies can help researchers figure out which types of interventions help people on the spectrum have better long-term effects.

APENDICES

Children with Autism Spectrum Disorders in Mizoram: Knowledge, Attitude and Practices of Primary and Secondary Care Givers QUESTIONNAIRE

Tecie Lalduhzuali Ph.D Research Scholar Department of Social Work, Mizoram University.	Dr. Henry Zodinliana Pachauau, Associate Professor Research Guide, Department of Social Work, Mizoram University.
Schedule No:	Date :

Dear friends,

I am a PhD Research Scholar from the Department of Social Work, Mizoram University conducting research on the topic ‘Children with Autism Spectrum Disorders In Mizoram: Knowledge, Attitude and Practices of Primary and Secondary Care Givers’. I kindly request you to render me your participation in this study by answering the following questions. Confidentiality and anonymity will be strictly maintained.

I. Personal Characteristics (Please tick the appropriate answer)		
1.	Name (Optional)	
2.	Age	24
3.	Sex	Female
4.	Marital Status	Unmarried
5.	Religion	Christianity
6.	Denomination	Presbyterian
7.	Category	Secondary Caregiver
8.	If Primary Care Giver, relation with the child	Mother/Father/Sibling/ Any Other (Specify)

9.	If secondary care giver, designation of work	Social Worker	
10.	Type of family	Nuclear	
11.	Form of family	Stable	
12.	Educational Qualification	Post Graduate	
13.	Primary occupation of family	Government Service	
14.	Monthly Income of family	Rs. 1 lakh and above	
15.	Socio- economic Status	APL	
16.	Any history of Disability in the family. If Yes Specify		
17.	Years of working experience with Children with Autism Spectrum Disorder (for professionals only)		
18.	Diagnosis history	By Medical Doctor / By Psychiatrist / By Clinical Psychologist / Any Other (Specify)	
II. Knowledge on Autism Spectrum Disorders (Please tick the appropriate answer)			
Sl.No	Statements	Response	
		Yes (1)	No (0)
i.	Autism Spectrum Disorder is a Developmental Disability.		
ii.	Autism is being diagnosed at the age range of between 2-3 yrs.		
iii.	Autism rate of co-morbidity is high with other genetic disorders and psychiatric disorders.		
iv.	Autism Spectrum Disorder affects people differently.		
v.	Autism Spectrum Disorder is a mental disorder.		
vi.	Autism Spectrum Disorder is a lifelong disorder.		
vii.	Autism Spectrum Disorder is not caused by vaccinations during childhood.		

viii	Autism Spectrum Disorder involves delays and impairment in social skills.		
ix	Children with Autism Spectrum Disorders find it hard to understand other people's feelings.		
x.	Autism Spectrum Disorder involves delays and impairments in behavioural skills.		
xi.	Autism Spectrum Disorder involves delays and impairments in language skills.		
xii.	Autism Spectrum Disorder cannot be diagnosed in adulthood.		
xiii	The prevalence of autism is greater in children than in adults.		
xiv.	Autism Spectrum Disorder involves sensory impairments.		
xv.	Autism Spectrum Disorder is caused by abnormalities in brain structures or functions.		
xvi.	Autism Spectrum Disorder is not curable.		
xvii.	Autism Spectrum Disorder does not involve physical illnesses.		
xviii.	Environmental factors (family, community, facilities) contribute to difficulties faced by children with Autism Spectrum Disorder		
xix.	Children with Autism Spectrum Disorder do not show affectionate behaviour		
xx	Autism Spectrum Disorder has different levels of impairment		
xxi	All children with Autism Spectrum Disorder do not have intellectual disability.		
xxii.	Autism Spectrum Disorder is not caused by poor parenting skills or poor home care.		
xxiii.	Autism Spectrum Disorder does not only occur in children.		
xxiv.	The level of support required by autistic people does not change with age.		
xxv.	Children with autism do not eventually overgrow autism.		
xxvi.	Children with Autism Spectrum Disorder find it hard to communicate and participate in social interaction		
xxvii	Right to Person with Disability Act 2016 protects and promote the rights of Children with Autism Spectrum Disorder.		

xxviii	There are services for intervention for children with Autism Spectrum Disorder in Mizoram.					
III. Attitude towards Autism Spectrum Disorder (Please tick the appropriate answer)						
Sl.No	Statements	Response				
		Strongly Agree 0	Agree 1	Neither Agree nor Disagree 2	Disagree 3	Strongly Disagree 4
i.	Having a child with Autism Spectrum Disorder is stressful.					
ii.	Having a child with Autism Spectrum Disorder causes Depression.					
iii.	Having a child with Autism Spectrum Disorder causes Anger.					
iv.	Having a child with Autism Spectrum Disorder is irritating.					
v.	Having a child with Autism Spectrum Disorder is fearful.					
vi.	Having a child with Autism Spectrum Disorder is not acceptable.					
vii.	Having a child with Autism Spectrum Disorder is an emotional burden.					
viii.	Having a child with Autism Spectrum Disorder is expensive.					
ix.	Children with Autism Spectrum Disorder do not need professional interventions.					
x.	Children with Autism Spectrum Disorder lack empathy.					

xi.	Children with Autism Spectrum Disorder cannot be improved					
xii.	Training is not important in managing a child with Autism Spectrum Disorder					
xiii.	There is no time for self-care if you have a child with Autism Spectrum Disorder					
xiv.	Children with Autism Spectrum Disorder should not have children after they grow up					
xv.	Children with Autism Spectrum Disorder are incapable of forming relationships and expressing emotions					
xvi.	Having a child with Autism Spectrum Disorder is embarrassing					
xvii.	I am not comfortable in helping a child with Autism Spectrum Disorder					
xviii.	It is hard to manage the behaviour of children with Autism Spectrum Disorder					
xix	Children with autism spectrum disorder should not marry after they group up.					
xx	Children with autism spectrum disorder are not able to have educational attainment.					

IV. Care Giving and Intervention Practices (Please tick the appropriate answer)

Sl.No	Statement	Response				
		Never 0	Seldom 1	Sometimes 2	Often 3	Always 4
i.	Educational Interventions.					
ii.	Improving self-care skills.					
iii.	Improving communication skills (Speech and					

	language).					
iv.	Improving social skills.					
v.	Improving cognitive skills.					
vi.	Improving behavioural skills.					
vii.	Improving sensory skills.					
viii.	Improving emotional management skills.					
ix.	Improving analytical skills.					
x.	Occupational Therapy.					
xi.	Counselling					
xii.	Early Intervention					
xiii.	Applied Behavioural Analysis					
xiv.	Sensory Integration Therapy					
xv.	Discrete Trial Training.					
xvi.	COMDEALL Intervention Model					
xvii.	Complementary and Alternative Medicine.					
xviii.	Family Psycho Educational Service.					
xix.	Play Therapy					
xx.	Any Other (Specify)					
xxi.	Any Other (Specify)					
18.	Challenges faced (Please Specify)					
19.	Coping Strategies- For Primary Care Givers only (Please Specify)					
20.	Suggestions to improve knowledge, attitude and care and intervention practices (Please Specify)					

Thank You for your Time

**Children with Autism Spectrum Disorders in Mizoram:
Knowledge, Attitude and Practices of Primary and Secondary Care Givers**

Kamwna Lehkha

Tecie Lalduhzuali Ph.D Research Scholar Department of Social Work, Mizoram University.	Dr. Henry Zodinliana Pachauau, Associate Professor Research Guide, Department of Social Work, Mizoram University.
Kawmna No:	Ni :

Ka Pi/ Ka Pu

Mizoram University, Department of Social Work atanga Ph.D Scholar ka ni a. Ka topic chu ‘Children with Autism Spectrum Disorders in Mizoram: Knowledge, Attitude and Practices of Primary and Secondary Care Givers’ tih a ni a. Khawngaih taka he ka questionnaire hi i hun hlu tak senga min chhan sak theih chuan ka lawm hle ang. I chhan dan te hi thup vek a ni anga, ka zirna atan chauh a hman a ni ang. Min puihna hian Autism Spectrum Disorder naupangte hmasawna atan rahbi pawihmawh tak a siam dawn a ni.

