# A STUDY ON EMPLOYER AND EMPLOYEE PERSPECTIVES ON THE WORKPLACE ACCOMODATIONS REQUIRED TO SUSTAIN A NEURODIVERSE WORKFORCE.

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By

# Ms. Elixir Sagar

#### 2K18/Ph.D/DSM/02

Under the supervision of:

# Dr. Shikha N. Khera

### Supervisor

Associate Professor, Delhi School of Management

k

**Dr. Naval Garg** 

# **Co-supervisor**

Assistant Professor, University School of Management and Entrepreneurship



# Department of Delhi School of Management DELHI TECHNOLOGICAL UNIVERSITY (Formerly Delhi College of Engineering) Shahbad Daulatpur, Main Bawana Road, Delhi-110042, India December, 2024

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#### ABSTRACT

"To measure the success of our societies, we should examine how well those with different abilities, including persons with autism, are integrated as full and valued members." — Ban Ki-moon

All human beings including those with hidden disabilities like autism have the potential to act as a catalyst for growth and prosperity of a nation provided they feel valued and respected for their abilities. Autistic individuals often have certain unique abilities like extreme attention to detail, strong mathematical skills, visual-spatial abilities and so on that are vital to any business, yet only 16% of autistic adults worldwide are employed full-time. The situation is even more gruesome in India where more than 18 million people are purported to be on the autism spectrum yet no data exists on their employment rates.

In recognition of the unique potential of autistic individuals, a few global MNC's like Microsoft, SAP, Google and so on have started recruiting autistic individuals who have unique abilities in the field of software testing, pattern recognition, logical reasoning to leverage their unique strengths for the benefit of their organization. Yet, in a country like India where prejudice and discrimination towards disability is a common occurrence, the employment scenario for individuals with autism remains bleak.

Autistic individuals due to their variant brain neurology require certain large scale and small scale accommodations to function optimally at their workplaces. Unfortunately, due to the lack of awareness of Autism Spectrum Disorders in Indian workplaces, the stigma around mental health issues, imprecise laws to safeguard the interests of autistic individuals and laxity in their implementation, accommodating autistic employees continues to remain a never ending challenge to Indian Business Organizations open to employing autistic talent.

Although there exists a substantial body of autism research specific to employment support for autistic individuals in the West, there is a dearth of research on workplace accommodations to sustain a neurodiverse workforce in India from the perspective of autistic employees and their managers.

The purpose of this study is to seek answers to certain research questions raised in the study pertaining to workplace experiences of late-diagnosed autistic women in India, stimming behaviours of autistic individuals and their importance as a workplace accommodations strategy, working from home experiences of autistic individuals during the Covid-19 pandemic in India and its potential as a workplace accommodation strategy and non-autistic Indian managers readiness to employ autistic talent.

This study has been executed with the help of semi-structured interviews and focus group discussions to collect primary data from late-diagnosed autistic Indian employees and non-autistic managers employed in Indian Business Organizations. Data analysis has been done using Nvivo.

Results from data analysis of first research objective revealed that late-diagnosed autistic Indian women face dual challenges at their workplace by virtue of their gender and variant

brain neurology, this necessitates that they be accommodated differently than autistic men at the workplace. Data analysis of results from second research objective revealed that stimming behaviours are integral to the mental health of autistic individuals and help them in regulating their emotions, which in turn leads to improved productivity levels for autistic employees, Additionally, acceptance of stimming behaviours by managers and colleagues of autistic employees can serve as a zero cost, mutually beneficial workplace accommodations strategy. Results from data analysis of third objective revealed that organizations open to offering indefinite work from home option to autistic individuals must refrain from adopting a one size fits all approach. They must also provide mental health support , childcare facility for autistic women employees and so on. Data analysis of the last objective revealed that autism awareness is abysmally low in non-autistic Indian managers and although a few of them are open to employing autistic individuals , yet they too are not willing to upend their existing organizational structure and rules to accommodate autistic employees.

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# LIST OF ABBREVIATIONS

ADHD	Attention Deficit Hyperactivity Disorder		
ASD	Autism Spectrum Disorders		
AQ-10	Autism Quotient 10 questionnaire		
DSM-V	Diagnostic and Statistical Manual -5 <sup>th</sup> Edition		
I.T	Information Technology industry		
STIMS	Stereotypie behaviour or repetitive movements		
	expressed through a part of the body or the entire body.		
NEUROTYPICAL	An individual with typical brain neurology		

NEURODIVERSE An individual with atypical brain neurology

# CHAPTER 1

#### INTRODUCTION

#### **1.1 Introduction**

Globally, around 1/100 children are diagnosed with autism spectrum disorder. (Autism, 2023).Yet, despite them making up a significant portion of the worlds population, they struggle with higher unemployment levels and social isolation than individuals with other disabilities(Palumbo, 2021).Their struggles with being gainfully employed are partly due to their personal characteristics and partly due to specific environmental barriers. This makes employment support a necessity for autistic individuals to not only survive but thrive at a workplace designed for neurotypical employees.(Waizman-Nitzan, Gal and Schruer,2021) However, recent studies have shown that if autistic individuals are provided a conducive work environment, they are able to leverage their unique strengths like superior problem solving abilities, visual spatial skills , extreme attention to detail and so on to outperform their neurotypical colleagues.(Austin & Pisano, 2017).

While the aforementioned studies are revolutionary in nature, they represent the context of lives of neurodiverse (Autistic, ADHD, Dyslexic)people in the global west. The economic, cultural and political context of South Asian is unique. Approximately 1.4% of the population in South Asia is comprised of autistic individuals.(Elsabbagh et al., 2012) (Singhal, Daley, & Barua, 2012).<u>Action for Autism</u> estimates that <u>18 million Indians</u> are on the autistic spectrum, and jobs for this group are hard to come by. Autism awareness is poor in both family and front-line health workers which leads to a delay in seeking support. Additionally, autistic children and their families face

considerable stigma and discrimination from their community. Specialist services are rare, concentrated in urban areas, and inaccessible to the majority (Srinath & Girimaji, 2010). Historically, employment practices for autistic individuals in the Indian subcontinent have been focussed on providing "sheltered employment" wherein individuals with intellectual and physical disabilities are provided vocational training in a safe and controlled environment of an NGO and the products and services produced by them are sold in the labour market by the NGO itself. (Preetham and Mahesh, 2017). In recent years, encouraged by the global shift and interest in hiring autistic individuals , many Multi-national organizations (For instance Ernst and Young , SAP, Microsoft ) with offices in South Asia as well as Indian business organizations (For instance Lemon Tree Hotels) have become open to the possibility of employing autistic talent (Rao and Polepeddi, 2019). There is a paucity of literature on the workplace experiences of autistic Indians. And therefore, little to guide the efforts of managers, work supervisors and job coaches who intend to serve the interests of autistic people.

Additionally, when it comes to providing reasonable workplace accommodations for autistic individuals, many well meaning managers and business organizations tend to focus on providing large scale , tangible accommodations like personal office spaces, dual screens , Assistive Technology etc. While these workplace accommodations have their place in modern business organizations , what is more important is a shift in the mindset of neurotypical managers and colleagues of autistic employees by making them aware of and sensitive towards autistic employees.

Our study is an attempt to understand the unique circumstances and accommodation needs of latediagnosed autistic individuals employed in Indian workplaces, the unique workplace experiences and accommodation needs of neurodiverse women employed in Indian organizations and the existing perception of neurotypical Indian managers towards Neurodivergent individuals. Thus, we adopted a multi-pronged approach to understand the varied workplace accommodation needs of different sects of the autistic population in India and non-autistic Indian managers perspectives towards employing autistic individuals.

Following were the research questions that were framed for the current study:-

- i.) How does the workplace experience of late-diagnosed autistic women employees differ from that of autistic male employees in India?
- ii.) What are the unique workplace accommodations required by autistic Indian women employees to function optimally in a male dominated , neuro-normative workplace?
- iii.) How do stimming behaviors help or hinder autistic individuals in their workplaces and ways to accommodate stimming behaviours?
- iv.) How has the work from home mandate impacted the lives of autistic employees India during the Covid-19 pandemic in India?
- v.) What is the readiness level of non-autistic Indian managers to employ autistic talent in India?

# 1.2 Background Information pertaining to neurodivergence, autism diagnostic criteria and severity levels of autism spectrum disorders.

The term neurodiversity refers to the cognitive diversity in all humans (Chapman, 2020). It is an umbrella term that includes neurodivergent conditions like attention deficit hyperactivity disorder (ADHD), autism, dyspraxia and dyslexia (see: BottemaBeutal et al., 2020; Doyle, 2020; Fung and Doyle, 2021). both neurotypical & neurodivergent women might face fluctuations in their physical

and mental health throughout their lives. Most modern workplaces are designed keeping in mind able-bodied males. Employees working in such workplaces are judged almost entirely on the basis of their productivity. Anything less than a perfectly functional body & mind that can cope with extreme workloads & undue mental or physical stress is not considered welcome in such a workplace. Neurodivergent individuals working in neurotypical workplaces end up facing issues like sensory overload, autistic burnout & so on that might periodically hamper their functionality at the workplace(Sagar et al., 2023)

Further, neurodiverse individuals just like disabled individuals may have varied degrees of disability. Those neurodiverse individuals who require minimum support to function and fit into neurotypical workplaces may never even be considered eligible for disability accommodations. In a similar vein, autistic individuals who are able to function 'normally' and do not have any intellectual disabilities may also never receive a formal diagnosis and may get denied reasobable workplace accommodations due to the non apparent nature of their disability(Baldwin & Costley,2015; Eckerd,2020).

Autism manifests as ongoing deficits in social communication and interaction across multiple contexts. An autistic individual may display difficulties in social-emotional reciprocity, evidenced by his/her abnormal social approach, problems maintaining the flow of conversation, problems sharing emotions and a general failure to initiate or respond to social interactions(Lydon et al.,2014;Tomczak et al., 2018).

Additionally, autistic individuals find it difficult to understand and engage in nonverbal communication used in social interactions. This may manifest as difficulty in maintaining eye contact, atypical body language or deficits in understanding and using gestures. Some autistic individuals may also display 'flat effect' wherein emotions being experienced by the individual

are not expressed on the face of the individual. Further, autistic individuals find it hard to develop, maintain and understand relationships. They may commit inadvertent Social faux pas in their social interactions thereby further alienating them from their neurotypical peers(Kirby and Smith, 2021).

When it comes to behavioral aspects of autism spectrum disorders, Autistic individuals tend to display repetitive behavior patterns, focused interests in certain activities. These repetitive behavior patterns may manifest as motor stereotypies, echolalia, idiosyncratic phrases and so on(Lanovaz et al., 2013). They also tend to insist on sameness, tend to do well with routines, or ritualized patterns or verbal nonverbal behavior and may express extreme distress when any changes are made to their routine. They may also become highly fixated on certain interests to the exclusion of other aspects of their lives. Autistic individuals may also be sensory seekers or avoiders based on hyper-reactivity or hypo-reactivity to sensory stimuli(Markram. (e.g., apparent indifference to pain/temperature, inordinately adverse reaction to certain textures, smells, sounds, lights etc) (Markram, 2007)

All of the aforementioned symptoms are present since early childhood but often times do not become apparent until adolescent or adulthood when the social demands placed on an autistic individual exceeds his/her capacity to mask these autistic traits. These symptoms cause significant impairments in social, occupational, or other areas of an autistic individuals life. Additionally, these symptoms cannot be explained by intellectual disability. Although often times Intellectual disability and autism spectrum disorders are considered comorbid when the social communication is below the general expected level for normal development.

## TABLE 1: SEVERITY LEVELS OF AUTISM SPECTRUM DISORDERS

SEVERITY LEVEL	SOCIAL	REPETITIVE
	COMMUNICATION	,RESTRICTIVE
		BEHAVIOUR
LEVEL 3	Severe deficits in verbal and	Inflexibility of behavior,
"Requiring very substantial	nonverbal social	extreme difficulty coping
support"	communication skills cause	with change, or other
support	severe impairments in	restricted/repetitive
	functioning, very limited	behaviors markedly interfere
	initiation of social	with functioning in all
	interactions, and minimal	spheres. Great
	response to social overtures	distress/difficulty changing
	from others. For example, a	focus or action.
	person with few words of	
	intelligible speech who	
	rarely initiates interaction	
	and, when he or she does,	
	makes unusual approaches to	
	meet needs only and	
	responds to only very direct	
	social approaches	

LEVEL 2	Marked deficits in verbal and	Inflexibility of behavior,
	nonverbal social	difficulty coping with
"Requiring substantial support"	communication skills; social	change, or other
support	impairments apparent even	restricted/repetitive
	with supports in place;	behaviors appear frequently
	limited initiation of social	enough to be obvious to the
	interactions; and reduced	casual observer and interfere
	or abnormal responses to	with functioning in a variety
	social overtures from others.	of contexts. Distress and/or
	For example, a person who	difficulty changing focus or
	speaks simple sentences,	action.
	whose interaction is	
	limited to narrow special	
	interests, and how has	
	markedly odd nonverbal	
	communication.	
LEVEL 1	Without supports in place,	Inflexibility of behavior
	deficits in social	causes significant
"Requiring support"	communication cause	interference with functioning
	noticeable impairments.	in one or more contexts.
	Difficulty initiating social	Difficulty switching between
	interactions, and clear	activities. Problems of
	examples of atypical or	

unsuccessful response to	organization and planning
social overtures of others.	hamper independence.
May appear to have	
decreased interest in social	
interactions. For example, a	
person who is able to speak	
in full sentences and engages	
in communication but whose	
to- and-fro conversation with	
others fails, and whose	
attempts to make friends are	
odd and typically	
unsuccessful.	
	social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically

Source : http://www.autismspeaks.org (autism speaks, 2023)

#### **1.3 SCOPE OF THE STUDY**

The study is administered to two sects of respondents, The first sect consists of Indian autistic individuals with low support needs and without any intellectual disabilities employed full time in various industries in India including Information Technology, Finance, Hospitality, Education and

so on. Due to time and resource constraints, data from autistic individuals who reside in rural areas of India were not included in the study. The aim is to take into consideration the heterogeneity of lived experiences of autistic employees in India in diverse neuro-normative work settings. The second sect consists of non-autistic Indian managers employed in various industries in India including I.T, Finance, Hospitality and Education. The aim is to capture the perception of non-autistic Indian managers employed in diverse towards the prospect of employing autistic individuals.