I. Mimal Chanchin		
1.	Hming (Ziah loh theih)	
2.	Kum	
3.	Mipa nge Hmeichhia	Mipa / Hmeichhia

4.	Nupui-pasal nei nge nei lo	Neilo / Nei / Inthen / Boral san
5.	Sakhua	Christianity/Hindu/Muslims/ Buddhist / Sikh / A dangte
6.	Kohhran	Presbyterian / Baptist / Seventh Day Adventist/ United Pentecostal Church/ Catholic/Salvation Army / A dangte
7.	Chhangtu nihna	Chhungkua a naupang enkawltu ber / Mithiam naupang enkawl thin tu
8.	Naupang enkawltute nih chuan, naupang nena inkungkaih dan	Nu/Pa/Unau/ A dangte (Specify)
9.	Mithiam naupang enkawl nih chuan, hna a, a nihna	Social Worker/ Doctor/Psychiatrist/Counsellor/ Psychologist/Clinical Psychologist/ Special Educator/ Occupational Therapist/Speech Therapist/ Teacher/ A dangte
10.	Chhungkaw Khawsak dan	Hringtu nu leh pa te nen a cheng ho/ Pi leh Pu te hnena cheng ho
11.	Chhungkaw ziarang	Chungkaw nghet/ Chhungkaw kehdarh/ Chhungkaw inzawmkhawm/ dang
12.	Lekhazir san chin	Lehkha thiamlo/ Primary/ Middle/High/Higher Secondary/Graduate/Post Graduate/PhD/ MBBS/MS
13.	Chhungkaw eizawwna ber	Government Service / Agriculture/ Large Business / Petty Business / Self Employed / Others (Specify)_____
14.	Thla khata sum lakluh zat	Rs.10000 hnuailam / Rs.10000 to Rs. 30000 / Rs.30000 to Rs.50000 / Rs. 50000 to Rs. 1 lakh / Rs 1 Lakh chunglam
15.	Ei leh bar chungchanga chhungkaw dinhmun	AAY / BPL / APL / Nihna nei lo
16.	Chhungkua ah rualbanlo dang an awm em? Awm chuan, eng rualbanlohna nge?	
17.	Thiamna thil a hnathawh hun chhung (Mithiambik te tan)	

18.	Tu in nge naupang chu Autism spectrum disorder a nei ngei tih hrihl tu che u?	Medical Doctor / Psychiatrist / Clinical Psychologist / Adangte		
II. Autism Spectrum Disorders chungchang kan hriatdan (Chhanna dik i tih zawn ah min lo thai sak)				
Sl.No	Statements	Channa		
		Aw (1)	Aih (0)	
i.	Autism Spectrum Disorder hi taksa leh rilru hmasawwna ti thuanawptu a ni.			
ii.	Autism Spectrum Disorder hi naupang kum 2-3 inkar an nih in a hriatchhuah theih.			
iii.	Autism nei theihna hi inthlahchhawn na atang leh rilru lam natna nei atangin a sang bik ni.			
iv.	Autism Spectrum Disorder hian mi hrang hrang ah thawh dan hrang hrang a nei.			
v.	Autism Spectrum Disorder hi rilru lam rualbanlohna ani.			
vi.	Autism Spectrum Disorder hi damchhung rualbanlohna thlentu ani.			
vii.	Autism Spectrum Disorder hi naupanlaia vaccine kan lak avanga awm ani lo.			
viii.	Autism Spectrum Disorder hian mi zinga khawsak kan thiamna tur a tih khawtlai bakah a ti muang			
ix.	Autism Spectrum Disorders nei naupangte hian mi rilru puthmang hriatthiam har an ti.			
x.	Autism Spectrum Disorder hian nungchang pangngai neih theihna a nghawng a, a ti thuanawp baw.			
xi.	Autism Spectrum Disorder hian tawng thiam theih na a nghawng a, a ti thuanawp baw.			
xii.	Puitlin hnuah Autism Spectrum Disorder hi an nei tih a hriatchhuah theih.			
xiii.	Autism Spectrum Disorder hi puitling aiin naupang in an nei nasa zawk.			
xiv.	Autism Spectrum Disorder hian hriatna thazam hrang hrang a ti khawlo.			
xv.	Autism Spectrum Disorder hi thluak zia rang awm dan lo leh a thawh dan tur ni lo a, a thawh avanga thleng ani.			
xvi.	Autism Spectrum Disorder hi tih dam theih a ni lo.			

xvii.	Autism Spectrum Disorder hian taksa lam natna a huam tel lo.					
xviii.	Autism Spectrum Disorder naupangte harsatna ti zual tu chu seilen na hmun (chhungkua/khawtlang/enkawlna hmun) a ni.					
xix.	Autism Spectrum Disorder naupangte hian mi lainatna an tilang thiam lo.					
xx	Autism Spectrum Disorder lan chhuah dan hi chhawng hrang hrang a awm.					
xxi	Autism Spectrum Disorder nei naupang zawng zawng hian thiamna (rilru chakna) lama harsatna an nei vek lo.					
xxii.	Autism Spectrum Disorder hi nu leh pa in fate an enkawl that loh vang leh inchhung kan in enkawl dan that loh vanga lo awm ani lo.					
xxiii.	Autism Spectrum Disorder hi naupangte ah chauh a thleng lo.					
xxiv.	Autism Spectrum Disorder naupangte hian puih an mamawh dan chen hi an kum a lo tam in a in thlak chuang lo.					
xxv.	Autism Spectrum Disorder naupangte hian Autism hi than hnan a dam thei a ni lo.					
xxvi.	Autism Spectrum Disorder naupangte hian midangte biak pawh leh nel an harsat.					
xxvii	Right to Person with Disability Act 2016 hian Autism Spectrum Disorder naupangte chanvo hi a humhalh in a chawi kang bawh a ni.					
xxviii	Mizoram ah hian Autism Spectrum Disorder nei naupangte tan hian in enkawlna hmun a awm.					
III. Autism Spectrum Disorder kan thlir dan (Chhanna dik i tih zawn ah min lo thai sak)						
Sl.No	Statements	Response				
		Pawm lutuk 0	Pawm 1	Pawm leh pawm lo inkar 2	Pawm lo 3	Pawm lo Lutuk 4
i.	Autism Spectrum Disorder hian rimtawngna a thlen					
ii.	Autism Spectrum Disorder hian rilru hahna a thlen					
iii.	Autism Spectrum Disorder hian thinurna/thinrimna a					

	thlen					
iv.	Autism Spectrum Disorder hian ninna a thlen					
v.	Autism Spectrum Disorder hian hlauthawwnna a thlen					
vi.	Autism Spectrum Disorder hi pawm harsa ka ti					
vii.	Autism Spectrum Disorder hian rilru lama phurritna a thlen.					
viii.	Autism Spectrum Disorder fa neih hi a hautak					
ix.	Autism Spectrum Disorder naupangte hian mi thiam bik enkawlna an mamawh lo.					
x.	Autism Spectrum Disorder nei naupang te hian midang dinhmun va hrethiamna an nei lo.					
xi.	Autism Spectrum Disorder nei naupangte hian hmasawwnna an nei thei lo.					
xii.	Autism Spectrum Disorder naupang enkawl dawn hian training neih kher a ngai lo.					
xiii.	Autism Spectrum Disorder fa neih chuan mahni inenkawlna hun a awm lo.					
xiv.	Autism Spectrum Disorder naupangte hian an puitlin hnu ah fa an nei tur ani lo.					
xv.	Autism Spectrum Disorder naupangte hian inkungkaihna siam dan an thiam lo in an rilru puthmang an sawi chhuak thiam lo.					
xvi.	Autism Spectrum Disorder fa neih hi azahthlak					
xvii.	Autism Spectrum Disorder naupangte tanpui hi ka harsa thin.					
xviii.	Autism Spectrum Disorder naupangte mizia enkawl hi a harsa.					
xix.	Autism Spectrum Disorder naupangte hian puitling an n hnu ah nupui pasal an nei tur ani lo.					

xx.	Autism Spectrum Disorder naupante hian an lehkhazir lamah hmasawwna an nei thei lo.					
IV. Care Giving and Intervention Practices (Chhanna dik i tih zawn ah min lo thai sak)						
Sl. No	Statement	Chhanna				
		Ngai lo 0	Zeuh zeuh 1	A Changin 2	Ngai fo 3	Engtik lai pawn 4
i.	Educational Interventions. (Thiamna lama zirtirna pek dan)					
ii.	Improving self-care skills. (Mahni in enkawl dan a hmasawwna)					
iii.	Improving communication skills (Speech and language). (Mi Biak pawhna lam thiamna/ tawng zir)					
iv.	Improving social skills. (Mi zinga khawsak dan thiam)					
v.	Improving cognitive skills. (Thluak hman thiam theihna tura hmasawwna)					
vi.	Improving behavioural skills. (Nungchang hmasawn theihna tura hmalak)					
vii.	Improving sensory skills. (Hriatna hrang hrang thazam Hmasawn theihna tura zirtir)					
viii.	Improving emotional management skills. (Mahni thinlung/rilru kaihruai dan zirtir)					
ix.	Improving analytical skills. (Mahni a thil chhut thiamna hmasawn thei tura inzirtir)					
x.	Occupational Therapy. (Taksa peng hrang hrang hman thiam inzirtir)					
xi.	Counselling (Mithiam hmanga inkawm)					
xii.	Early Intervention (Harsatna awm tirh a tanga enkawl na pek)					

xiii.	Applied Behavioural Analysis					
xiv.	Sensory Integration Therapy					
xv.	Discrete Trial Training.					
xvi.	COMDEALL Intervention Model					
xvii.	Complementary and Alternative Medicine (Damdawi hmanga Enkawl)					
xviii.	Family Psycho Educational Service. (Chhungkua te nena thawkho A inzirtirna lak/pek)					
xix.	Play Therapy (Infiamna hmanga enkawl)					
xx	A Dang (Ziak lang rawh)					
xxi	A Dang (Ziak lang rawh)					
18.	Harsatna tawhte (A nih dan tak min lo hrilhfiah sak)					
19.	Harsatna tawhte Hmachhawn Dan- A enkawl tak tu te tan (A nih dan tak min lo hrilhfiah sak)					
20.	Autism Spectrum Disorder hriatdan, thlir dan leh kan enkawl dan te a hmasawn theihna tura ; Rawtna nei te(A nih dan tak min lo hrilhfiah sak)					

I hun hlu tak min pek avangin ka lawm e

CONSENT FORM

(English version)

Information to the participants

I *Tecie Lalduhzuali Ph.D Scholar, Department of Social Work, Mizoram University* conducting a research on 'Children with Autism Spectrum Disorder in Mizoram: Knowledge, Attitude and Practices of Primary and Secondary Care Givers'. You are requested to participate in the study and your participation will require approximately one hour of your time, your answers will be kept confidential and will be used only for research purpose.

Consent

'I have been informed about the aim of the study. The procedure has also been explained to me as stated above. I have understood that I have the right to refuse my consent or withdraw the same at any time during the study without giving any explanation'

I..... undersigned to give my consent to participate in the study.

Name & Signature of

Researcher

For any information kindly contact :

Researcher: Ms Tecie Lalduhzuali, Ph D Scholar, Department of Social Work, Mizoram University. Ph. No. 7551470048

Research Guide: Dr Henry Zodinliana Pachuau, Associate Professor, Department of Social Work, Mizoram University.

Phalna
(Mizo Version)

Chhangtute te hriattur

Kei Tecie Lalduhzuali Ph.D Scholar, Department of Social Work, Mizoram University
hian research ka ti mek a, ka topic chu ‘Children with Autism Spectrum Disorder in
Mizoram: Knowledge, Attitude and Practices of Primary and Secondary Care Givers ‘ tih
a ni a. He study atan hian zawhnate dik taka min chhansak turin ka ngen che a. I chhanna
te chu puanzar a ni lo vanga, zirna atan chauh hman a ni ang.

Phalna

He study a a tul zawng zawng hriattir ka ni a. Engkim hriatir ka nih hnuah ka remtihna
ngei in he study a tel tur hian kei hian phalna ka pe e.

Hming leh Signature

Hriatduh in neih chuan biak thieh reng kan ni e:

Researcher: Ms Tecie Lalduhzuali, Ph D Scholar, Department of Social Work, Mizoram
University. Ph.No. Ph. No. 7551470048

Research Guide: Dr Henry Zodinlana Pachuau, Associate Professor, Department of
Social Work, Mizoram University

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2	2020	'Impact of Domestic Violence on Children'	International Webinar on 'Issues and Challenges among Children: Prospects and Interventions'	Higher and Technical Institute, Mizoram (HATIM) & Department of Social Work, Mizoram University
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1.	2025	Challenges and Coping Strategies of Primary Caregivers of Children with Autism Spectrum Disorder in Mizoram	Mizo Studies, Vol. XIV No.1 (A quarterly refereed Journal)	Department of Mizo, Mizoram University ISSN: 2319-6041
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ABSTRACT

CHILDREN WITH AUTISM SPECTRUM DISORDER IN MIZORAM: KNOWLEDGE, ATTITUDE AND PRACTICES OF PRIMARY AND SECONDARY CARE GIVERS

**AN ABSTRACT SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF
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**CHILDREN WITH AUTISM SPECTRUM DISORDER IN MIZORAM:
KNOWLEDGE, ATTITUDE AND PRACTICES OF PRIMARY AND
SECONDARY CARE GIVERS**

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**In partial fulfillment of the requirement of the Degree of Doctor of
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INTRODUCTION

The purpose of this study is to find out the knowledge, attitude and practices of primary and secondary caregivers of children with autism spectrum disorder in Mizoram. It also tries to understand the challenges faced by the primary and secondary caregivers and try to understand the relationship between knowledge, attitude and practices of primary and secondary caregivers of children with autism spectrum disorder in Mizoram. Further it will suggest measures for social work intervention and policy making.

Autism spectrum disorder (ASD) is a developmental disorder, considered by researchers to be one of the most widespread and serious developmental disorders of childhood, with the most implications in all spheres of development. Every family member is impacted by the autism spectrum disorder diagnosis in a unique way. Helping a child with autism requires all of a parent's attention, which can be difficult and have an impact on marriage, other couples' children, employment, savings, connections with others, and obligations.

Autism is considered a spectrum disorder, which implies that a child's symptoms can range from moderate to severe. Autism can be detected in some children as early as 12 months with babies do not babble, while others may develop normal language and social skills for a while before regressing with autism, a condition known as "regressive autism". Early identification and diagnosis will assist parents in developing a good and efficient intervention plan, reducing stress as they discuss and share their burden with specialized specialists to arrive at a correct diagnosis. Lack of awareness increases the probability of misdiagnosis or late diagnosis, especially the signs of this diseases parents who are the first to notice any unusual behavior compared to other children or siblings of the same age group.

International Scenario

Autism was first identified by an American psychiatrist named Leo Kanner in a paper published in 1943 entitled ‘Autistic disturbances of affective contact’. A year later an Austrian medical student called Hans Asperger published a paper in 1944 entitled ‘*Autistic Psychopathy in Childhood*’. The individuals described by both Kanner and Asperger differed from each other in some respects and also considerable overlap between the descriptions. However, both the works of these two researchers led to the evolvement of identifying autism over the years (Boucher, 2022).

Through the 1970s, research began to shift toward biological and neurological explanations. Autism was recognized as a neurodevelopmental disorder, not a result of parenting style. In 1980 Autism was formally included in the DSM-III (Diagnostic and Statistical Manual of Mental Disorders). Between 1981 – 1994, Asperger’s syndrome was re-evaluated and included in the DSM-IV in 1994 as a distinct diagnosis. In 2013, in the DSM- 5, the separate diagnosis of autistic disorder, Asperger’s Syndrome and PDD-NOS were unified under the umbrella term autism spectrum disorder.

The prevalence of autism spectrum disorder is increasing drastically all over the world. Autism spectrum disorder prevalence may be rising for a number of reasons, including expanding the diagnostic criteria through frequent, timely modifications of the DSM, along with PDD and other autistic conditions considered as single entities as ASD in recent times. Public awareness about the symptomology of the condition and increased practice of universal screening for ASD by health practitioners led to early and increased detection of children with autism. Easily available facilities of early intervention and active school participation in providing school-based services for children with ASD might add to increased prevalence and improved outcomes (Uke et. al., 2024).