#### **1.4 ORIENTATION OF THE STUDY**

The research orientation of the study is such that it is divided into three main aspects. The first part captures the neurodivergent workplace experience from the perspective of neurodiverse or autistic women employees in India. The second part captures the neurodivergent workplace experience from the perspective of autistic employees working from home during the Covid-19 pandemic in India to understand the significance of low cost, high adaptability workplace accommodations strategies like acceptance of stimming behaviors and working from home for autistic Indian employees and the last part captures the perspectives of non-autistic Indian managers with regards to their readiness to employ autistic individuals and the workplace accommodations they are willing to provide them in a predominantly neurotypical workplace. Objectives of the study have been formulated keeping in mind the aforementioned aspects.

#### **1.5 SIGNIFICANCE OF THE STUDY**

Organizations the world over are always in competition to acquire the best talent (Krishnan & Wellins, 2010). In recent years, some of the worlds largest M.N.Cs like Google, Ernst and Young, Microsoft etc have started acknowledging the competitive edge that comes from recruiting neurodiverse individuals who display above average abilities in highly sought after skills like software testing, attention to detail, Visual spatial reasoning and so on.

Many neurodiverse individuals while being extremely skilled in certain spheres of their life, often struggle with debilitating hidden disabilities in certain aspects of their lives. They may struggle with social-emotional reciprocity which makes it difficult for them to engage in back and forth communication, focused interests in certain pursuits of their lives to the exclusion of all other pursuits, difficulty in expressing emotions etc. They may also struggle with understanding and using context appropriate nonverbal communicative behaviors used commonly in social interaction for instance difficulty in maintain eye contact, abnormal body language or deficits in understanding gestures, lack of facial expressions and nonverbal communication. Many of them also struggle with developing and maintaining social relationships, for example, difficulty in deciphering contexts appropriate behavior, making friends etc. They may also display hyper or hypo – reactivity to sensory stimuli(Markram, 2007)

Taking cognizance of the importance of employing neurodiverse talent and to accommodate their hidden disabilities, neurodiverse friendly organizations across the globe have made several large scale and small scale workplace accommodations in order to maximize productivity and well-being of their neurodiverse workforce while at the same time minimizing their discomfort.

In stark contrast to western Business Organizations, Indian Business Organizations are yet to embrace the idea of employing Neurodivergent individuals. This is because of the lack of awareness of neurodiversity paradigm in Indian organizations and the pervasive societal stigma towards autistic individuals who are viewed as mentally challenged and lesser beings.

In such a scenario, the significance of this study lies in making a conscious effort to highlight the lived experiences of autistic individuals in India, the systemic exclusion they face at every step of their lives and the remedial actions which ought to be taken by neuro-normative institutions and non-autistic individuals alike in order to become inclusive

Our study findings highlighted that despite possessing the necessary qualifications and skills, neurodivergent individuals still struggle in finding and keeping a job. Unemployment rate is as high as 85% for neurodiverse population.(Pesce,2019) Having an opportunity to work is closely tied to the level of well being, dignity of life and identity of an individual. Thus, our study is also significant from a Human Rights perspective of providing dignity of labour to autistic employees.

Additionally, autistic individuals possess certain sought after skill sets like superior mathematical ability, extreme attention to detail, software testing capabilities, musical abilities and out of the box thinking which can prove beneficial to business organizations suffering from group think phenomenon. Despite these capabilities, neurodiverse individuals face rejection and bullying during the recruitment stage by business organizations who would benefit most from their expertise. Our study paves the way for managers of such organizations who would be open to employing neurodiverse talent.

#### **1.6 Chapter Outline**

Chapter 1: Introduction- this chapter is a brief account of the concepts that were studied in detail to find probable solutions to the emergent research problems encountered during the course of this research. This chapter also included the future scope of research on this topic, the research orientation and the significance of the study.

Chapter 2: Literature Review-the chapter discusses in detail the concepts of the study pertaining to key topics such as the neurodiversity paradigm, challenges faced by neurodiverse individuals, the female autism phenotype, stimming behaviours of autistic individuals and researches pertaining to work from home experiences of autistic individuals. Prior researches on the aforementioned topics done in the west and Indian context have been cited extensively in this chapter.

Chapter 3: Research Methodology- this chapter deals with the research design which serves as a blueprint of the study. The chapter has also included the actions taken by the researchers in drafting semi-structured interview and focus group discussion questions, respondent demographics. Decisions on choice of research methodology were influenced by the slogan "Nothing about us without us" (Latin: Nihil de nobis, sine nobis) which communicate the idea that no policy should formulated by a representative without the full and direct participation of members of the group directly affected by the policy.

Chapter 4: Data Analysis and Results– This chapter consists of excerpts from the published and under review manuscripts of the researchers. The results have been achieved by the application of varied qualitative research tools and techniques on the data collected. Under the current study, data analysis has been done through the help of Qualitative thematic analysis, Reflexive thematic analysis, template analysis through the aid of N-Vivo data analysis software. Chapter 5: Discussion and Conclusion- In this chapter, the results achieved from all four aspects of the study have been summarized in order to draw meaningful conclusions that have implications for Indian Business Organizations, Indian Business Managers and society at large. The chapter also highlights the contribution done by the study to the existing body of knowledge in the field of autism employment research and also delineates the future scope of autism employment research in India and abroad

#### **CHAPTER 2**

#### LITERATURE REVIEW

#### **2.1 Introduction**

Review of literature is a significant part of the study which guides the researcher in identifying the problem and development of a conceptual model. The theoretical basis of any significant research study comes from existing literature on the topic in the form of empirical and conceptual studies. An extant review of existing literature helps the researcher in identifying the various factors and their interrelationships as well as the gaps in existing literature.

This chapter deals with all the Empirical studies on autism spectrum disorders conducted in the Indian subcontinent in the past 50 years through the means of a Scoping review.

#### 2.2 Scoping Review of empirical studies in India

Autism is described as a neurodevelopmental disability characterized by deficits in social reciprocity behavior ,restricted interests and repetitive behavior patterns. It is a lifelong disability (Baxter et al., 2015) which necessitates the need for long-term support and interventions making it a costly intellectual disability (Buescher et al., 2014). Studies focused on understanding the autism phenotype, biological aspect of autism and evidence-based interventions are more prevalent in Western countries. Whereas, the LMIC nations lag behind in autism research.(Khan et al., 2012). Hence, the researchers performed a scoping review focused on India as it is the most populous country in the world today with a population of 1.3 billion. For the literature review the researchers scoured the existing research on autism spectrum disorders in India. This scoping

review adhered to the standard methodology used in scoping review which includes formulating a research question, identification of published articles, selecting the suitable articles based on inclusion criteria, tabulation, and summary of the articles with the results presented in a concise manner. (Arksey & O'Malley, 2005)

#### Database and search criteria

The researchers searched in PubMed and SCOPUS databases.

The search criteria for PubMed has been as follows:

 "Aspergers syndrome OR Child Development Disorders OR autism OR autistic OR Asperger's OR "pervasive developmental disorder".

2. India

3. #1 AND # 2

For SCOPUS the researchers used 'autism' and 'India.' And 'autistic Indian employees'

The researchers included all English language articles up to December 2021. All articles were segregated on the basis of research themes (psychological, biological, intervention, social) and research setting (tertiary care centres, Non-Governmental Organizations (NGO), Technological Institutions, Hospital setting, Clinic setting School setting).

#### Inclusion and exclusion criteria have been as follows

Articles dealing with Autism spectrum disorder as a primary concern ii. Indian participants iii. Articles involving data generation iv. Articles published in English v. Availability of article full text. Review studies and editorials have been excluded as they did not have primary data. The researchers also excluded articles based on participants who were not of Indian nationality Results of scoping review have been summarized in the thesis.

### TABLE 2: SCOPING REVIEW OF STUDIES ON AUTISM SPECTRUM DISORDER IN INDIA

Authors,	Study setting	Research	Research	Participants	Findings
Year of publication		Category	design		
Rao and Sreedhar (1975),	Tertiary medical care	Phenotype	Case study	One autistic infant	The clinical symptoms of autism resonated with Kanner's symptoms of autism in babies.
Narayanan (1978)	Tertiary medical care	Phenotype	Case Study	Seven autistic infants	Autism symptoms in Indian infants resonated with Kanner's description of autism in babies
Malhotra and Singh (1993)	Tertiary medical care	Phenotype	Case study	Five children diagnosed with disintegrative identity psychosis	The study described symptoms of childhood disintegrative psychosis and differentiated it from autism.

Singhi and	Tertiary	Phenotype	Case study	Sixteen	Social and communication deficits in six different
Malhi (2001)	medical			autistic	areas including imaginative play, peer-
	care			infants	relationship ,non-verbal behavior, socio-emotional
					reciprocity, , and restricted range of interest. All of
					the participating infantss scores coincided with
					autistic range in Childhood autism rating scale.
Kalra et al.	Tertiary	Phenotype	Case study	Autistic	62 autistic infants assessed for clinical symptoms
(2005)	medical			infants	of autism. Infants were diagnosed between three to
	care				six years old, Boy:Girl ratio was 8:1, comorbid
					mental retardation noted in 95%, seizure in 10% and
					hyperactivity in 53% cases.
Juneja et al.	Tertiary	Phenotype	Case study	Autistic	51 autistic infants assessed for autism using with
(2005)	medical			infants	Infanthood autism rating scale, mean age at
	care				presentation 3.28 years. 47 infants scored highly
					and 4 scored in the mild to moderate range
Malhi and	Tertiary	Phenotype	Case study	Autistic	32 autistic infants matched with 32 infants with
Singhi (2005)	medical			infants	developmental delays. Autistic infants had poor
	care				social skills but superior motor skills.
Kaur et al.	Tertiary	Phenotype	Cross	100	Amongst the infants attending Early Intervention
(2006)	medical		sectional	develop	Centre, 4% infants were autistic
	care			mentally	
				delayed	
				infants	

Ghosh et al.	NGO	Phenotype	Case study	Eight	Downs syndrome infancts with comorbid autism
(2008)				autistic	had more social and communication impairment
				infants	than infants with Down's syndrome.
				with co	
				morbid	
				Down	
				syndrom	
				e and	
				eight	
				infants	
				with	
				Down	
				syndrom	
				e	
Datta et al.	Tertiary	Phenotype	Case study	One	One autistic infant with co morbid Tuberous
(2009)	medical			autistic	sclerosis, mental retardation and seizures.
	care			infant	
Sitholey et al.	Tertiary	Phenotype	Case study	One	5.5 year old severely autistic male child
(2009)	medical			autistic	spontaneously recovered after 13 days of in
	care			infant	hospital.
Krishnamurth		Phenotype	Case study	One	Behavioural abnormalities noted in an autistic child
y (2010)	NGO			autistic	following Mumbai terror attack. The child
					experienced anxiety and shirked school. He also

				male	displayed separation anxiety and verbally stimmed
				child.	about the terror attack incident.
Nizamie et al.	Tertiary	Phenotype	Case study	One	Autistic age regressed child responded to
(2010)	medical			autistic	multimodal intervention.
	care			infant	
Arora et al.	Tertiary	Phenotype	Case study	Three	Three Aspergers adults displayed psychotic
(2011)	medical			Asperger	symptoms.
	care			s adults	
Meera et al.	Tertiary	Phenotype	Case study	One	Separation anxiety noted in a 9-year old female
(2013)	medical			autistic	child diagnosed with Pervasive developmental
	care			female	disorder Authors discuss difficulties faced in
				child.	diagnosing autism in children plagued by
					comorbid anxiety disorder
Pushker et al.	Tertiary	Phenotype	Case study	One	CHARGE syndrome is a genetic condition that
(2013)	medical			autistic	causes congenital deformities the cranial nerves,
	care			infant	nose and eyes. Autistic symptoms found to be
					comorbid with the same.
Mehta and	Tertiary	Phenotype	Case study	One	A 10-year old boy diagnosed with comorbid
Bhatia (2013)	medical			autistic	autistic symptoms and Cornelia de Lange
	care			male	syndrome.
				child.	

Kishore	Psycholog	Phenotype	Case study	One	Intelligence test on an autistic 5.5 year old child
(2012)	y institute			autistic	using Gessel Test and Binet Kamat Test revealed a
				infant	spikey profile.
Kumar et al.	Rehabilitat	Phenotype	Cross	30	Majority of the autistic infants regressed in their
(2014)	ion		sectional	autistic	verbal and non-verbal language skills by their 20
	institute			infants	month.
Chatterjee et	Tertiary	Phenotype	Case study	One	Autistic traits found in an eight year old with Bardet
al. (2014)	medical			child	Biedel Syndrome
	care			with	
				genetic	
				syndrom	
				e	
Malhi and	Tertiary	Phenotype	Retrospect	523	Adaptive behaviour scores are lower in autistic
Singhi (2015)	medical		ive chart	autistic	infants than in typically developing infants.
	care		review	infants.	Adaptive behaviour correlates in a positive way
					with cognition and negative manner with autism
					severity.
Rao et al.	Tertiary	Phenotype	Cross	20	Autistic children scored lower on coloured
(2015)	medical		sectional	autistic	progressive matrices than typically developing
	care			children	children. Authors noted challenges in
				and 21	administering standard intelligence tests to autistic
				non-	children and stressed on alternative approaches.

				autistic	
				children	
Rao et al.	Tertiary	Phenotype	Cross	30	Weschler Intelligence Scale administered to verbal
(2015)	medical		sectional	autistic	autistic children, Raven's Progressive Matrices to
	care			infants	cooperative non-verbal autistic children.
Sreedaran	Tertiary	Phenotype	Cross	12	Asperger's syndrome individuals have higher rates
and Ashok	medical		sectional	Asperger	of comorbid psychiatric conditions like ADHD and
(2015),	care			,	OCD and anxiety disorder.
Karnataka				individua	
				ls(5 adult	
				& 7	
				infants)	
Chandekar et	Tertiary	Phenotype	Case study	One	Lesch Nyhan syndrome infant had autistic
al. (2015),	medical			infant	symptoms. Administering allopurinol improved
Maharastra	care			with	autistic behavioral symptoms.
				Lesch	
				Nyhan	
				Syndrom	
				e	
Ghosh et al.	Tertiary	Phenotype	Cross	20	Autism Treatment Evaluation Checklist revealed
(2015),	medical		section	children	impaired socialization, communication and
Odisha	care			with	behavior in 20 autistic children.

				clinical	1
				chinear	
				autism	
Chauhan et	Tertiary	Phenotype	Case study	One	Infant suffering from congenital rubella had
al. (2016),	medical			autistic	comorbid presentation of autism, ADHD and
Chandigarh	care			infant	mental retardation.
Kommu et al.	Tertiary	Phenotype	Retrospect	200	Socio-demographic and clinical profile with
(2017),	medical		ive chart	autistic	comorbiditiy reported by authors. Clinical
Karnatak	care		review	infants	symptoms appeared before 3 years, there was delay
					in seeking professional help. Delay in development
					of communication and social skills was noted.
					More than two-thirds of infants had co-occuring
					epilepsy, ADHD.
Mukherjee et	Tertiary	Predictors	Retrospect	18	18 autistic infants were assessed for predictors of
al. (2014),	medical	of response	ive	autistic	response to integrated therapy. Age at which
Maharastra	care			infants	therapy was initiated age was a negative predictor
					while initial autism symptoms severity levels and
					duration of therapy were positive predictors.
Shubrata et	Tertiary	Predictors	Cross	25	Autistic infants with comorbid epilepsy had worst
al. (2015),	medical	of response	section	autistic	treatment outcomes. They displayed EEG
Karnataka	care			infants	abnormalities, seizures non responsive to treatment
				with	and regression in milestones
				comorbi	
				d	

				epilepsy	
				and 25	
				without	
				epilepsy	
Gautam et al.	Tertiary	Comorbities	Case study	Case	Autism may be comorbid with intellectual
(2014), New	medical			study	disability .Co-morbidities intellectual disability
Delhi	care				and autism increase the burden of care.
Nahar et al.	Tertiary	Comorbities	Cross	33	94% patients having low support needs autism
(2019),	medical		section	autistic	showcased psychiatric comorbidities, most
Karnataka	care			adults	commonly Obsessive compulsive disorder.
				with low	
				support	
				needs	
Malhi and	Tertiary	Course	Case study	77	95% of the children diagnosed autistic below 3
Singhi	medical			autistic	years old continued to showcase autistic traits at 4
(2011),Chand	care			infants	years of age.
igarh					
Mhatre et al.	Tertiary	Course	Longitudi	80	Longitudinal study on autistic infants in India
(2016),	medical		nal follow	autistic	spanning 10 years. Ten years follow up on 80
Maharastra	care		up study	infants	children showed promising outcomes in autistic
					children with low support needs, more parental
					involvement and educated mothers

Muthusamy	Tertiary	Medical	Case study	Two	Lysosomal storage diseases like fucosidosis may
et al. (2014),	medical	problems		autistic	have traits similar to autistic traits.
Tamil Nadu	care			siblings	
Kaur et al.	Tertiary	Medical	Cross	35	35 autistic infants were assessed for visual
(2016),	medical	problems:	section	autistic	function, 25% had vision problems most
Punjab	care	Visual		infants	commonly refractive errors.
Raghavan et	Tertiary	Medical	Case study	Two	Authors reported Joubert syndrome in two autistics
al. (2016),	medical	problems:		autistic	siblings.
Tamil Nadu	care	Neurologica		siblings	
		1			
Zachariah et	Tertiary	Medical	Cross	Autistic	Miles Autism Dysmorphology used for assessment
al. (2017),	medical	problems:	sectional	children	of Dysmorphic autism features in autistic children
Tamil Nadu	care	Dysmorphic			and compared to normal controls. Autistic children
					had more dysmorphism than typically developing
					children and had higher support needs.
Kaur et al.	Tertiary	Medical	Cross	35	35 autistic infants were assessed for visual
(2016),	medical	problems:Vi	sectional	autistic	functioning, 25% had visual findings, commonest
Punjab	care	sual		infants	being refractive errors
Prakash et al.	Tertiary	Medical	Case study	One	Authors report use of distraction techniques to
(2016), UP	medical	problems :		autistic	administer midazolam to an autistic infant prior to
	care	Anesthesia		infant	dental surgery.
		Difficulties			

Tertiary	Medical	Cross	41	Autistic infants showed more feeding problems
medical	problems:	section	autistic	than intellectually disabled infants. Sensory issues
care	Feeding		infants	and behavioral problems in autistic children were
			and 56	found to be responsible for feeding problems.
			infants	
			with	
			intelllect	
			ual	
			disorders	
			in 3–10	
			year age	
			group	
Tertiary	Medical	Cross	63	63 autistic infants compared with 50 typically
medical	Problems:	section	children(	developing infants for their diet on the Children
care	Nutrition		4–10	Eating Behaviour Inventory. Autistic infants scored
			year age)	more than typical children on CEBI scale and had
			with	lower Thiamine, vitamin C, copper levels as
			autism	compared to typically developing children.
			and 50	
			typically	
			developi	
			ng	
			controls.	
	medical care Tertiary medical	medical problems: care Feeding	medical problems: section care Feeding	medical problems: section autistic care Feeding and 56 infants and 56 infants with intelllect ual disorders in 3–10 year age group Tertiary Medical Cross 63 medical Problems: section children( care Nutrition 4–10 year age) with autism and 50 yeirally developi jng

Juneja et al.	Tertiary	Medical	Cross	150 (2-	No correlation between autism and coeliac disease
(2018), New	medical	problems:C	section	12 year)	found.
Delh	care	oeliac		infants	
				with	
				ASD	
Nagaraj et al.	Tertiary	Intervention	Randomiz	40	Risperidone one mg/day given for 6 months to
(2006),	medical	:	ed Control	infants of	autistic group. They displayed marked
Chandigarh	care	Pharmacolo	trial	age 2–9	improvement in ability to socialize and
- in in iteration		gical		years	communicate and reduced aggression and
		giour		with	hyperactive traits. Their CARS scores also
				autism	improved. They also displayed healthy weight gain
					and improved sleep.
Desousa	In hospital	Intervention	Quasi-	40	Risperidone 2 mg and Fluoxetine 20 to40 mg were
(2010),		:	experimen	autistic	administered daily for 4 months Risperidone
Maharastra		Pharmacolo	tal, two	children	displayed improved mood and reduced
		gical	armed,	between	hyperactivity. Fluoxetine group displayed
			pre-post	5–16	improved speech and reduced stimming.
			design	years of	
				age.	
Sahu et al.	Tertiary	Intervention	Quasi-	20 boys	Donepezil 5 mg administered for 12 weeks had no
(2013),	medical	:	experimen	with	impact on autistic traits.
Chandigarh	care	pharmacolo	tal, pre-	Fragile X	
		gical			

			post	syndrom	
			design	e	
Srivastava et	Tertiary	Intervention	Case study	Single 5	Donepezil improved autism symptoms in an infant.
al. (2011),	medical	:		year old	
Uttarakhand	care	pharmacolo		autistic	
		gical		child.	
Suresh et al.	Tertiary	Intervention	Case study	Three	Hyperthyroidism treated with neomarcazole also
(1999), Tamil	medical	:		infants	had a positive impact on hyperactivity and
Nadu	care	pharmacolo		with	language problems.
		gical		autistic	
				features	
Karanth et al.	Tertiary	Intervention	Quasi-	30	Improved communication skills, adaptability,
(2010),	medical	:	experimen	autistic	reduction in abnormal behavior noted on statistical
Karnataka	care	Behavioral	tal, pre-	children	analysis.
			post		
			design		
Nair et al.	Tertiary	Intervention	Quasi-	39	Clinic interventions reduced autism severity.
(2014),	medical	: Behavioral	experimen	autistic	
Kerala	care		tal, pre-	infants	
			post		
			design		

Patra et al.	Tertiary	Intervention	Quasi	18	Parent mediated psycho-education intervention
(2015),	medical	:	experimen	parents	positively impacted parental outcomes of stress.
Chandigarh	care	Behavioural	tal before	of 12	The intervention consisted of take home knowledge
			after study	autistic	of autism and home based interventions to improve
				infants	communication, socialization and behavioral
					issues.
Sivaraman	Private	Intervention	Quasi	2 autistic	Discriminative reinforcement had a positive effect
(2017),	clinic	:	experimen	children.	on empathy level in autistic children.
Chennai		Behavioural	tal before		
			after study		
Malhotra et	Tertiary	Intervention	Quasi-	One	Child showed improved social and adaptive
al. (2010),	medical	:communica	experimen	autistic	behavior after six phases of PECS
New Delhi	care	tio	tal, pre-	child	
			post		
			design		
Karanth and	NGO	Early	Quasi-	102	102 autistic children were followed up to see the
Chandhok		intervention	experimen	autistic	outcome of an early intervention program. It lead
(2013),			tal, pre-	children.	to improved integration into mainstream schools.
Karnataka			post		
			design		
Nair et al.	Tertiary	Intervention	Quasi-	52	Authors reported on Behavioral intervention
(2014),	medical	: Home	experimen	autistic	techniques taught to parents of autistic children to
Kerala	care	based	tal, pre-	toddlers	improve their social skills, language

			post		skills, cognitive abilities and adaptability. Authors
			design		concluded that in those areas were therapist led
					behavioral interventions are scarce, parent led
					home based interventions can be used just as
					effectively.
Paul et al.	Research	Intervention	Single-	3 autistic	Socio-communicative responsive improved in
(2015),	centre	: music	subject	children.	autistic children who were interacted with using
Gurgaon			design,		sung directive language as opposed to spoken
			pre-post		language.
Divan et al.	NGO	Intervention	Cultural	53	Preschool Autism Communication Therapy was
(2015), Goa		: Parent	adaptation	primary	adapted to be administered by parents in India.
		mediated	of parent	school	Cultural adaptation of the therapy in terms of both
			mediated	educator	content and context makes it feasible to the local
			interventio	s and 40	population
			n	special	
				educatio	
				n	
				teachers	
Rahman et al.	NGO	Intervention	Randomiz	32	Parent mediated evidence-based intervention
(2016), Goa		: Parent	ed control	infants in	applied to autistic children over a period of twelve
		mediated	trial	parent	weeks led to improved parent-child interaction and
				mediated	more communication initiated by the autistic child
				intervent	than usual treatments.

			ion group	
			and 33	
			infants in	
			treatment	
			as	
			control	
			group	
Tertiary	Intervention	Interventio	36	After 19.5 months of parent mediated interventions
medical	: Parent	n: pre-post	autistic	which was customized to fit needs of autistic child
care	mediated		infants	,social interaction and communication. A marked
				improvement in CARS, VSMS and ABC scores
				was noted.
NGO	Intervention	Randomiz	40 parent	Autism severity scores ,parent synchronous
	:	ed control	infant	responses and infant initiation of communication
	Community	trial	Dyads	improved with community health worker mediated
	health			interventions.
	worker			
	mediated			
Clinic	Intervention	Quasi	10	autologous bone marrow concentrate given to 10
	: Biological	experimen	autistic	autistic infants who were evaluated once every
		tal, pre-	infants	three months for a year.
		post		
		design.		
	medical care NGO	medical : Parent care mediated NGO Intervention : Community health worker mediated Clinic Intervention	medical : Parent n: pre-post care mediated . NGO Intervention Randomiz : Gommunity ed control Community trial health trial health uvorker . mediated . Clinic Intervention Quasi : Biological experimen tal, pre-	And 33and 33infants in treatmentas controlgroupTertiaryInterventionmedical::ParentmediatedMGOInterventioninfants:ed control:ed controlinfantCommunitytrialbalthworkermediatedClinicInterventionInterventionQuasiifologicalexperimenautistictal, pre-infantspost

Shroff	Clinic	Intervention	Case study	3 autistic	Three autistic infants showed marked improvement
(2017), New		: Biological		infants	in cerebral perfusion on SPECT scans after being
Delhi					given human embryonic stem cells. infants with
					clinical diagnosis of ASD
Sharma et al.	Hospital	Intervention	Quasi-	Infants	Bone marrow mononuclear cell implant led to
(2013),		: Biological	experimen	with	improvement in functioning of autistic infants.
Maharastra			tal, pre-	muscular	
			post	dystroph	
			design	у,	
				cerebral	
				palsy,	
				and	
				injury to	
				the brain	
				and	
				spine,	
				autism,	
				Retts	
				Syndrom	
				e, giant	
				axonal	
				neuropat	
				hy	

Narasinghara	Yoga	Intervention	Before	Autistic	A 90 day yoga intervention given to autistic
o et al.	university	: yoga	after	children	children and their parents. Chief symptoms were
(2017),			interventio	and their	gastrointestinal, sleep and behavioral problems.
Karnataka			n study	parents	Imitation ability improved in autistic children who
					were able to participate in yogic asanas,
Radhakrishna	Rehabilitat	Intervention	Interventio	6 autistic	Autistic children administered ABA and manual
(2010), Tamil	ion	: yoga	n, before	children	yoga intervention displayed improved
Nadu	Institute		after		communication, language, attention and play
Vidyashree et	Tertiary	Intervention	Interventio	50	Enhanced parasympathetic balance of heart rate
al. (2019),	care centre	: yoga	n, before	autistic	variability noted after yoga intervention.
			after	infants	
Daniel et al.	Tertiary	Intervention	Pre-post	Primary	35 primary school teachers given training on
(2013), New	medical	:		school	childhood psychiatric disorders which led to
Delhi	care	educational		teacher	improved knowledge of childhood psychiatric
					disorders
Lahiri et al.	Technolog	Intervention	Proof of	Eight	Virtual Reality Based Social Communication
(2011),	ical	: Computer	concept	autistic	System shown to improve performance in autistic
Gujarat	institute	assisted	study	adolesce	children.
				nts with	
				low	
				support	
				needs	

Lahiri et al.	Technolog	Intervention	Proof of	Eight	Virtual reality-based interaction system equipped
(2015),	ical	: Computer	concept	autistic	with adaptive response technology that is sensitive
Gujarat	institute	assisted	study	adolosce	to gaze helps improve social -communication in
				nts with	autistic individuals.
				low	
				support	
				needs	
Guhathakurta	NGO	Genetics	Case	79	5HTTLPR gene responsible for serotonin transport
et al. (2006),			control	autistic	not linked to autism in Indian study
				infants,	
				136	
				parents	
				and 145	
				controls	
Dutta et al.	NGO	Genetics	Case	76	GluR6 gene not linked to autism susceptibility in
(2007), West			control	autistic	India
Bengal				families	
				and 95	
				non	
				autistic	
				controls.	