The prevalence of autism spectrum disorders which was previously in the order of 1 to 650 to 1000 is now according to CDC’s Autism and Developmental Disabilities

Monitoring Network released data in 2007 to be about 1 in 150 8-year-old children in multiple areas of the United States. The exact reason for this has been debated and a consensus was not reached to the satisfaction of many (CDC's Autism and Developmental Disabilities Monitoring Network, 2007).

Autism Spectrum Disorders (ASD) are the most common developmental disability in the world, and their incidence is rising daily. According to WHO estimates from April 2017, 1 in 160 children globally suffers from autism spectrum disorders. The global prevalence of autism spectrum disorder varies across regions and studies, influenced by factors such as diagnostic criteria, awareness, and healthcare infrastructure. A comprehensive meta-analysis completed by Salara et. al. (2022) estimated that approximately 0.6 per cent of the global population is affected by ASD. Their studies also concluded the prevalence rates across different continents such as:

- Asia: 0.4 per cent
- America: 1 per cent
- Europe: 0.5 per cent
- Africa: 1 per cent
- Australia: 1.7 per cent

Another study completed by Minhas et al (2015) stated that in South Asia 1.4 per cent of people suffer from autism spectrum disorder however relatively few of them has access to any kind of medical care.

National Scenario

Autism Spectrum Disorder (ASD) was initially acknowledged in India during the early 20th century. In 1944, A. Ronald, a Viennese pediatrician who was employed in Darjeeling, described children who exhibited behaviors that are now associated with autism. However, he did not use the term "autism." The disorder's formal

recognition in India was initiated in 1959 with the publication of the first explicit mention of "autism" in Indian literature. The awareness and comprehension of ASD in India were minimal during the 1960s and 1970s. The disorder was frequently misdiagnosed or confused with other conditions, as the medical community had limited exposure to it. The term "autism" was rarely employed, and there was a dearth of specialized knowledge or resources to assist individuals with ASD.

The establishment of specialized centers and advocacy groups during the 1980s marked a significant turning point. The Tamana School of Hope in Delhi was the first institution in India to acknowledge autism as a distinct disability in 1985. The school provides specialized programs for individuals with autism spectrum disorder

In 1991, Action For Autism (AFA) was founded in New Delhi as a parent-led initiative to advocate for children and adults with autism. Action For Autism played a pivotal role in raising awareness, providing training, and influencing policy changes. Their efforts led to the inclusion of autism in the National Trust for Autism, Cerebral Palsy, Mental Retardation, and Multiple Disabilities Act in 1999 and the revised Persons with Disabilities Act 2016.

Based on prevalence estimates, there could be up to 2 million autistic individuals in India. However, research on autism is still in its early stages in the Indian subcontinent. In India, the frequency of autism has been rising significantly. In India, the estimated prevalence of autism is 1 in 68 children. The prevalence of autism is higher in boys than in girls, with a male-to-female ratio of roughly 3:1 (Malhi & Sankhyan, 2021; Krishnan et al., 2021)

According to a systematic analysis completed by Raina et al 2013, the prevalence rate among children aged 0-17 in South Asian Countries (Bangladesh, India, Sri Lanka) ranges from 0.09% to 1.07% for ASD. This discrepancy is attributed to underdiagnoses, lack of awareness, and limited mental health services.

Regional Scenario

As per the 2011 Census, Mizoram had a total of 15,160 persons with disabilities (PwDs), accounting for approximately 1.38 per cent of the state's population. The breakdown of disabilities was as follows:

- Hearing Impairment: 3,354
- Visually Impaired: 2,035
- Speech Impairment: 1,163
- Orthopedic Disabilities: 1,976
- Mental Retardation: 1,585
- Mental Illness: 1,050
- Multiple Disabilities: 2,083
- Other Disabilities: 1,914

These figures were based on the 2011 Census data, and the next comprehensive data collection on disabilities is expected in the 2021 Census. However, the detailed disability data from the 2021 Census has not been released yet. In the interim, a 2021 survey reported that there were 13,418 registered Persons with Disabilities in Mizoram, with 27.9 per cent residing in the Aizawl district. However, there is no record of autism population according to 2011 census.

Although global prevalence rates have been found and presented, there is a scarcity of data that pertains to Mizoram, a state in the north eastern region of India. Studies from neighboring regions provide some insights, despite the absence of first-hand data from Mizoram. For example, a study conducted in Himachal Pradesh revealed a prevalence of 0.9 per 1,000 children between the ages of 1 and 10 (Raina et. al.,2017). It is conceivable that the prevalence of ASD in Mizoram may be within a similar range, given the socio-economic and cultural similarities between Himachal

Pradesh and Mizoram. Although there is no direct data on the prevalence of ASD in Mizoram, the prevalence may be comparable to other north-eastern states based on extrapolation from regional studies. Nevertheless, the absence of specific studies emphasizes the necessity of targeted research in Mizoram to assess the prevalence of ASD.

Definition and Concepts

Autism Spectrum Disorder

Autism spectrum Disorders are a group of neuropsychiatric disorders with specific delays and deviance in social, communicative and cognitive development. ASD includes autism, Asperger's syndrome and pervasive developmental disorder-not otherwise specified (PDD-NOS) (Kommu, 2011).

According to National Institute of Mental Health (2024), autism spectrum disorder is a neurological and developmental disorder that affects how people interact with others, communicate, learn and behave. 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.

The Centre for Disease Control and Prevention defines ASD as a developmental disability that causes significant social, communication, and behavioral challenges. It emphasizes the importance of early identification and intervention to support individuals with ASD in reaching their full potential. The CDC provides resources for understanding signs, symptoms, and available support for individuals with autism spectrum disorder (Centre for Disease Control and Prevention, 2025).

According to the Persons with Disabilities Act 2016, autism spectrum disorder is defined as a neuro-developmental condition that typically appears in the first three years of life. This condition slightly affects a person's ability to communicate, understand relationships and interact with others. It is often associated with unusual or stereotypical behaviors and rituals (Government of India, 2016).

According to Watson & Happe (2019), Autistic spectrum disorder is a broad term. To provide an answer to the question in any given situation. The contrast between the various meanings of question in terms of the various degrees of explanation is another possible interpretation of this concept. The biological, cognitive, and behavioral levels are particularly helpful in the academic study of autism. These three levels are the most important. In 1995, Morton and Frith presented a particular diagrammatic tool that was designed to facilitate the process of thinking about the levels of explanation that are present in developmental problems such as autism.

According to World Health Organization (2016), the ICD 10 categorizes pervasive developmental disorders into the following sub types:

- Childhood Autism:

A pervasive developmental disorder which is defined by the presence of abnormal and/ or impaired development that is manifested before the age of 3 years, and by the characteristic type of abnormal functioning in all three areas of social interaction, communication, and restricted, repetitive behavior. The disorder occurs in boys three to four times more often than in girls. Usually there is no period of unequivocally normal development but, if it is there, abnormalities become apparent before the age of 3 years. There are always qualitative impairments in reciprocal social interaction. These take the form of an inadequate appreciation of socio emotional cues, as shown by a lack of response to other people's emotion and /or a lack of modulation of behavior according to social context, poor use of social signals and a weak integration of social emotional and communicative behaviors and a lack of socio emotional reciprocity. Similarly, qualitative impairments in Communication is universal. These take the form of a lack of social usage of whatever Language skills are present; impairment in make believe and social imitative play; poor Synchrony and lack of reciprocity in conversational interchange; poor flexibility in Language expression; lack of emotional response to other people's verbal and non-verbal overtures, etc.

- Atypical Autism

A type of pervasive developmental disorder that differs from childhood autism either in age of onset or in failing to fulfill all three sets of diagnostic criteria. This subcategory should be used when there is abnormal and impaired development that is present only after age three years, and a lack of sufficient demonstrable abnormalities in one or two of the three areas of psychopathology required for the diagnosis of autism (namely, reciprocal social interactions, communication, and restricted, stereotyped, repetitive behavior) despite characteristic abnormalities in the other area(s). Atypical autism arises most often in profoundly retarded individuals and in individuals with a severe specific developmental disorder of receptive language.

- Rett's Syndrome

A condition, so far found only in girls, in which apparently normal early development is followed by partial or complete loss of speech and of skills in locomotion and use of hands, together with deceleration in head growth, usually with an onset between seven and 24 months of age. Loss of purposive hand movements, hand-wringing stereotypies, and hyperventilation are characteristic. Social and play development are arrested but social interest tends to be maintained. Trunk ataxia and apraxia start to develop by age four years and choreoathetoid movements frequently follow. Severe mental retardation almost invariably results.

- Other Childhood Disintegrative Disorders:

A type of pervasive developmental disorder that is defined by a period of entirely normal development before the onset of the disorder, followed by a definite loss of previously acquired skills in several areas of development over the course of a few months. Typically, this is accompanied by a general loss of interest in the environment, by stereotyped, repetitive motor mannerisms, and by autistic-like abnormalities in social interaction and communication. In some cases, the disorder can be shown to be due to some associated encephalopathy, but the diagnosis should be made on the behavioral features.

- Asperger's Syndrome:

A disorder of uncertain nosologically validity, characterized by the same type of qualitative abnormalities of reciprocal social interaction that typify autism, together with a restricted, stereotyped, repetitive repertoire of interests and activities. It differs from autism primarily in the fact that there is no general delay or retardation in language or in cognitive development. This disorder is often associated with marked clumsiness. There is a strong tendency for the abnormalities to persist into adolescence and adult life. Psychotic episodes occasionally occur in early adult life.

- Pervasive developmental Disorder, Unspecified:

This is a residual diagnostic category that is used for disorders which fit the general description for pervasive developmental disorders but in which a lack of adequate information, or contradictory findings, means that the criteria for any of the above said disorders cannot be met. Through the commitment of a community of parents, siblings, other relatives, and autistic people themselves, people with autism and their families now have a voice in the disability legislation and movement in India. It is also providing hope to the Autistic people and their families that Autism now receives recognition; there are still many issues to be negotiated, legal and otherwise.

Children with Autism Spectrum Disorder has specific characteristics in nature. According to DSM V, Autism spectrum disorder is presented with two main core features i.e. the deficit in social/communication and restrictive, repetitive patterns of behavior.

Screening and Diagnosis

There is an increase in the prevalence of autism spectrum disorder worldwide which emphasizes on the importance of identifying children with clinical manifestations of autism spectrum disorder as early as possible. The earlier autism is identified; the sooner interventions can begin (Isaac et. al.,2025). Early therapy especially behavioral, speech, and occupational therapy has been shown to

significantly improve communication, social skills, learning and adaptive behavior. Early childhood is a period of rapid brain development and intervening during this critical window helps shape neural pathways in ways that can reduce the severity of symptoms and improve long-term developmental trajectories. Early screening for autism spectrum disorder is crucial for initiating timely interventions that can significantly improve developmental outcomes.

Uke et. al. (2024) has highlighted common screening tools_autism spectrum disorder used in India as indicated in the table below.

Table 1: Screening Tools

Sl. No.	Name of Screening Tool	Age Group for Application	References
1	Modified Checklist for Autism in Toddlers	16-30 months	1
2	Trivandrum Autism Behavioural Checklist	2 to 6 years	2
3	Social Communication Questionnaire	4 years and above	3
4	Autism Behaviour Checklist	18 to 35 months	4
5	Ages and Stages Questionnaire	6 months to 5 years	5
6	Screening Tool for Autism in Toddlers	24 to 35 months	6
7	Communication and Symbolic Behaviour Scales Developmental Profile	6 to 24 months	7
8	Parents' Evaluation of Developmental Status	Birth to 7 years and 11 months	8
9	Indian Autism Screening Questionnaire	3 to 18 years	9
10	Chandigarh Autism Screening Instrument	1.5 to 10 years	10

According to the American Psychiatric Association (2013), there are two classifications guideline for the diagnosis of autism spectrum disorder. They are Diagnostic and Statistical Manual (American Psychiatric Association) and World Health Organization. The current versions are DSM V and ICD 10. The DSM-V criteria for diagnosing autism spectrum disorder are as follows:

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history.

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take the same route or eat the same food every day).

3. Highly restricted, fixated interests that is abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or preservatives interests).

4. Hyper- or hypo reactivity to sensory or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make co morbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Uke et.al. (2024) has constructed common diagnostic tools used in diagnosing autism spectrum disorder in India as indicated in the table below.

Table 2: Diagnostic Tools

Sl.No.	Name of Diagnostic Tools	Age group for Application	References
1	Diagnostic and Statistical Manual of Mental Disorders	Above 1 year	1
2	Autism Diagnostic Observation Schedule	Above 1 year	2
3	Indian Scale for the Assessment of Autism	3-9 yrs	3

4	INCLIN Diagnostic Tool for Autism Spectrum Disorder (NDT-ASD)	2-9 years	4
5	Childhood Autism Rating Scale (CARS)	2 years and above	5
6	Autism Diagnostic Interview – Revised (ADI-R)	2 years and above	6
7	Gilliam Autism Rating Scale (GARS)	3-22 years	7

According to Uke et. al. (2024), the diagnosis and management of autism is quite complex. As such the assessment and management should be done with the help of a multidisciplinary team which consists of pediatrician, psychiatrist, psychologist, audiologist, occupational therapist, speech therapist, special educator and social worker.

Social Work and Autism Spectrum Disorders

The social work profession has not yet taken a leadership role in addressing the myriad of challenges that individuals on the Autism spectrum encounter across the lifespan. In this essay, we argue that social workers are well equipped to engage in research and practice aimed at promoting full and meaningful inclusion in society, as well as social and economic justice, for individuals on the autism spectrum. Short- and long-term goals that provide the social work profession with a framework to engage in research, practice, education, and advocacy aimed at supporting individuals on the Autism spectrum and their families were highlighted (Bishop-Fitzpatrick et al, 2018).

A study conducted by the Minnesota School Social Workers Association examined the role of school social workers in supporting parents of children with autism spectrum disorder (ASD). The survey revealed that the most common support provided by social workers was connecting parents to community resources, acting

as a liaison between school and home, and providing emotional support. The study also highlighted the need for further research to understand the stressors faced by parents and develop effective interventions (Marnie et. al., 2012).

Policies and Programmes

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was adopted in 2006 which is the most important international treaty in protecting the rights of persons with disabilities including autism. Article 12 of the United Nations Convention on the Rights of Persons with Disabilities reaffirms equal recognition before the law for all people with disabilities and underlines that they have an inalienable right to exercise their legal capacity on an equal basis with others. UNCRPD emphasizes non-discrimination, equal opportunities, accessibility and full participation in society. UNCRPD also requires signatory countries to adopt laws and policies that support people with disabilities. India also signed the UN convention on the 30th March 2007 (UNCRPD, 2006).

The Constitution of India also highlights various provisions securing the right to justice and equality of status in the community.

- Article 14- They like every citizens of India are equal before the law.
- Article 15(1) - The Government cannot discriminate any Indian including the person with autism on the ground of religion, caste of sex.
- Article 15(2)- Every citizens including the people with disability cannot be discriminated on any grounds for the access of any public places.
- Article 17- Autistic people cannot be treated as untouchable which is a punishable offence.
- Article 21- Every person has a right to life and liberty. It also includes right to education for the children with autism in the age group of 6 to 14.
- Article 23- Prohibition of forced labour.
- Article 24- Prohibition of employment of children under the age of 14 years.
- Article 32- Right to seek constitutional remedy and can move to the Supreme Court by filing Writ Petition.

- Article 300A- No person shall be deprived of the right to property.
(Government of India. (1950). Constitution of India)

Under Sections 80DD and 80U of the Income Tax Act 1961 states that people with disability have the right to enjoy earnings of tax concession.

The First Legislation in India pertaining to Autism was passed in the National Trust Bill- National Trust for Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act 1999 which resulted in the establishment of the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation, Multiple Disability and other related conditions.

The Rights or Persons with Disabilities Act which was reviewed in 2016 which considers Autism as one of the 21 recognized disabilities. It gives certain rights and facilities to the autistic people so that they can live their lives in a better way and not be deprived because of their disorder. Under the Act, 4 per cent of the people with disabilities can be given employment in Government establishment. And the person who has the disability benchmark of 40 per cent is entitled to certain benefits.