Sen et al.	NGO	Genetics	Cross	128	Genotype of 80 autistic Indians compared to 149
(2007), West			section	families	controls. Homeobox transcription factors HOXA11
Bengal				with	and HOXB1 levels found to be less in Indian
				autistic	individuals as compared to western individuals, so
				individua	they cannot be considered markers of autism in
				ls from	Indian population.
				West	
				Bengal	
				and	
				Assam	
Dutta et al.	NGO	Genetics	Cross	Autistic	Glutamate receptor 6 linked to autism in Indians.
(2007), West			section	individua	
Bengal				ls	
Dutta et al.	NGO	Genetics	Cross	102	Genetic link of reelin to autism not noted in Indians
(2008), West			section	autistic	
Bengal				children	
				and 182	
				parents	
				and 101	
				neurotyp	
				ical	
				children	

NGO	Genetics	Cross	83	Serotonin transporter gene polymorphism link
		section	autistic	noted by authors.
			children.	
			150	
			parents	
			and 160	
			non-	
			autistic	
			children.	
Hospital	Genetics	Case	138	A study of genetic polymorphism of folate
		control	autistic	pathways showed the linkage of certain genetic
			infants	alleles with autism was noted.
			and 138	
			non-	
			autistic	
			children	
NGO	Genetics	Cross	93	Serotonin transporter receptor gene linked to
		section	autistic	autism
			children,	
			their	
			parents	
			and 160	
			non-	
	Hospital	Hospital Genetics	NGOGeneticsSectionsection<	NGOGeneticssectionautistic children.NGOGeneticsCase138Inon- autistic children.infants and 138Inon- autistic children.infants and 138Inon- autistic children.infants and 138Inon- autistic children.infants and 138Inon- autistic infantsinfants and 138Inon- autistic infantsinfants autistic infantsInon- autistic infantsinfants autistic infantsInon- autistic infantsinfants autistic infantsInon- autistic infantsinfants autistic infantsInon- autistic infantsinfants autistic infantsInon- autistic infantsinfants autistic infantsInon- autistic infantsinfants autistic infantsInon- autistic infantsinfants autistic infantsInon- autistic infantsinfants autistic infantsInon- autistic infantsinfants autistic infantsInon- autistic infantsinfants autistic infantsInon- autistic infantsinfants autistic infantsInon- autistic infantsinfants autistic infantsInon- autistic infantsinfants autistic infantsInon- autistic infantsinfants autistic infantsInon- autistic infantsinfants autistic infantsInon- autistic infantsinfants autistic infant

				autistic	
				children	
				children	
Sen et al.	NGO	Genetics	Cross	128	Engrailed 2 gene linked to autism in Indians.
(2010), West			section	families	
Bengal				of	
				autistic	
				infants	
				and	
				parents	
				of	
				autistic	
				infants	
Vaishnavi et	NGO	Genetics	Cross	No	CNV-microRNAs were found to be distinctly
al. (2013),			section	human	linked to autism.
Tamil Nadu				subjects	
				included,	
				existing	
				genomic	
				S	
				retrieved	
Singh et al.	NGO	Genetics	Autism	Autistic	ITGB3 and TPH2 genes liked to autism in India
(2013), West			database	families	
Bengal					

				and	
				controls	
Jaiswal et al.	NGO	Genetics	Cross	169	SLC6A4 gene markers influence behavioral
(2015), West			section	Autistic	attributes of autistic individuals through their
Bengal				probands	influence on serotonin content.
				, 317	
				parents	
				and 168	
				unrelated	
				ethnicall	
				у	
				matched	
				non-	
				autistic	
				individua	
				ls.	
Sheth et al.	Tertiary	Genetics	Case study	One	Pure interstitial dup(6)(q22.31q22.31) linked to
(2015),	medical			autistic	autistic traits.
Gujarat	care			infant	
Arun et al.	Tertiary	Genetics	Case study	25	Changes in chromosomes 2, 3, 7, 22 and X (2q32,
(2015),	medical			autistic	3q25-q27) linked to autism. No such linkage found
Karnataka	care			patients	for SNPs of MTHFR gene for autism.

Chakraborti	NGO	Genetics	Case study	203	203 autistic individuals and 236 controls examined
et al. (2016),				autistic	to analyze link of autism with eight markers of
West Bengal				individua	MAOB and also to examined its effect on platelet
				ls and	5-HT Content. High levels of MAOB biomarker
				236 non-	linked to severe autism as indicated by high CARS
				autistic	scores.
				individua	
				ls from	
				communi	
				ty	
Bindu et al.	Tertiary	Neuroimagi	Case study	Three	Diffuse hyperintense signals in white matter,
(2007),	medical	ng		autistic ,	thalami and globus pallidus noted on MRI
Karnataka	care			mentally	
				retarded	
				infants	
				with	
				Maple	
				syrup	
				urine	
				disease	
Kothur et al.	Tertiary	Neuroimagi	Cross	Two	Cortical tubers in temporal lobe noted on MRI.
(2008),	medical	ng	section	autistic	
Chandigarh	care			infants	

				with	
				tuberous	
				sclerosis	
				complex	
Udani et al.	Hospital	Neuroimagi	Cross	100	13 percent of infants with Neonatal Hygo-
(2009),		ng	section	autistic	glycemic Brain Injury were autistic.
Maharastra				infants	
Gupta and	clinic	Neuroimagi	Case-	Ten	Generalized cerebral hypoperfusion,
Ratnam		ng	control	autistic	hypoperfusion in frontal and prefrontal areas noted
(2009),				and	in autistic infants on SPECT scan
Rajasthan				mentally	
				retarded	
				children	
				and five	
				non-	
				autistic	
				children	
				between	
				4–8 years	
				of age.	
Sharda et al.	Brain	Neuroimagi	Case study	22	Fronto-temporal connectivity found to be intact in
(2015),	research	ng		autistic	sung word perception but disturbed in speech-
Haryana	centre			infants	perception as seen on fMRI of autistic infants.

Fredo et al.	Tertiary	Neuroimagi	Case-	Not	Negative correlation of anisotropy index found
(2014), Tamil	medical	ng	control	given	with the performance IQ of autistic individuals.
Nadu	care		study		
Assis et al.	Tertiary	Neuroimagi	Case-	19	The brains of autistic infants showed marked
(2015),	medical	ng	control	autistic	impairment in white matter tracts infants as well as
Karnataka	care			childrena	abnormal optic tract on MRI in Diffusion Tensor
				nd 34	Imaging
				non-	
				autistic	
				children	
				between	
				2-20	
				years of	
				age.	
Manglunia	Tertiary	Neuroimagi	Case study	6 years	Bilateral temporal diffuse hypometabolism noted in
(2016),	medical	ng		old	PET scan.
Maharastra	care			autistic	
				child	
Anil Kumar	Tertiary	Neuroimagi	Case-	10	PET scan revealed aberrant brain functioniing in
et al. (2017),	medical	ng	control	autistic	autistic infants. Hypometabolism or
Chandigarh	care		study	infants	hypermetabolism was also noted in frontal and
				and 15	occipital cortices.
				neurotyp	

				ical	
				infants in	
				age range	
				of 8 to 19	
Sharma and	Tertiary	Neuroimagi	Case-	45	Autistic children had lower metabolism levels than
Bhushan	medical	ng	control	autistic	non-autistic in FDG PET scan.
(2018),	care		study	children	
Maharastra				and	
				controls	
Kaku et al.	Tertiary	Neuroimagi	Cross	17	Aberrant brain connectivity in fMRI scans
(2019),	medical	ng	sectional	autistic	
Karnataka	care			infants	
Narayan et al.	Tertiary	Monoamine	Case study	17	CSF levels of 5HIAA and HVA of autistic infants
(1993),	medical	rgic		autistic	found comparable to 15 non-autistic infants.
Karnataka	care	metabolites		infants	
Lakshmi	Education	Protein	Cross	Autistic	Autistic infants had lower protein content in their
Priya and	al institute	content	sectional	infants	hair and nails.
Geetha					
(2011), Tamil					
Nadu					
Naik et al.	Tertiary	Inflammator	Case	67	Nuclear Transcription Factor Kappa B (NF-jB)
(2011),	medical	y cytokines	control	autistic	found to be higher in autistic individuals.
Telangana	care			infants	

				and 29	
				controls	
Damodaran	Education	Oxidative	Case	45	Urinary oxidative stress marker higher in autistic
and	al institute	stress	control	autistic	infants.
Arumugam		markers		infants	
(2011), Tamil				and 50	
Nadu				controls	
Malhotra et	Tertiary	Vit B12	Case study	One	Developmentally delayed child had Vitamin B12
al. (2013),	medical			infant	deficiency and hyperhomocysteinemia
Chandigarh	care			diagnose	
				d with	
				disintegr	
				ative	
				identity	
				disorder	
Lakshmi	Education	Catecholam	Case-	45	Autistic infants secrete more cortisol than non-
Priya et al	al institute	ine	control	autistic	autistic infants.
(2013), Tamil				infants	
Nadu				and 45	
				non	
				autistic	
				infants	

Verma et al.	NGO	Monoamine	Case-	194	Less active rs6323 allele of MAOA in boys leads to
(2014), West		enzyme	control	autistic	high serotonin secretion in brain that can be linked
Benga		metabolizer		infants	to autistic traits.
				and 227	
				controls.	
Suganya et al.	Tertiary med	likaliware	Cross	30	Urinary kininogen higher in autistic children than
(2015), Tamil		Proteome	section	autistic	typical children.
Nadu				children	
Basheer et al.	Tertiary	Vitamin D3	Case-	40	Both case and control had equal vitamin D levels.
(2017),	medical	levels	control	autistic	
Karnataka	care			infants	
Basheer et al.	Tertiary	Peripheral	Cross	50	Increased levels of IL6 and IL17A noted in Indian
(2018),	medical	immune	section	autistic	autistic infants.
Karnataka	care	aberrations		infants	
				and 30	
				age	
				matched	
				controls	
Juneja et al.	Tertiary	Psycholgica	Cross	51	Aberrant Behavior Checklist sensitivity score
(2010), New	medical	1	section	autistic	tested on autistic children, cut-off score of 45 found
Delhi	care			infants	to be optimum by authors.

Russell et al.	Tertiary	Psychologic	Cross	103	CARS and ICD 10 performed at par in diagnosing
(2010), Tamil	medical	al	section	autistic	autism. CARS was shown to be a good measure of
Nadu	care			infants	reliability and validity. Cut off points 33 has been
					suggested for Indian infants.
Patra and	Tertiary	Psychologic	Cross-	35	Feasibility of ISAA was studied in a clinical setting.
Arun (2011),	medical	al	section	autistic	
Chandigarh	care			infants	
Alwinesh et	Tertiary	Psychologic	Cross	116	Psycho Educational Profile was found to be better
al. (2012),	medical	al	section	autistic	at measuring developmental profile of infants with
Tamil Nadu	care centre			and	comorbid mental retardation and autism than those
				mentally	with autism.
				retarded	
				infants	

This scoping review aimed to assess the current state of Indian autism research. Our goal was to identify knowledge gaps and recommend priority areas for future research and policy development.

India has produced a substantial body of autism research, covering various aspects, including phenotype, biomarkers, psychological instruments, prevalence, and interventions. Researchers from diverse settings, such as medical centers, NGOs, and educational institutions, have contributed to this research. Family experiences have provided valuable insights into the social impact of autism and the challenges faced by families.Despite significant efforts by parentmediated service centers, significant gaps persist in service delivery, particularly for adults with autism and those transitioning from care agencies to community settings. There is a need to improve awareness of autism among parents, teachers, healthcare providers, and policymakers to facilitate early identification and intervention. Available prevalence estimates are limited and may underestimate the true prevalence of autism in India. Rigorous, nationally representative studies are needed to accurately assess prevalence rates.

We could not find any publication on the interface of the education system with care agencies. No publications were found on transition-care arrangements that would smoothen the movement of an autistic individual from a care-agency to the community. Only one publication could be located on the parental experience of care for autistic adults In the management domain, one secondary research paper o neurodiversity friendly workplace practices was found during the scoping review. The researchers found a paucity of research on the lived experiences of late-diagnosed autistic individuals in India.

Future research should focus on areas such as transition care, adult interventions, neurodiversityfriendly workplaces, and the lived experiences of late-diagnosed individuals. There is a need for collaborative research between, clinicians, educators, policymakers, and families to facilitate knowledge sharing and evidence-based practices.

# **CHAPTER 3**

# **RESEARCH METHODOLOGY**

# **3.1 Introduction**

The chapter on research methodology provides deep insight into the way the research study has been performed. A studies essence lies in using a sound methodology and research approach to achieve the objectives of the study. This study focused on employer and employee perspectives on workplace accommodations required to sustain a neurodivergent workforce in India.

Chapter begins with research gaps and research objectives and research approach. It is followed by research design, procedure used for development of interview and focus group manuals and the various techniques used for data analysis.

#### **3.2 Research Gaps**

From the above review of literature, it becomes evident that much of the aforementioned research has been conducted in Hospital or clinical settings and focussed on autistic children and adolescents. The researchers found substantial gaps in literature regarding the experiences of late diagnosed autistic Indian adults in their personal and professional lives. Thus, for the purpose of the current research work, the focus has been on the following four research gaps when it comes to employing neurodivergent talent in India.

**3.2.1** Dearth of research on workplace experiences of late-diagnosed autistic women in India.

**3.2.2** Dearth of research on neurodiverse individuals experiences around stimming behaviours at the workplace and its importance as a workplace accommodations strategy.

**3.2.3** Dearth of research in India on work from home and reintegration experiences of neurodiverse individuals in India.

3.2.4Dearth of research on Indian managers perspective on employing neurodiverse talent

### **3.3 Research Objectives**

The following are the research objectives:

- 3.3.1 To study the workplace experiences of late diagnosed autistic women in India
- **3.3.2** To study neurodiverse individuals' experiences around stimming behaviors at the workplace and its importance as a workplace accommodations strategy.
- **3.3.3** To study work from home experiences of neurodiverse individuals during the Covid -19 pandemic in India.
- **3.3.4** To study existing workplace accommodations at neurodiverse friendly organizations in India and determine the readiness level of managers in non-neurodiverse friendly Indian organizations in adopting these accommodations

#### **3.4 Research Approach**

The study employed a qualitative approach to answer the research questions. The research involved autistic individuals right from the stage of inception of ideas to creation of interview and focus group manuals, collection of data and its subsequent analysis. This approach has been adopted keeping in mind the slogan 'Nihil de nobis , sine nobis' which is Latin for "Nothing about us without us" which communicates the idea that no policy should be formulated without the full and direct participation of members of the group affected by that policy.

'Qualitative Research' approach through in-depth interviews was adopted. Qualitative semistructured, in-depth interviews of Indian neurodiverse individuals and Indian managers were conducted to explore the employer and employee perceptions on workplace accommodations required to sustain a neurodiverse workforce in India. In-depth interview method helps in understanding the complex ways in which people think and feel about a particular phenomenon (Moran, 2009). In-depth interviews allow probing for additional information when the key insights about a particular phenomenon are uncovered (Zikmund, W. G., Babin, B. J., Carr, J. C., & Griffin, 2013).

### 3.5 Research Design

The research design adopted for this study is a qualitative one. Of the six common qualitative design approaches viz., Phenomenological, Ethnographic, Grounded theory, Historical studies, Case study and action research approach, the Phenomenological approach and Grounded theory approach have been considered apt by the researchers keeping in mind the objectives of the study.

# 3.5.1 Phenomenological research design

This research design involves examining the human experience through the lens of the vivid descriptions provided by the individuals involved in the research. These experiences are referred to as lived experiences. The goal is to ascribe meaning to the lived experience of each participant. This research design is considered apt for areas in which little to no knowledge exists. (Donalek, 2004). In this research approach, respondents' perception of the phenomenon under study are obtained through interviews. To understand the lived experience of the respondents , it is essential

that the researcher put aside his own ideas and biases related to the phenomenon and the individual participants, this happens through the process of bracketing. Only after bracketing his own beliefs about the phenomenon is a researcher able to experience it from the eyes of the person who has lived through the experience.

Parse, Coyne, and Smith (1985) opined that data from a phenomenological study be subjected to "quiet contemplation" by the researcher. This is followed by the researcher efforts to uncover the meaning behind the lived experience of each participant. This helps researcher in finding themes and patterns in the data. Data collection and data analysis may take place simultaneously. Phenomenological research methods differ vastly from quantitative research methods. Although phenomenological research is often viewed as a soft science, Streubert and Carpenter (2002) opine that it a critical, rigorous and systematic research design.

In this research study, Phenomenological research design constituted a bulk of the research including the study on workplace experiences of late-diagnosed autistic Indian women, the study on working from home experiences of autistic individuals in India, the study on stimming behaviors of autistic individuals and the study on non-autistic Indian managers perception of autistic employees.

### 3.5.2 Grounded theory

Grounded Theory approach has been developed by sociologists, Glaser and Strauss (1967). Grounded theory involves the collection and analysis of data and the development of a theory rooted in the analysed data. Grounded theory approach involves both inductive and deductive approach to theory development. According to Field and Morse (1985), "constructs and concepts are grounded in the data and hypotheses are tested as they arise from the research". In this study, grounded theory approach was used primarily in the study on stimming behaviours of autistic individuals which lead to the development of "An autistic individuals experiences around evolution of stimming behaviors framework ". As researchers we looked for certain autistic individuals who were able to shed new light on the phenomenon of stimming. Diversity in the sample has been encouraged by including autistic individuals from diverse work settings and socio-economic backgrounds .Data collection consisted of participant interviews recorded through a recording device. Data collection and analysis occur simultaneously. Constant comparison has been used, to compare data being collected to data that has already been collected. Important concepts were identified and assigned codes. These codes provided us with new interpretations of the data. An open mind and intuitive approach has been adopted in viewing data and assigning codes. Once concepts were identified and their relationships specified, the researchers consulted the literature to determine if any similar associations were already existing. Consulting literature at a later stage of research is a vastly different approach as compared to quantitative research in which the literature is consulted fairly early on in the research process. Despite the diversity of the data obtained, the grounded theory approach presumes the possibility of discovering fundamental patterns in all social life which are called basic social processes. Grounded theory is not as much concerned with the the testing of hypotheses as it is with its generation. The theory generated is considered self-correcting. This implies that as additional data is gathered, adjustments can be made to the theory to allow for the interpretation of newer data.

### 3.6 Sources of data

A mix of primary and secondary data has been used in this study. Information from secondary sources such as journal articles, books, newspapers and study reports has been utilized to deepen understanding of the research subject and in development of semi-structured interview questionnaires. Primary data has been collected from Indian autistic individuals using a set of semi-structured interview manuals and focus group discussion question.

## 3.7 Study Sample

A mix of convenience and purposive sampling was used by the researchers to identify the sample.

- For the study on workplace experiences of late diagnosed autistic women in India a total of 15 Late diagnosed autistic women were approached through an NGO working with autistic individuals, Social media advertisements and personal contacts of the researchers.
- For the study on work from home experiences and stimming behaviours of autistic employees a total of 18 autistic adults were initially approached for the semi structured interviews aspect of the study, of which 15 autistic adults consented to take part in the in depth interviews. An additional seven individuals were approached to take part in a Focus group discussion related to stimming behaviours at the workplace, out of which ultimately 5 consented to participate. Recruitment of the participants took place in Delhi, Bombay and Hyderabad. To sample autistic adults with a diverse set of needs, the researchers interviewed participants through an organization employing autistic adults, an NGO for autistic adults and existing networks.

• For the study on Neurotypical Indian managers perceptions of neurodiverse employees, initially 12 individuals were approached for in depth interviews of which 10 consented to take part.

# Sampling criteria for different objectives of the study.

For the first objective related to the study of workplace experiences of late-diagnosed autistic women in India , the demographics were as follows:-

- (a) Indian nationality;
- (b) Age between 18 -65 years
- (c) Diagnosed with ASD by a certified professional (psychiatrist or clinical psychologist)
- (d) Diagnosed in late adolescence or adulthood (aged 15 years or older)
- (e) No intellectual disability (I.Q. over 70)

For the second objective related to study on workplace experiences related to stimming behaviors of autistic employees the demographics was as follows:-

- a) Participant is a citizen of India.
- b) Participant age is above 18 years and less than 65 years.

c) Participant had received or were in the process of receiving an official clinical diagnosis of an autism spectrum condition through a qualified Psychologist based in India or abroad

d) Participant is employed in their present organization or present role for a period of one year prior to the date of Interview.

e) Had no intellectual disability

For the third objective related to work from home experiences of autistic employees during the covid-19 pandemic in India the inclusion criteria was as follows:-

a)Indian nationality

b) Age between 18-65 years

c) Diagnosed as autistic/ADHD/Dyslexic by a licensed professional (Psychiatrist or Clinical Psychologist)

d)Had no intellectual disability

e) Had worked from home for a minimum period of one year at the time of data collection for the study.

For the fourth objective related to neurotypical Indian managers perceptions of neurodiverse employees the demographics was as follows:-

- a) Indian nationality
- b) Employed in managerial position(front line, middle or top management)
- c) Employed full time for minimum one year in said managerial position
- d) Age between 21-65

## 3.7.1 Sample Frame

Indian neurodiverse employees, their managers, psychologists, autism rights advocates and psychologists who have worked closely with neurodiverse employees.

#### 3.7.2 Sample size

Since there is no definite rule to determine sample size of qualitative research. We have taken into consideration the scope and nature of our study for determining our sample size.(Sandelowski,1995). In an article by Guest et al , they found that saturation of meta-themes can usually be achieved with 12 interviews. Data saturation is when sampling can be terminated as n (Guest & Johnson, 2006) Keeping in mind these findings the sample size was determined by when the saturation of meta themes was achieved for the different objectives of the study.

#### 3.8 Pre-test and Pilot Testing

Pilot testing is pivotal for a sound research design and for the purpose of refining the research instrument. For the pre-test, the semi structured interview questions were discussed with an autistic Indian autism rights advocate. Based on the feedback received, some questions were reformulated or rephrased.

Pre-testing phase was followed by pilot testing phase, wherein the questionnaires were administered to two autistic individuals. Pilot testing was done with the aim of further improving the semi-structured interview questionnaires and also to ensure that all questions were easily comprehensible to autistic individuals.

#### **3.9 Trustworthiness in Qualitative research**

Trustworthiness in qualitative research refers to the confidence that readers can place in its findings and conclusions. the findings and conclusions. While Quantitative researchers rely on statistical measures to establish reliability and validity, qualitative researchers use a different criteria to ensure trustworthiness of their research (Shenton, 2004). Credibility is one key criteria to ensure trustworthiness in qualitative research. Credibility is akin to establishing internal validity in quantitative research. It is the extent to which the findings accurately reflect the participants lived experiences and perspectives. Credibility is enhanced through prolonged engagement with the research setting, continuous observation, triangulation of data from various sources, and member checking.

In the present research the researchers used prolonged engagement to develop a deeper understanding of the context and to build rapport with the participants (Kornbluh, 2015). Researchers also made use of persistent observation to aid in systematic and focused data collection over time. This helped the researchers in ensuring that the nuances of the phenomenon under investigation were captured. Data triangulation strategy which involves the use of multiple data sources (Interviews, Focus groups etc) was used in the study on stimming behaviours of autistic individuals in India and also in the study on work from home experience of autistic individuals in India to verify the findings and cross-check information (Brooks et al., 1996). Lastly, member checking criteria of trustworthiness which involves researchers sharing their interpretations with participants to obtain feedback and validate their understanding was made use of in all four objectives of the study to ensure trustworthiness.

Another important aspect of trustworthiness is transferability which is akin to the concept of external validity in quantitative research (Kornbluh, 2015).Transferability of research findings refers to the extent to which the findings of a qualitative study can be generalized to other contexts. Although complete transferability is not always feasible in qualitative research. The researchers

sought to enhance transferability of findings by providing a detailed description of the context of research, the participants involved, and data collection methods.

Dependability is yet another aspect of trustworthiness. Dependability in qualitative research is related to the consistency and reliability of the research process and findings. The researchers ensured dependability by maintaining an audit trail which involved thorough documentation of the research design, data collection process, methods used to analyse the data and the findings. An audit trail allows others to review the research process and assess its rigor. The principal researcher also undertook peer debriefing wherein the research findings were discussed with colleagues to gain an alternative perspective.

The last criteria of trustworthiness is confirmability. Confirmability refers to the objectivity of the findings and whether the researcher's biases and values have had any influence on them. The principal researchers used reflexive journaling to enhance confirmability in the study on workplace experiences of late-diagnosed autistic women in India and the study on stimming behaviours of autistic individuals. Reflexive journaling involves documenting of thoughts, feelings, and assumptions by the researchers al through the research process. This helps to identify and mitigate potential biases. Additionally, researchers used data triangulation from interviews and focus group discussions to ensure confirmability and reduce the impact of individual perspectives.

#### **3.10 Ethical Considerations in qualitative research**

The researchers followed the Committee on Publication Ethics Guidelines for all aspects of the study (Wager, 2012). Toward this end, agreement on the role of contributors and collaborators and

on matters of authorship and publication were established early on. Further, formal and documented ethical approval from the Institutional review and ethics board at Action for Autism, India was sought for all aspects of the study involving people. Lastly, fully informed consent was sought from all study participants beforehand.

### 3.11 Reliability

The meaning and way of measuring reliability in Qualitative research differs vastly from quantitative research. Reliability in qualitative research is centered around "being thorough, careful and honest in carrying out the research" (Robson, 2002). In semi structured interviews all these aspects of reliability can be achieved by keeping certain practical considerations in mind during the interview process. This includes wording the interview questions aptly, establishment of rapport with the interviewees and being cognizant of the power dynamics between the interviewer and the interviewee. (e.g. Breakwell, 2000; Cohen et al., 2007; Silverman, 1993).

For the purpose of attaining reliability in our study, the study questions were worded in such a manner so as to be sensitive to the disability of autistic individuals. Wherever possible, identity first language as opposed to person first language was used to address autistic individuals. Individuals with disability prefer identity first language as they feel that their disability is inextricably linked to their identity. They use identity-first language to show solidarity with their community, to showcase a sense of pride in their identity as a disabled individual and also to emphasize that it is society that is disabling , in line with the social model of disability(Oliver,2013).Rapport with the interviewees was established before the semi structured interview by means of an informal discussion in which the interviewees were able to reveal their

apprehensions regarding the interview process. Further, all interviews took place with the video mode turned off keeping in mind the sensory sensitivity of autistic individuals. Interviewees were given the option to skip questions that they were not comfortable answering.