The Rehabilitation Council of India (1992) is another initiative of the Indian Government that was formulated to train and guide special educators in India. It also plays a pivotal role in setting and upholding the minimum standards for the education and training of diverse professionals in this field. This initiative also introduced special diploma courses for educators in this field.

The Scheme for Implementation of the Persons with Disabilities (PwD) Act, 1995 (SIPDA) in Mizoram is a government initiative that is designed to enhance the rights and welfare of persons with disabilities (PwDs). This initiative is a component of India's dedication to the United Nations Convention on the Rights of Persons with Disabilities. SIPDA advocates for the establishment of accessible infrastructure in public structures. A variety of government offices and public spaces in Mizoram have been retrofitted with ramps, railings, adapted toilets, and elevators to ensure physical accessibility for PwDs as part of this initiative. The Directorate of Social Welfare Department, District Commissioner offices, and the Secretariat Complex in

Aizawl are among the most notable examples. Through a variety of initiatives, SIPDA enables individuals with disabilities to achieve economic recovery. The National Handicapped Finance Development Corporation (NHFDC) scheme provides loans to persons with disabilities (PwDs) through the Mizoram Rural Bank. Training centres in Aizawl and Lunglei provide one-year courses in shoemaking, needlework, and tailoring, as well as hostel accommodations. Stipends for pupils: Financial assistance is offered to pupils with disabilities at various educational levels. A monthly allowance is provided to persons with disabilities who have been registered with the Employment Exchange for a period exceeding two years without a placement.

The Rights of Persons with Disabilities Act, 2016, is overseen by the Office of the State Commissioner for Persons with Disabilities, Mizoram which was established in 2012. This office ensures the redress of grievances, promotes public awareness of the rights of Persons with Disabilities, and monitors compliance with accessibility standards.

The Samagra Shiksha- Inclusive Education_aims to integrate children with disabilities, including those with autism spectrum disorder into mainstream school from cl 1- X11. The key features include provisions of aids and appliances, learning materials and allowances. It also includes barrier free access in schools to ensure accessibility to classrooms, laboratories, libraries and toilets. Teachers are also being trained through Samagra Shiksha in special education to support children with disabilities.

Deendayal Disability Rehabilitation Scheme is a Central Scheme under the Ministry of Social Justice and Empowerment that provides financial assistance to voluntary organizations working for the education and rehabilitation of persons with disabilities including Autism. Examples of such institution in Mizoram are: Samaritan Society for the blind, Spastic Society of Mizoram etc. Spastic Society of Mizoram is one of the first NGO that supports parents with Autistic Children in Mizoram and started the only Centre for Autism in Aizawl, Mizoram through Gilead Special School.

The Mizoram State Legal Services Authority implements the NALSA Scheme, 2015 to provide legal aid to individuals with mental disabilities including autism through free legal assistance and sensitization programs for legal and medical professionals to better support with individuals with disabilities.

Though programmes and policies exist, the situational analysis and scenario in India in the field of autism spectrum disorder is found to be quite deplorable, especially in northeast and particularly in Mizoram. Cases of Autism spectrum disorder is increasing year after year with some improvement in awareness and diagnosis. These increasing cases has to be met with an atmosphere where provisions not only exist but are made used of in the fullest capacity. This research therefore intends to be a window that helps open up research discourses in the area of autism spectrum disorder.

Statement of the Problem

Social work as a profession deal with autism and its related disorders, however not much work has been done in working directly with the individual itself but continuously work with the caregivers in terms of rendering social work services at home and deals with emotional burden and coping strategy. Social work specialist working with an autistic child and their caregivers are very much needed especially in an area where there is shortage of mental health professionals especially in a remote area like Mizoram where there is less opportunity for receiving in depth training. The role of a Social Worker is to understand and adapt their ways of working to accommodate the complexities and challenges a life with autism presents. The challenge of social worker involves working with care givers, family, and friends and moreover the individual itself, giving awareness and home-based intervention in this area is crucial as our society view autism as a disease and sever disability whereas in fact if given proper intervention can result in better prognosis and improvement in functionality.

Overview of Literature

According to the study's outcomes completed by Hena Chandra et al, primary caregivers who received video-assisted instruction had improved knowledge, a more optimistic outlook, and appropriate practices when it came to caring for children with ASD (Hena Chandran et al, 2019).

Studies conducted in Saudi Arabia by Alyami et al. in 2022 on attitudes and knowledge regarding autistic spectrum disorder revealed that participants had a low degree of understanding of the condition. Additionally, they suggest that government funding should be made accessible to support educational assistance for kids with ASD.

Studies by Alyami et al. (2022) on the attitudes and knowledge regarding Autism spectrum condition is not widely known in India.

Families play a variety of roles in the lives of their children, especially if one of them has autism spectrum condition (Harris, 1994).

A child who has been diagnosed with autism causes ongoing stress in the family unit, affecting not only the caregivers but also siblings and family connections (Higgins et al., 2005).

The child with autism often requires a significant amount of parental attention and effort (Tarakeshwar & Pargament, 2001).

Mothers of autistic children have been observed to be more stressed and have difficulty adjusting than mothers of children with various physical and intellectual disabilities (Pakenham et al., 2005).

A study on educational and therapeutic treatments for families of autistic children was carried out by Jocelyn et al. in 1998. They contrasted day care services only with

an enhanced intervention. Compared to the daycare alone group, parents participating in the group obtaining support and education services reported higher levels of satisfaction, enhanced feelings of control, and more understanding regarding autism.

Given that autistic children struggle to fully absorb and appreciate what is going on in their surroundings, interventions with them must be more thorough, methodical, and prolonged. Brief hospital stays might not be effective for them (Uthaman, 2008).

The well-researched programs use applied behavioral analysis principles to provide treatment. (Odom et al., 2003; Dunlap, 1999; Merlin and Simpson, 1998; National Research Council, 2001; Rogers, 1998), which offer a diverse set of Early Intervention techniques for children with autism spectrum disorder.

Research Gap

There is still a substantial lack of comprehensive, region-specific literature that addresses the many facets of autism spectrum disorder in India let alone Mizoram, despite the fact that there is a growing amount of research on autism spectrum diseases in India. Through the synthesis of previously conducted research and the provision of an in-depth analysis of autism spectrum disorder (ASD) prevalence, diagnostic methods, intervention techniques, and social impact within the setting of India, the purpose of this literature review is to fulfil the aforementioned need.

The research literature also reveals a gap in research among secondary caregivers at the international and national level. There is ample research on impact but very few of knowledge, attitude and practices.

By concentrating on Mizoram and India, the purpose of this review is to bring attention to the difficulties and opportunities that are specific to the treatment of autism spectrum disorder in a growing nation that has a diverse cultural fabric. The findings are intended to provide important information to policymakers, healthcare professionals, educators, and researchers in India and Mizoram with the goal of

encouraging an approach to autism spectrum disorder management that is more inclusive and effective.

Objectives of the study

- To profile the demographic characteristics of primary and secondary caregivers of children with autism spectrum disorders in Mizoram.
- To assess the knowledge on autism spectrum disorders among primary and secondary caregivers of children with autism spectrum disorder in Mizoram.
- To assess the attitude of primary and secondary caregivers towards children with autism spectrum disorder.
- To explore the practices of primary and secondary caregivers of children with autism spectrum disorder in Mizoram.
- To find out the differences in knowledge, attitude and practices between primary and secondary caregivers of children with autism spectrum disorder in Mizoram.
- To find out the relationship between knowledge, attitude and practices of primary and secondary caregivers of children with Autism Spectrum disorder in Mizoram.
- To find out the challenges faced by primary and secondary caregivers of children with autism spectrum disorder in Mizoram
- To find out the coping strategies of primary caregivers of children with autism spectrum disorder
- To suggest measure for social work intervention and social policy in the field of autism spectrum disorder.

Methodology

Field of the study

The field of study was Mizoram covering 8 Districts out of 11 Districts namely Aizawl, Lunglei, Champhai, Serchhip, Khawzawl, Kolasib, Mamit and Lawngtlai.

Research Design

The study is exploratory in nature and adopted mixed method using both quantitative and qualitative techniques.