### 3.12 validity

The concept of validity in Qualitative research also differs substantially from validity in quantitative research. For a qualitative research to be considered valid, it needs to be free from researcher bias, reactivity and respondent bias as much as possible. (Lincoln and Guba, 1985).

Researcher bias in qualitative research refers to any negative influence caused by researchers knowledge, assumptions on the study, including the assumptions around the design, analysis or, sampling technique used. Reactivity refers to an influence of the researcher herself on the studied situation and participants involved. Respondent bias refers to a situation wherein respondents fail to furnish honest responses to the questions asked, this is more likely to happen if they perceive the given topic as a threat or if they are attempting to appease the researcher by providing responses that they think may be considered more desirable by the researcher.

Robson (2002) identified a number of strategies to counteract researcher bias, reactivity and respondent bias in research which include prolonged involvement, triangulation of data, peer debriefing, member checking, negative case analysis and keeping an audit trail.

#### Table 3 : Strategies to deal with the threats to validity (Robson, 2002; 174)

Strategies	Reactivity	Researcher Bias	Respondent Bias
Prolonged	Reduced threat	Increased threat	Reduced threat
involvement			
Triangulation	Reduced threat	Reduced threat	Reduced threat
Peer Debriefing	No impact	Reduced threat	No impact
Member Checking	Reduced threat	Reduced threat	Reduced threat
Negative Case	No impact	Reduced threat	No impact
Analysis			
Audit Trail	No impact	Reduced threat	No impact

Of the aforementioned strategies, we used Data triangulation strategy through Focus group discussion to reduce the researcher bias, reactivity bias and respondent bias in the study on latediagnosed autistic women in India, the study on stimming behaviors of autistic individuals at the workplace and work from home experiences of autistic individuals in India. Negative case analysis as a strategy was adopted for study on late-diagnosed autistic women in India and also for the study on Work from home experiences of autistic individuals in India. Further, member checking as a strategy was adopted for all four objectives of the research.

## **3.13 Data Collection Tools and Process**

# **3.13.1Data Collection Tools:**

Data collection tools are interview manuals developed on the basis of (a)extensive literature review on the topic (b) exploratory interviews of autistic psychologists, autism rights advocate , neurodiverse individuals and Neurotypical managers of neurodiverse employees autistic.

#### **3.13.2 Data collection process**

The data for qualitative analysis was collected through in-depth interviews and focus group discussions. We conducted a total of 53 interviews, which included; two interviews of Vice President and managers of neurodiverse friendly organizations, one interview of an autistic psychologist in USA, 10 interviews of late diagnosed autistic women in India, 10 interviews of neurotypical Indian managers working in non-neurodiverse friendly organizations, 15 interviews of neurodiverse individuals working from home during Covid-19 pandemic in India, 15 interviews of autistic individuals related to their stimming behaviours and one focus group comprised of 5 participants.

#### 3.13.3 Interview protocols

The interviews with neurodiverse individuals were conducted over a period of six months from July 2021 to December 2021. The interviews were conducted online, keeping the video mode off for the comfort of the neurodiverse participants. The study participants provided oral or written consent to their data being recorded on the conditions of anonymity prior to their interviews. The interviews and focus groups were conducted in English. The study participants spoke a few filler words to confirm the internet connectivity at their ends during the online interviews(for instance Haan which means yes, na which means no ,kya which means what, acha which means okay) in their native language Hindi which were omitted as they were not relevant to the context of the

study Semi structured interview questions were displayed on the computer screens of the participants for the duration of the interview. Questions displayed on screen were read out loud for the participants. Interviews and focus groups were recorded on a recording device and transcribed verbatim. Pertinent snippets of the conversations were included as quotations in the 'Results' section. To preserve the identity of the study participants, each participant was given a pseudonym consisting of an alphabet and a number. Participants were addressed using this pseudonym throughout the study. The interviewer gave a brief description about the purpose of the study at the beginning of each interview.In order to promote open discussion, the participants were informed that there are no right or wrong answers. All the interviews were audio-recorded after seeking permission from the participants. The interview questions were open-ended and semi-structured, giving an unobstructed way for various themes to emanate. This interview method enabled participants to express freely their workplace experiences and also allowed the interviewer to seek clarification by asking follow-up and probing questions. On an average, the duration of each interview was 1 hour to 1 hour 30 minutes.

The interviews with Neurotypical managers working in non neurodiverse friendly organizations in India were conducted online and in person. The study participants were given a brief description of the purpose of the interview beforehand. All participating managers provided oral consent on the condition of anonymity.

#### **3.14 Method of Data Analysis**

The data collected from the semi structured interviews and focus group discussions was transcribed verbatim. The transcripts were exported to Nvivo software to aid in processing and analysis of

data. The data analysis techniques used for each objective of the study have been outlined in the following table and elaborated below.

#### **3.14.1 Qualitative thematic analysis**

Qualitative thematic analysis consists of five steps. In the first step, the researcher reads through the transcripts and familiarizes oneself with the data. After the researcher has familiarized himself with the data, he carries out preliminary coding of the data which involves highlighting parts of the transcript that contribute to his understanding. This step is followed by generating themes on the basis of the coding process. The next step involves review and revision of the generated themes, many themes discovered in last step may be combined into one main theme while many other themes may be eliminated due to lack of substantial data. This step is followed by defining and naming themes. Finally, a narrative surrounding each theme is written by the researcher.

The data for the last objective of the study has been analyzed thematically based on the work of Braun and Clarke (2006). An inductive approach has been adopted to analyze data. Data has been experientially oriented and the theoretical perspective adopted has been a critical realist one (Braun & Clarke, 2012), to systematically examine Indian managers subjective accounts of their experiences with neurodiverse employees. Direct quotes from the participants were used in illustrating the themes that had been identified. Authors read and re-read the transcripts of interviews, which helped in observation of recurring themes in the data. A coding framework was developed and used to code the data. Finally, entire transcripts was read, observed and categorized in different themes and subthemes.

#### **3.14.2Reflexive thematic analysis**

Reflexive thematic analysis is a form of Qualitative thematic analysis. It involves the same core steps of familiarization with data, preliminary coding of data, generation of themes, reviewing and refining the themes, defining and naming themes and writing a narrative centred around each theme. However, in reflexive thematic analysis, the researchers perspective or vantage point assumes utmost importance while analysing the data.

In the study on workplace experiences of autistic individuals around stimming behaviors, reflexive thematic analysis approach was adopted. This was done keeping in mind that thematic analysis does not paint a 'real picture'. It is largely dependent on the coders active, reflexive creative process. For this reason, a reflection journal was maintained by researcher E.S to note down her thoughts throughout the coding process. . E.S took the help of an autistic autism rights advocate in India to deepen her understanding of the neurodiversity paradigm and also to clarify her assumptions on stimming behaviours. The knowledge gained was used in the development of the interview questionnaire.

#### 3.14.3Template analysis

Template Analysis is a kind of thematic analysis in which hierarchical coding is given utmost importance. Unlike qualitative thematic analysis, in template analysis a high degree of structure in the data analysis process is balanced with the flexibility of adapting it to the needs of a study. A coding template is developed on the basis of a subset of data, which is then applied to further data, revised and refined. This approach helps researcher maintain flexibility regarding the template format and unlike other thematic approaches to coding of data, it does not suggest a set sequence of coding levels in advance. In template analysis, the researcher is encouraged to develop themes where the richest data with respect to the research question is found. Additionally, Template Analysis does not distinguish between descriptive and interpretive themes, nor does it insist on adopting a particular position for each kind of theme used in the coding structure. In the present study , data from study on work from home experiences of autistic individuals in India was analysed using Template analysis. The steps adopted towards this end were as follows

**Step 1: Familiarization** In this step, the researchers read through the transcripts to get a feel of the data. Since our study was relatively large, the researchers selected a sub-set of the transcripts to start with.

**Step 2: Preliminary coding** This step is the same as used in most thematic approaches, wherein the researcher highlights anything in the text that adds to her understanding. In Template Analysis, it is slowed to start with a few a priori themes that have been identified in advance as likely to be relevant to the analysis. These themes are tentative, and can be removed later on if they are not considered useful for the analysis.

**Step 3 Organizing the themes** The emerging themes are organized into relevant clusters, and inter and intra group relations are established between them. This includes hierarchical relationships, wherein narrow themes are nestled within broader themes. It also includes lateral relationships across clusters. Themes which permeate different clusters are called "integrative themes".

**Step 4 Defining an initial coding template**. An initial version of the coding template is developed on the basis of a subset of data, rather than carrying out preliminary coding of all transcript before defining the thematic structure. In our study consisting of seventeen face-to-face interviews the researcher developed the initial coding template based on five interviews. The exact number of interviews appropriate to construct the initial template is dependent on the study and researchers judgement. Thus, the researcher should ideally select initial accounts to analyse that capture a diverse set of experiences.

**Step 5 Apply the initial template to further data and modify as necessary**. The researcher examines remaining transcripts and wherever relevant material is identified, the researcher tries to ascertain whether it can be fit into the existing template of a priori themes. Modification of the template may be done if new data doesn't fit existing themes. Existing themes maybe redefined or deleted if they are redundant. Several transcripts are worked through noting possible revisions to construct a new version of the template.

**Step 6 Finalizing the template and applying it to the full data set**. Although there is never one finished version of the template, the researcher takes a pragmatic decision when the template meets her needs for the research study keeping in mind the resources available. A template is considered insufficient if there are still substantial sections of data relevant to the research question that cannot been coded into it, in which case it warrants further revision.

TABLE 4:	Objective	wise data	analysis	techniques used	

Objectives	Data Analysis Technique used
RO1→ To study the workplace experiences of late diagnosed autistic women in India	Qualitative Thematic Analysis

<b>RO2</b> $\rightarrow$ To study neurodiverse individuals experiences around stimming	Reflexive thematic analysis
behaviors at the workplace and its importance as a workplace	
accommodations strategy.	
<b>RO3</b> $\rightarrow$ To study work from home experiences of neurodiverse	Template analysis
individuals during the Covid -19 pandemic in India.	
<b>RO4</b> $\rightarrow$ To study existing workplace accommodations at neurodiverse	Qualitative Thematic analysis
friendly organizations in India and determine the readiness level of	
managers in non neurodiverse friendly Indian organizations in adopting	
these accommodations.	

# CHAPTER 4

### RESULTS

#### 4.1 Introduction to data analysis and results.

This stage commences when researcher has completed data collection for the thesis and has applied analysis tools as per the research design. The present study was qualitative in nature wherein data was collected through semi structured interviews and focus group discussion and in this chapter the results obtained from analysing the aforementioned data are discussed.

The focus of this study was to ascertain employer and employee perspectives on workplace accommodations required to sustain a neurodivergent workforce in India. Within the purview of this larger objective, we explored the workplace accommodations required to sustain neurodivergent women, use of stimming behaviours by autistic individuals as a workplace accommodation strategy, working from home as a workplace accommodation strategy and non autistic Indian managers perceptions of autistic workers. This chapter includes the population Demographics for each objective of the study followed by excerpts from published and under review manuscripts as results of the the study objectives.

#### 4.2 Demographic information

The demographics of the sample includes information pertaining to the gender of employees, age of the employees, age of diagnosis, profession of the employees and industry employed in. The population demographics varied according to the objectives of the study and have been elaborated in the tables below.

Participant	Age at time of	AQ-10	Employment		
	interview				
P01	33	8	Quality Associate		
P02	32	9	Currently unemployed. Previously employed at an		
			NGO for autistic individuals.		
P03	26	8	Counselor at school		
P04	29	6	CSR Consultant		
P05	32	6	Freelance consultant inclusive education		
P06	30	7	Currently unemployed, previously employed in		
			geoinformatics		
P07		9	Control systems engineer		
P08	33	9	Freelance illustrator		
P09	28	9	Research assistant		
P10	24	7	Freelance journalist ,previously employed as		
			copywriter		

 Table 5 : Demographics of participants for study on stimming behaviors and work from

 home experiences of autistic individuals in India.

Participant	Gender	Age	Race	Official	Education	Job	Focus group or
		Ran		Diagnosis	level	Descriptio	interview(Online
		ge				n	unless stated
							otherwise)
P01	F	31-	South	yes	Masters	Special	Online Interview
		40	Asian			Educator	
P02	М	21-	South	yes	Masters	Technical	Online Interview
		30	Asian			analyst	
P03	М	21-	South	yes	Masters	Software	Online Interview
		30	Asian			Developer	
P04	М	21-	South	yes	Masters	Hotel	Online Interview
		30	Asian			manager	
P05	F	31-	South	yes	Bachelors	Freelance	Online interview
		40	Asian			illustrator	

P06	М	21- 30	South Asian	yes	Bachelors	Inclusion fellow	Online interview
P07	F	31- 40	South Asian	In process of receiving	Masters	Technical writer	Online Interview
P08	М	21- 30	South Asian	In process of receiving	Masters	Consultant	Interview(Instant messaging)
P09	F	21- 30	South Asian	In process of receiving	Masters	Journalist	Online interview
P10	F	21- 30	South Asian	In process of receiving	Bachelors	Co- founder	Online interview
P11	F	31- 40	South Asian	yes	Masters	Systems control engineer	Interview(Email)

P12	F	31- 40	South Asian	In process of receiving	Bachelors	Content writer	Online Interview
P13	М	31- 40	South Asian	yes	Bachelors	Consultant	Online interview
P14	М	41- 50	South Asian	yes	Doctorate	Assistant professor	Online interview
P15	F	21- 30	South Asian	yes	Masters	Research assistant	Online Interview
P16	М	21- 30	South Asian	Yes	Bachelors	Content Creator	Online focus group
P17	F	21- 30	South Asian	Yes	Bachelors	Content Creator	Online focus group
P18	F	21- 30	South Asian	Yes	Masters	Autism rights advocate	Online Focus group

P19	М	21- 30	South Asian	Yes	Bachelors	Teacher	Online group	focus
P20	М	21- 30	South Asian	Yes	Bachelors( pursuing)	Student	Online group	focus

# Table 5 : Demographics of non-autistic Indian managers

Participant	Industry	Work Experience(in years)
P01	Software	3
P02	Transportation	5
P03	Transportation	5
P04	FMCG	7
P05	Edtech startup	2
P06	Fitness Equipment	2
P07	Recruitment agency	3
P08	Chemical manufacturing	10
P09	Software	4
P10	Software	4

#### 4.3 Results of objective 1

As discussed, we conducted interviews of ten late diagnosed autistic women in India .We used Qualitiative Thematic Analysis to investigate the female autism phenotype and its manifestations in the workplace experiences of late diagnosed Autistic Indian women. Ten Indian women on the spectrum (between 21 to 35 years of age ) diagnosed in adulthood gave in-depth accounts of their workplace experiences, of difficulties faced while trying to fit in at the workplace and of how their gender made them uniquely vulnerable to certain problems at the workplace and of conflicts that exist between the female autism phenotype and maintaining a traditional feminine identity at the workplace. Experiences of autistic burnout, unemployment despite being highly qualified, social exclusion and sexual abuse at the workplace were abundant in this sample, partly reflecting on the unique challenges faced by autistic Indian women at the workpace. Themes identified from the study as well as pertinent snippets from the semi-structured interviews have been summarized below

#### Theme 1 "Pretending to be feminine"

This theme dealt with the manifestations of the female autism phenotype and how it conflicts with the traditional feminine identity and gender roles of Indian women. A majority of the women who were interviewed reported having a hard time fitting into their traditional gender roles as well as forming reciprocal relationships with non-autistic women colleagues.

#### Subtheme 1: Difficulty fitting in with own gender

The autistic women who were a part of this study reported finding male friendships easier to sustain than female friendships.

"I preferred the company of men because they were less competitive and more accepting of my differences" P05.

"I feel that I get along better with people of the opposite gender. Even when I try my hardest to blend in with my gender... I do not understand why. Before my Aspergers diagnosis, my partner and family would tell me that maybe other females were jealous of me because I was attractive and intelligent, and my stand-offish nature made me come across as arrogant."P09

However, it was difficult for some of them to gauge the true intentions behind the friendly behavior of male colleagues and the hostile behavior of female colleagues.

"I could sense jealousy from some of my female colleagues; however, my male colleagues often treated me nicely, sometimes overtly so, which was, I believe, often due to ulterior motives even if I appeared weird/different than others. However, most women colleagues were openly hostile towards me as they had nothing to gain from me."P09

For one of the women interviewed, the issue was not so much about the gender of the other person but about the individual traits of that person.

"There was no issue with the gender of the individual. Rather it was individual traits that were affecting our relationships." P06

#### Subtheme 2: Atypical interests and mannerisms

Although half the women interviewed had masculine interests growing up an equal number of women reported having mixed or stereotypically feminine interests. However, what differentiated them from neurotypical women was the intensity with which they followed these interests.

"I had more masculine interests. I had high energy. Would get into lots of fights. I used to paint on walls. I enjoyed sports a lot." P03

"Both loved dolls at the same time wanted to dismantle entire cassette recorder and fridge just to see how it works. Also loved Lego and solving maze puzzles" P07

"I mostly had masculine interests. Loved playing with robots, video games instead of dolls. However, as a teenager and a young adult, I liked dressing up and wanted to look pretty" P09

"I loved caring for children and animals. I hated the typical boyish games. But, I had a fetish for collecting odd things like broken pencil leads, shells of pistachios, broken bangles/ earrings, beads that fell off necklaces, diaries, bookmarks, snakeskin, and earrings" P05

#### Subtheme 3: autistic masking and its consequences for autistic women

autistic women learn to camouflage or mask their behavior at an early age in an attempt to fit in with their peers, gain acceptance from family, and avoid getting bullied for being different.

"(Between ages of)6-10: moved to Muscat. Played with dolls, was part of a group of girls. in retrospect, I was always trying to imitate the group leader and popular girl. Went along with shoplifting and bullying, trying to imitate the group leader, trying to fit in" P02

"I masked more than a boy. However not masking would have led to different kinds of problems. I would have been labeled a retard by my own family because of lack of awareness of ASD" P08.

Prolonged periods of masking tends to negatively impact the mental health of autistic women.

"Was an ideal student in school, but a difficult child at home. Not girly, more tomboyish. Lots of anxiety that I recognize in retrospect. Always not knowing what is expected of me, from teachers and peers. Felt intense pressure to be 'proper', as is expected. Very critical of self, low self-esteem, self-confidence, very confused." P02

"Since I have been masking since I was a child it was very hard for me to accept that I was autistic. I was depressed even as a child. I could never understand it. As I grew up my selfesteem eroded further. I went through 30 years of my life with low self-esteem. I wouldn't have been so harsh on myself if I knew that this is the best I can do." P08 "People don't understand the concept of masking. People are more accepting of violent meltdowns displayed by autistic men. Autistic women's meltdowns are termed as hormonal." P03

#### Subtheme 4: Pressure to conform to traditional gender identity

Nearly all of the autistic women who were interviewed reported facing immense pressure to conform to traditional gender identity failing which they were ridiculed or singled out.

"When you cut your hair in boys style, people will have different thoughts about you"P01

"If I was an autistic man, I wouldn't have so much pressure from family and friends to be more social or agreeable or likeable. What I wear wouldn't be an issue I guess. I'm comfort driven rather than fashion driven. "P02

The issue was not just restricted to their personal appearance but also included the way autistic women are expected to conduct themselves. They were expected to be more subservient to and not question any authority figures.

"Because you are a woman, you might be expected to behave according to certain norms. If I challenge authority being a woman, then I was questioned, which a man might not have been" P04.

"Being a woman, I was expected to shut up, be more tolerant, accept the status quo of a lower place than men etc. As one autistic woman had said, I wish I were a boy so I could break a few things. Then, at least, people would realize that I needed help."P05 "Me being honest and transparent is taken as a rude behavior, and many male egos at work gets hurt. People tend to take your suggestions lightly because you are a female engineer"P07

#### Theme 2: Workplace challenges unique to autistic women employees

#### Subtheme 1: Juggling home and work responsibilities

Autistic women struggled with managing home and work responsibilities.

"I find just the business of running my life so exhausting. Every day, I have to take care of my responsibilities at work and come back home to take care of my aging parents and pets...My stressful home environment tends to burn me out more than my work environment." P09

#### Subtheme 2: Social exclusion at the workplace

Because of their unconventional ways of doing and being, the autistic women who were interviewed reported facing difficulties socializing at the workplace.

"Majorly not being able to fit in at work. Not having work relationships that work at all" P03.

"I have an unconventional sense of humor. I also tend to do self-stimulatory behavior when I am anxious or stressed. Women colleagues tend to notice these things about me more than male colleagues. Maybe that is why they ostracize me from their groups. It is really lonely being an autistic woman sometimes" P09

#### Subtheme 3: Difficulties around menstrual cycle

Many autistic women found it difficult and sometimes impossible to work during their menstrual cycles.

"Emotional regulation is challenging, especially during PMS. Every month, one week of a very depressive phase, which negatively affects productivity and clarity, makes me inconsistent and less confident in myself "P02

"My boss thinks I'm being lazy when I call in sick two to three days a month because of my menstrual cycle. The truth is that I can barely function as a human being during those days of my monthly cycle, let alone go to work" P09

#### Subtheme 4: Dismissive attitude of management

Indian managers tend to stereotype autism based on depictions in popular media and ambiguous information available on websites. Since autism presents differently in women, any attempts made by autistic women to reveal their autism diagnosis and seek workplace accommodations were met with disbelief and dismissed by Indian managers.

"Maybe because they were comparing me to a stereotype that doesn't exist. Every support and accommodation I asked for felt like it was given as a favor. It has been a bad experience. I am not sure if I will disclose this in the future because autism awareness and understanding are poor in my country, and understanding of autistic women is lacking in the whole world. If I mention my autism in the future, and if I try to explain, I will be treated with disbelief. Moreover, if they look up information on the internet, they will find 'lack of empathy', 'rigid', 'emotionless', challenging behavior, and other misinformation or negative terms which will color how they know me or understand me. I think it will be better if they get to know me for who I am without any preconceived notion. I'm not sure what I will do at my next workplace, if and when I find something. "P02

"Divulged and got into trouble and then got branded as a sympathy seeker(because they were clear, I was just a troublemaker and had no issues. Finally got terminated" P05.

"It's a hidden issue unlike Darwinism or physical disability so people are dismissive about it which should change. when I had a bandage on my hand many were willing to help me but otherwise if you had a fever or hidden issue like autism, they were not accommodating" P06

#### Theme 3: Pretending to be normal

This theme includes challenges faced by autistic workers while trying to fit in and work in a predominantly neurotypical setting.

#### Sub-theme 1: Difficulty dealing with workplace politics

Workplace politics was described as a phenomenon that was difficult to cope with, toxic, unnecessary, a precursor to bullying, and a necessary evil.

"Find workplace politics very difficult to cope with" P02

"Politics is hard, toxic, unnecessary, mindless, and a big distraction from work. Everything is hard about it: communication, the structure, the timing, the people, the expectations, etc. I have developed trauma because of it" P05

"Workplace politics, for me, has been a vicious form of bullying and isolation. It makes my bullies happy while taking away my mental peace and ability to be productive at work" P09.

#### Sub-theme 2: Sensory overload and autistic burnout.

Almost all the women interviewed reported experiencing varying levels of sensory overload brought on by crowded spaces, bright lights, and noisy open-plan offices.

"I like to work in ambient, low lighting, but most workplaces have really bright light, and I am very sensitive to light such that I hate facing bright light and look away from people if they are talking to me under bright lighting. It almost looks like I am ignoring them. "P09

"Sensory overload at work comes in the form of noise. I require body pressure-stimming to relieve it" P03

When faced with prolonged sensory overload, eight autistic women reported experiencing autistic burnout. Three of the women were between jobs or had had to resign because of burnout at the workplace.

"I am unemployed because of burnout" P06.

#### Subtheme 3: Communication difficulties

Autistic women interviewed reported being more direct in their communication style than their non-autistic peers, facing difficulties in oral communication as opposed to written communication, and an inability to understand innuendos and metaphorical language.

"I find communication extremely difficult – it makes me feel stupid. I have to make a lot of presentations in my profession, so I have acclimatized myself to giving presentations by preparing myself thoroughly well in advance. Yet, I still find it very difficult to answer questions thrown at me at the moment. It is very difficult for me to avoid circumlocution around the main point. It often makes me feel stupid and like i should not be here." P09

"The first step is to try to solve the double empathy problem. They need to be translated more than we need to be; it's a two-way process, with more effort from neurotypicals, because they are the majority and they are the ones who don't mean what they say or say what they mean, making communication all the more difficult for us."P02

#### 4.4 Results of Objective 2

As mentioned above, 15 autistic individuals took part in a semi structured interview to recount their experiences around stimming behaviours at the workplace. An additional 5 participants took part in a focus group discussion aspect of this study. The purpose of this study was to critically examine autistic stimming through the lens of Indian autistic individuals who are employed in a work environment dominated by neurotypicals and also to evaluate the social and cultural confines imposed upon Indian autistic employees by neurotypical managers, colleagues and society at large and integrate autistic thought leaders opinions about striving for inclusion (Gernsbacher, 2017; Milton, 2012). The study focussed on Indian autistic employees experiences while stimming at

their workplace and other public places to provide fresh insight into a hitherto under researched aspect of the lived experiences of autistic individuals in India.Data collected through interviews and focus group discussions with autistic Indian professionals helped shed light on their need to stim and the associated social stigma. Most autistic individuals reported similar experiences with regards to stimming behaviors at the workplace. The reflexivity statement and thematic analysis results excerpted from published manuscripts have been summarized below.

# 4.4.1Reflexivity statement paraphrased from published research paper on Workplace experiences of Indian autistic individuals centred around their stimming behaviors:

The coding process was primarily done by first author E.S. This is an acceptable practice(Braun,2005;Braun & Clarke,2006b;Clarke,2005)based on the premise that thematic analysis does not paint a 'real picture'It is largely dependent on the coders active, reflexive creative process. For this reason, a reflection journal was maintained by researcher E.S to note down her thoughts throughout the coding process. Further, Interpretation of two way communication as posited in the continuous process model of communication.(Stamp & Knapp 1990, Fogel 1993) is largely influenced by the knowledge and assumptions of the participants( Sperber & Wilson, 1995)

E.S' understanding of her close friends stims and awareness of the years of judgement and ridicule faced by her close friend for stimming at the workplace and in public spaces compelled her to undertake this research. However, in the absence of awareness on this topic and stigma associated with stimming behaviours, E.S. found it difficult to justify to her non autistic supervisors ((S.N.K )and (N.G) who are the second and third authors of this research) as to why this topic was worthy of research.

E.S took on the role of principal investigator for this this study so as to allow the autistic individuals who were interviewed to feel at ease while sharing their experiences around stimming behaviours. E.S found certain interviews to be extremely emotionally charged and draining for the participants as they brought up childhood memories of being bullied while stimming for them. Such interviews took more than the stipulated time to complete as some parts of the interview had to be postponed to the next day to give both the study participant time to regain emotional composure. E.S felt anger at the unjust retribution faced by study participants and compassion at all the poignant memories shared by interview participants regarding their stimming behaviours. She also felt a sense of poetic justice in getting to highlight this pertinent issue through her research work. E.S. took the help of an autistic autism rights advocate in India to deepen her understanding of the neurodiversity paradigm and also to clarify her assumptions on stimming behaviours. The knowledge gained was used in the development of the interview questionnaire. When certain participants were being interviewed ,they had trouble finding the right words to describe their feeling regarding stimming as English is not their primary language. The author of the study gave them space to describe their experiences using whatever English word they felt was the most appropriate in the context despite the grammatical inaccuracy of their sentences.