Population and Unit of the Study

The population of the study includes all primary and secondary caregivers in Mizoram. Caregivers of children with autism spectrum disorder and professionals who are working with children with autism spectrum disorder represent the unit of study.

Source of Data Collection

Data were collected from both primary and secondary sources. Primary source included data collected from both the primary and secondary caregivers of children with autism spectrum disorders. Secondary sources were collected from books, literature and Government and Non- Governmental published and unpublished records.

Sampling Procedure

A purposive sampling procedure was utilized for the identification of both primary and secondary caregivers. The primary caregivers were identified from registered and diagnosed cases of children with autism spectrum disorder from recognised health settings across the districts in Mizoram.

Overall, the sample size of the study covered 186 respondents.

Tools of Data Collection

A semi-structured interview schedule formed the tool for data collection. The tool included information related to the profile of the respondents, the knowledge on autism spectrum disorder, their attitude towards children with autism spectrum disorder and their intervention practices in the care and rehabilitation of children with autism spectrum disorder. It also included information regarding the challenges faced by the respondents, coping strategies of the primary caregivers in particular and suggestions to reduce the challenges of the caregivers.

To measure, the knowledge, attitude and intervention practices, standardized tools were constructed and to assess them, different items, categories and models were taken from various studies and literature related to autism spectrum disorder. (Liu et al, 2016; Uthaman, 2018; COMDEAL, Bangalore, DSM 5 & ICD 10).

To assess the knowledge on autism spectrum disorder, 28 factual items about autism spectrum disorder were developed for respondents to answer Yes (1) and No (0). The tool was statistically tested for reliability. Guttman Split –half coefficient reliability value for the Knowledge scale was .659 respectively.

To assess the attitude towards children with autism spectrum disorder, 20 negative items against children with autism spectrum disorder were developed. A 5-point scale was constructed to assess the attitude where 0 indicated Strongly Agree, 1 indicated Agree, 2 indicated Neither Agree nor Disagree, 3 indicated Disagree and 4 indicated Strongly Disagree. The tool was statistically tested for reliability. The Cronbach Alpha reliability value for attitude scale was .837.

And finally, to assess the caregiving and intervention practices, 19 items with scope for adding additional items by respondents were developed. The items included various models and skill related caregiving and intervention practices related to autism spectrum disorder. A 5-point scale to assess the frequency of caregiving and

intervention practices was constructed where 0 indicated Never, 1 indicated Seldom, 2 indicated Sometimes, 3 indicated Often and 4 indicated Always. The tool was statistically tested for reliability. The Cronbach Alpha reliability value for attitude scale was .901.

Qualitative techniques such as in-depth interview and focus group discussion were also conducted to gather additional information.

Data Analysis

The quantitative data was analysed using Microsoft Excel and SPSS package. Simple frequency, descriptive statistics and means were used to present the quantitative data. Pearson Correlation Coefficient was used to find out the relationship of knowledge, attitude and practices of the caregivers. To find out the differences in knowledge, attitude and practices between the primary and secondary caregivers, t-Test was also analysed. In-depth Interviews were analysed to form case studies and focus group discussions were presented accordingly to find out the objectives of the study.

Ethical Consideration

Written informed consents were obtained from the respondents. Confidentiality was strictly maintained as part of the research process.

Major Findings from Quantitative Study

The study shows that 79.8 per cent of the respondents were primary caregivers and the remaining 20.2 per cent were secondary caregivers.

The result also indicated that 48.5 per cent of the primary caregivers were mothers and 37.7 per cent were fathers. This finding is similar to Hoefman et. al, (2015)

where caregivers of children with ASDs predominantly were the biological parents (95%), and mostly mothers on average.

Among the primary care givers, more than half (59.4%) of them belong to the age-group of 25-39 years of age while among the secondary caregivers, more than two third (74.3%) of the respondents belong to the age group of 25-39 years of age.

Among the primary caregivers, more than half of the respondents (57.2%) are females and from the secondary caregivers, majority (80%) of the respondents are females.

Majority (77.5%) of the primary caregivers are married while among the secondary caregivers, less than two third (62.9%) of the respondents are unmarried.

All respondents are Christians and majority (76.4%) of the respondents belong to the Presbyterian denomination.

Majority (71.7%) of the respondents belong to nuclear family.

Majority (92.5%) of the respondents are from a stable family.

Among the primary caregivers more than a third (36.9%) of the respondents are graduates while from the secondary caregivers, almost half (48.6%) of the respondents attained education up to Post Graduation.

More than half (52%) of all the respondents' primary occupation of family is government service.

From the primary caregivers, less than half (47.8 %) of the respondents have a family monthly income of Rs.20000-Rs.50000 and from the secondary caregivers, more than more than a third (40.0 %) has a family monthly income of Rs.1 Lakh and above.

More than half (52%) of the respondents belong to the APL category.

A few (4.6%) of the respondents reported that there is history of disability in their family.

Secondary caregivers work as clinical psychologist, social worker, special educators, doctors, psychiatrists, teachers, psychologist, counsellors and speech therapist. More than half (57.1%) of them have a working experience of 0-5 years.

The children are diagnosed by Clinical Psychologist, Psychiatrist and Medical doctors.

Among the primary caregivers, knowledge is low (0) in items such as ASD cannot be diagnosed in adulthood and on the level of support required by children with autism does not change with age.

Among the secondary caregivers, knowledge is low (0) in 3 items such as ASD rate of co-morbidity is high with other genetic disorders and psychiatric disorders, ASD is not caused by poor parenting skills or poor home care and the level of support required by children with autism does not change with age.

Overall, among the primary and secondary caregivers, the table shows that the average mean knowledge is high (1) in 27 items and low (0) in 1 item which is on the level of support required by children with autism does not change with age. There is no difference (1.11) in the knowledge on Autism spectrum disorder between the primary and secondary caregivers.

Among the primary caregivers, the is bad in 1 item (1) which is on having a child with ASD as being stressful. The total mean average in the attitude of primary caregivers shows a moderate (2) attitude towards children with Autism spectrum disorder. Among the secondary caregivers, the attitude is bad in 4 items (1) such as having a child with ASD causes depression, having a child with ASD causes anger, having a child with ASD is expensive and having a child with ASD is stressful. The mean average of the overall assessment among the primary and secondary caregivers shows a moderate (2) attitude towards children with Autism spectrum disorder.

There is no difference (0.408) in the attitude towards children with Autism spectrum disorder between the primary caregivers and secondary caregivers.

Caregiving and intervention practices such as applied behavioural analysis, sensory integration therapy, family psycho educational service, play therapy and complementary and alternative model are seldom (1) used by the respondents. Further, discrete trial training, COMDEALL intervention model and supportive psychotherapy are never (0) used by the primary caregivers. Overall, the mean average on the frequency of usages on the caregiving and intervention practices by the primary caregivers are found to be average (2) in the scale measurement. Among the secondary caregivers, practices such as discrete trial training, COMDEALL intervention model and complementary and alternative model are seldom (1) used. Supportive psychotherapy is never (0) used. Overall, the mean average on the frequency of usages on the caregiving and intervention practices by the secondary caregivers are found to be average (2) in the scale measurement. The overall mean score of caregiving and intervention practice among the respondents shows an average score in the assessment scale.

There is a significant difference (-4.309) in the caregiving and intervention practices between the primary and secondary caregivers. This indicates that the frequency in the usages of caregiving and intervention practice is higher among the secondary caregivers than the primary caregivers.

There is a significant positive relationship (.220) between knowledge and attitude among the primary caregivers. This finding indicates that among the primary caregivers, higher the knowledge on Autism spectrum disorder, better the attitude towards children with Autism spectrum disorder.

There is a significant positive relationship (.416) between attitude and practices among secondary caregivers. This finding highlights that better the attitude towards children with Autism spectrum disorder, higher the frequency in the usages of caregiving and intervention practices on children with Autism spectrum disorder among secondary caregivers.

Challenges faced by the primary caregivers of children with Autism spectrum disorder includes challenges related to the nature of disability, challenge relating to mental health such as depression, stress, low self-esteem, sleeping disorders, anger and hopelessness., no time to socialize and no leisure time, non-acceptance, lack of family support, discrimination, lack of services, joblessness, and lack of awareness about Autism spectrum disorder respectively, expensive services, work being affected, family functioning being disrupted and unrealistic advice given by others.

Challenges faced by secondary caregivers include the nature of disability of the child, lack of awareness, non-acceptance by parents, lack of services, stress, expensive services, over thinking, lack of support from family members, no space and time and low follow up rates respectively.

Coping strategies of primary caregivers include religious faith and prayer, acceptance, seeking social support, working hard, patience, seeking professional support, positive thinking, following a therapy schedule, venting out to others, positive family support, home-based practice, seeking individual counselling, self-learning, attending parents training programmes, teaching social skills to children, giving phone to children, pharmacological treatment to children, providing recreational resources to children, being alert and setting up surveillance camera.

Suggestions to solve the challenges of primary caregivers include more awareness on Autism spectrum disorder, government provisions, more human resources in the field of Autism spectrum disorder, accessible services, more family support, availability of institutional care for children with Autism spectrum disorder, affordable services, continuation of education services from the government, disciplining the children, early intervention, seeking professional help, receiving adequate training for parents and playground for children.

Suggestions of secondary caregivers include more awareness on Autism spectrum disorder, adequate training for skill enhancement, accessible services for children with Autism spectrum disorder, early intervention, more human resources, proper

care and support, availability of institutional care, disciplining children, family support, structured play intervention and acceptance.

Major Findings from Qualitative Study

Effects on emotions and mental health:

The case studies completed shows how hard it can be on parents to raise a child with ASD. Some common themes are: There was a lot of stress, worry, and depression, especially after diagnoses. Parents generally have a hard time not knowing what will happen with the child.

Coping:

Parents said they dealt with their emotional and physical problems in several ways, such as, seeking help from family, friends, and parent groups. Taking part in spiritual or religious activities to feel more in charge, setting up routines and learning about ASD is also a positive way of coping.

Financial Constraints:

The case studies also depicted the financial constraints on the parents for availing services for their children with autism spectrum disorder. Families also need to relocate for the sake of their children to access better services for their children with autism spectrum disorder. Accessing autism-related services is a major challenge, particularly outside Aizawl. Even within the city, the high cost of therapies (e.g., speech, occupational, behavioural) places a financial strain on middle-income families. Districts outside Aizawl lack specialized schools and professionals.

Caregiver Burden:

The challenges of caregivers include depression, stress, sleeping disorders, marital discord and divorce, denial, anger, self-blame, role conflicts, and socialization. Family Dynamics also plays an important role in understanding the family environment and how it can have an impact on the child. Findings also indicate the

surmounting burden of the parents and also the need of intervention at the family level

Lack of Awareness:

The case studies also evident how the lack of awareness and knowledge can have an impact on the children's well-being and safety. There is a strong call from parents for greater public awareness and education about autism to reduce stigma and promote community understanding.

Early Diagnoses and Intervention:

Early diagnoses and intervention of children have helped children to develop skills for daily living. This in turn has reduced stress and burden on the part of the caregivers.

Mothers as primary caregivers:

The study reveals that mothers are the primary caregivers of children. Their grit and proactivism has helped their children acquire skills of daily living. Most mothers have developed a strong understanding of autism over time, primarily through various information sources and school support. However, initial reactions to the diagnosis often involved denial, confusion, and emotional distress. Mothers expressed feelings of sadness and pity, especially in response to public stigma. A strong desire to protect their children from judgment and discrimination was evident.

The need for constant care often forces one parent—typically the mother—to leave their job, impacting household income and increasing caregiving pressure.

Limitations of the study

- There are several limitations that hindered the consistencies and the efficacy of the research processes. The covid -19 pandemic was one of them as there were certain government restrictions to adhere to.

- Diagnosis cases were also limited across all the districts.
- Many professionals were not available for interview.
- Due to the geographical terrain, there was difficulty in accessing the respondents.
- District Mental Health Programmes was not developed and were absent in some districts.

Suggestions

Studies on Autism Spectrum Disorder in India highlight the urgent need to support individuals on the spectrum and their families in addressing the unique challenges they encounter. While awareness has improved in urban areas, a significant gap persists in rural and remote regions such as Mizoram. The following recommendations aim to enhance awareness, intervention strategies, professional training, policy implementation, and research, with sensitivity to the socio-cultural context of Mizoram.

- Improving awareness of ASD is fundamental to fostering understanding and acceptance. Social workers, acting as a bridge between families, healthcare systems, and communities, play a crucial role in this process. Awareness initiatives should operate at both micro (individual/family) and macro (community/policy) levels.
- The study indicates that increased knowledge among primary caregivers leads to more positive attitudes toward children with ASD. Therefore, awareness and sensitisation must be prioritized as a key strategy for attitudinal change. Similarly, among secondary caregivers, positive attitudes are associated with better caregiving and intervention practices. Efforts should thus focus on cultivating empathy and acceptance across all caregiving groups.

- Findings reveal that primary caregivers demonstrate comparatively lower levels of caregiving and intervention practices than secondary caregivers. This highlights the need for targeted initiatives to enhance their practical knowledge and skills.
- At the local level, social workers should engage directly with families by: Educating them about ASD symptoms and variability, Providing coping strategies and offering counselling and support programs. These interventions are important to empower and strengthen a child's development.
- At the societal level, social workers should advocate for inclusive policies and community awareness. Campaigns conducted in schools, workplaces, and neighbourhoods can reduce stigma, promote inclusion and encourage peer acceptance. These initiatives should emphasize the importance of integrating children with ASD into mainstream educational and social settings.
- The research evidence also stated that ASD awareness in India has largely focused on diagnosis and medical intervention. This research suggested that the approach must also expand not to parenting challenges and their needs, more on their independent living skills and their legal rights and entitlements. Awareness efforts should involve not only professionals but also families and community members to ensure a holistic understanding of ASD.
- The Rights of Persons with Disabilities Act, 2016 provides a legal framework for supporting individuals with disabilities. However, implementation remains uneven. In Mizoram, the government should ensure to establish more resource centres and provisions not only in Aizawl but all other districts.
- Caregivers, particularly in underserved areas, require structured support. Recommended measures include: Training programs on behavioural strategies and coping mechanisms and Mental health support to reduce stress

and burnout and community-based peer support groups. The study highlights significant mental distress among primary caregivers, underscoring the need for systematic, evidence-based interventions.

- Training programs should be sensitive to different cultures, considering things like Mizoram's traditions, beliefs, and family structures. Content that is culturally relevant can help carers connect with it better and feel more comfortable using what they've learnt in their everyday lives. Including community leaders, local languages, and resources that are specific to the area in training programs can also make them easier to reach and more useful. Stigma and abuse against people with autism spectrum disorder make it hard for them to fit in with their peers. A lot of people in India, including people in Mizoram, still don't understand neurodevelopmental disorders. This leads to bad stereotypes and being left out of social groups.
- Campaigns to raise knowledge, community involvement, and practices that include everyone are all important ways to deal with these problems. For families who live in rural areas or places where specialized services are hard to get to, home-based treatments are essential for helping people with ASD all the time. Therapeutic strategies can be regularly used with home-based interventions, even when professional help is not easily accessible.
- The study shows dearth of data related to children with ASD in different districts of Mizoram. Government resources and services need to be strengthened to improve diagnosis as well as services related to ASD in Mizoram.

Future Research Directions

Some study can be replicated with both primary and secondary caregivers of children with autism spectrum disorder and comparisons can be made on the knowledge, awareness, challenges and coping to get better understanding of gender roles and differences. More number of respondents, larger samples can be taken for the intervention. Specific groups for fathers and mothers could be conducted so that specific issues each one face can be discussed and dealt with, in detail. The caregivers of children with autism spectrum disorder can be supported with a specific systematically intervention programme. Indian research on autism spectrum disorder is still in its early stages, especially in rural areas that aren't well studied, like Mizoram. To learn more about the problems and needs of people with ASD, more study is needed with a lot of different kinds of people as samples. Also, methods used in future studies should be more open and sensitive to different cultures. To learn about the long-term outcomes of people with ASD, especially those who have gotten early intervention and support, longitudinal studies are needed. The results of these studies can help researchers figure out which types of interventions help people on the spectrum have better long-term effects.

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