Lastly, the second author (S.N.K) and third author (N.G) are non-autistic and do not have any background in autism research. They offered their insights during the data analysis stage of the study. This helped E.S in gaining a more holistic perspective of the data. Further, to avoid bias, the non-autistic co-authors (S.N.K and N.G) took notes on all preconceived notions about the study population in order to bracket these notions during data analysis (Lincoln & Guba,1985)

#### 4.4.2 Results of reflective thematic analysis

Interview participants were initially asked to give in depth accounts of their workplace experiences centred around stimming behaviours displayed by them at their workplaces. Their experiences were further reaffirmed through focus group discussions. Additionally, participants of the study discussed the bodily movements that comprised stimming for them and how stimming impacted their lives. Participants described their stims as being a set of repetitive movements like rocking, shaking their legs etc. Most of these movements were carried out subconsciously. A few participants also described stimming with the use of props like their own hair, pens, ropes etc..Three main themes emerged from the data Theme 1 Stimming as a (beneficial)coping mechanism , Theme 2 Repercussions of suppressing stims for autistic employees and Theme 3 (De)Stigmatization of stimming at the workplace. Each of these themes comprised of several subthemes.

#### Theme (1): Stimming as a (beneficial) coping mechanism.

Participants described stimming as a repetitive, rhythmic bodily movement like rocking, hand flapping, twiddling the fingers, shaking the legs, playing with pens, pulling hair etc. It could also include vocalization like grunting

Most participants said that they had no conscious or voluntary control over their stims, especially at the beginning of their stimming movement. Most participants said that they derived certain benefits from their stimming. Stimming helped calm them down and regulate their overwhelming emotions. Our analysis yielded four major subthemes, including reduction in stress caused by sensory overload, emotional regulation, improved mental clarity and improved productivity. All these themes are interrelated: stimming has been described as having a calming effect on the autistic employees, this greatly helped them deal with the workplace stress caused by sensory overload and in regulating their emotions, which helped them achieve mental clarity that ultimately translated into improved focus and productivity at work. Sensory overload was mainly caused by a noisy, overwhelming work environment and or intrusive thoughts. A thematic framework of this process is shown in Figure 1.

#### Sub theme (1): Reduction in stress caused by sensory overload.

Most participants reported stimming as being beneficial in reducing the stress caused by working in a work environment that was too jarring for their senses, the demands placed on them by their managers and colleagues, difficult tasks at work and intrusive thoughts. Stimming has been reported as having a calming effect that helped take the edge of the stressful situation.

'When I'm thinking, thinking deeply. At home ...I rock myself to sleep everytime. When I'm nervous, anxious. I stim when I'm happy...Yes..a lot. Extreme anger or helplessness also trigger me to stim.'P01

#### Sub theme (2): Emotional regulation.

Most participants described stimming as being extremely beneficial to regulate the intensity of their emotions. Most participants reported stimming being beneficial in calming a state of hyper arousal caused by extremes of positive emotions like happiness or excitement or negative emotions like anxiety or anger.

'In a hyper state I stim, Even in happiness I stim. Extremes of emotion cause me to stim.'P02

As P02 explained, thus, although stimming has been described as being instinctual yet, it could also serve as an outlet for pent up emotions and thus help with emotional regulation.

#### Sub theme (3) and (4): Improved mental clarity and productivity:

Participants who were able to stim regularly at work reported having better focus and mental clarity to deal with difficult tasks or situations at work. Stimming helped put them in a "flow state" as described by Participant 15.

' My stims really help me de clutter my mind of my thoughts as well as tone down the sensory overload caused by external stimuli. This helps me free up a ton of mental space which I can then use to attempt difficult or challenging tasks. ...I am basically able to go into a "flow state", a trance like state wherein I am able to use my ability to hyper focus to maximize my productivity.'

#### Theme (2): Repercussions of suppressing stims for autistic employees

Study participants reported a host of issues that cropped up when they were not allowed to stim freely by virtue of their work environment or judgmental colleagues. The subthemes identified include ; Impact of stim suppression on mental health, impact of stim suppression on productivity and impact of stim suppression on stress levels. Most participants reported an experience of a sharp decline in their productivity, an increase in their overall stress levels . A few participants also reported suffering from autistic burnout in the absence of stimming which served as a mechanism to self soothe or actively manage their stress levels.

#### Sub theme (1): Impact of stim suppression on mental health

Participants reported a dip in their mental health when they were forced to suppress their stims due to pressure from society or colleagues. This made many participants feel anxious or depressed.

'Supressing my stims would make me confused, frustrated, overwhelmed, overloaded. ...like I'm imagining a thousand cars coming and hitting me at once and I don't have any control...like, I can't even step away... I'm tied to one place and thousand cars are coming and hitting me.'P01

'Actually, I can't really comment on it as far as work is concerned....but, right from my school days I know that ....like when I was very young I used to hum a lot. At some point I stopped humming and I realized that anytime I stopped my stim, it really affected my mental health negatively. ...Like, when I stopped singing/humming, I got more depressed. The cloth rubbing, when someone pointed it out to me, I felt that they must be pointing it out to me because it must be odd. So, I stopped doing that as well for a period of time. I had used that stim to help lull me to sleep, so when I stopped doing that stim, I couldn't sleep. So ,that added to my anxiety and depression. So yeah...it makes me depressed if I can't stim for a long period of time. 'P05

#### Sub theme (2): Impact of stim suppression on productivity

Participants reported a dip in productivity levels when they were forced to suppress their stims in the company of their colleagues. They could not focus on the task at hand and felt slowed down as far as their mentally processing faculties are concerned.

'This is what used to happen at work, like I was put in staff rooms and there were people around me. Only about once in my life I had a room to myself so I wouldn't be able to stim. I would become very slow in understanding. This has been my habit...like, my parents and even my husband used to say ...that you don't do all the work at the office, instead we've seen you coming home and doing the work. Why am I coming home and doing all the work ? because ...I just lock myself in a room, there is silence...I can just say don't disturb me ...I can control the sensory environment, I can stim when I'm thinking ...so I was always doing the work at home. 'P01 'it agitates me and doesn't allow me to focus at my best'P08

'I would be more agitated, more irritated. It would affect the focus ...there'll be not so much focus on work' P02

Sub theme (3): Impact of stim suppression on stress levels.

Most participants reported feeling extremely stressed if they were not allowed to stim freely.

'That's gonna be very stressful. Like if I have a nerve that's creating problem on my forehead and I can't really touch that then its not gonna go away on its own. Its like an itch. I wont be able to work because I can't focus on the work ...I'll be focusing on the itch thing ...whatever. Mental health goes down...stress levels go up'P07

#### Theme (3): (De)Stigmatizing stimming at the Indian workplace.

This theme consists of four major sub themes (1) Negative reactions from colleagues and managers towards stimming behaviors of autistic employees (2) Autistic employees internalization of negative reactions(3)Fear of repercussion (4) ways to promote acceptance of stimming behaviors at the workplace. Participants felt a range of emotions when told not to stim including embarrasment, resentment, anger, and belittlement. Participants felt that colleagues and managers felt irritated or alarmed by their stim viewed their behavior as strange, unprofessional and childish. This led to them stimming in private or avoiding stimming in the company of their colleagues or managers so as to be spared the ridicule.

Sub theme (1): Negative reactions from colleagues and managers towards stimming behaviors of autistic employees

Elaborating on this subtheme, Participant 1 stated 'Only once at my previous workplace I discussed with a colleague...she initially tried to be understanding but later on told that if you continue acting this way then how will people perceive you? You already get bullied, they target you...on top of them, if you do this, they'll think you are being unprofessional. So, just control yourself for a while and do it when you are alone. So, that was an issue. I discussed it with my school coordinator. At the same place where I had this colleague... she told me that yeah, I understand but you are an adult, you can't behave like all those children you know, so I had to say yes ma'am, okay ma'am... it was like, you can't do this, you can't be this way, this is not professional conduct...I don't know what the hell professional means. I wish they'd just let us be.'

Since, the data for this study has been collected during covid 19 induced lockdown, wherein many companies had a work from home mandate in place, a few participants expressed relief at the opportunity to stim freely that working from home had given them.

'Nowadays its work from home, so I'm very happy that I can do things with my hands and legs and they can only see my face. Most of my stims are with my thighs and my hips and I keep on doing that.'P01

Alternatively, some participants like P15 tried to conceal their stims from view. Repression of stimming arose primarily from a desire to fit in and be accepted by their non autistic colleagues.

'The best part about Covid-19 is the mask mandate, I am able to chew on my lip freely under the mask ...this makes me really happy and I no longer have to repress my stims in order to fit in with my non autistic colleagues.'P15

#### Subtheme (2): autistic employees internalization of negative reactions

Most participants did not receive acceptance from their close friends and family and colleagues for their stimming behaviors as seen in the views expressed by P15. Thus, they preferred to stim freely in absolute privacy

'One of my most prominent stims is chewing on my lips ...when I was a child, my parents used to reprimand me a lot for this stim...they put red chilli paste on my lips to avoid me from chewing it. There was no acceptance ...in hindsight, I feel they were only doing it as a misguided attempt at making me correct my "abnormal behaviour", so I learnt not to do it in the company of my friends or in public so as to avoid being labelled mad or crazy. 'P15

'Yeah before ....(when I was )working in a Non autistic workplace if I stimmed in front of people ...(they) could not understand the stim, they look at you ...like, they stare at you and see why would you be doing that or they even if I'm wearing the ...the prop then they'd be like why is he wearing this but they give you those looks'P06

Sub theme (3): Fear of repercussions

A few participants like P09 and P11 expressed reluctance in telling their non autistic managers about their stims for fear of repercussions.

Participant 9 stated 'I'm not ever going to bring this thing up with any of my managers because from my experience Indian companies are not very accommodating of mental illnesses in general. Mental illness or I mean neurodivergence is I think pretty ..like... far fetched right now. I don't think like people here in india are very well aware of this thing so I would prefer not to bring it up and because I think its just gonna be disadvantageous for me . like they are gonna under estimate me or something. So I'm not gonna bring up autism or stimming with my managers in future. Colleagues ... if they are my friends I probably will. But I'm not sure, I'm not comfortable telling people about this thing. People who are not very close with me.'

'I have not shared it with my colleagues because of fear of judgement. I fear I would be considered somewhat lesser of an employee and more of a burden and that I might get fired'P11

In depth interviews with 15 participants and further group discussions with 5 new participants revealed a host of ways in which Indian managers and colleagues of autistic employees can be made more open and accepting of stims

Ways to promote acceptance of stimming behaviors at the workplace.

Most participants opined that creating awareness about Autism Spectrum Disorders in Indian workplaces would go a long way towards making stimming acceptable in the context of an Indian organization

'Yeah sensitivity training exercises will definitely help. You know if somebody has a difficult thing to conquer like if they make a noise(like in Tourettes syndrome) and it causes trouble to the other person then it definitely helps. So the other person atleast understands why the person is doing this and they can probably ask you know for a change of seat or something like that. 'P07

'Organizations need to work hard to make employees feel at ease in sharing their diagnosis. This can be done by giving seminars to the Non autistic employees so that they can somewhat understand and relate to Neurodivergent employees'P11

'More awareness probably, but it's harder to make the autistic person feel comfortable stimming in public more than it is to convince people its normal'P08 The participants of this study have been divided over the efficacy of other workplace accommodations suggested in the question prompts like Open communication with managers on the stimming behaviors, providing designated spaces to stim and providing stimming breaks to autistic employees.

'Providing designated spaces for autistic employees to stim freely-no, no no, lets not do that ...because in my school they had something like this and it actually stigmatizes them much more. Rather than...its like a special class which they have created for those guys. so integrate these people within the non autistic population, that's fine. but make the non autistics understand that these people are behaving like this because they have a condition...and this is how they are gonna behave and if you guys can adjust that's gonna be even better. If you have a problem then you speak to either that person or somebody else and you can you know find a solution , common solution on that topic and that's it.'P07

'Providing stimming breaks.-not really cause you never know when you may need to stim or whatever. Like you've just taken a break and you suddenly need one more. Then your productivity may be affected. So just integrate this within your work.'P07

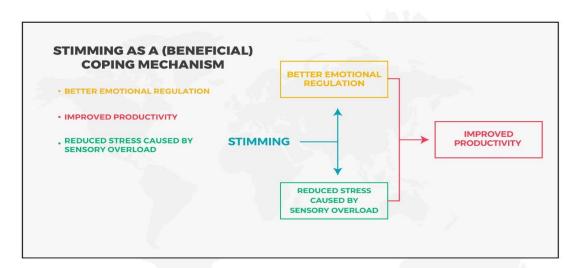
On the other hand some participants like P09 felt that providing workplace accommodations like a designated room to stim in would be more helpful to Autistic employees

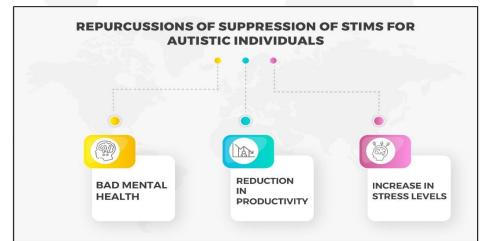
P0 9 stated 'I just think that having a space for yourself would be better because I think even if I tell my manager that I have this thing that I do which you know is because of my autism and makes me feel better, helps me think better. When I sit their and I do it I'm still gonna be the odd one out like nobody else is gonna be doing that . now that it is out in the open it just makes you feel more different or just like the odd one out . I think probably would add even more pressure to not do it.

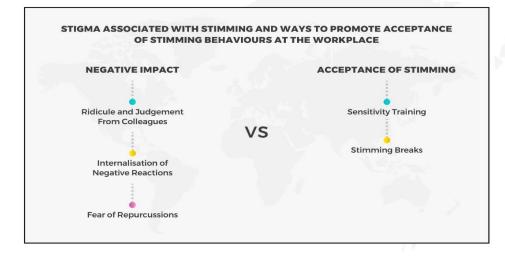
*I just prefer having my own space where nobody is looking at me*, *I'm not being watched and I can do whatever I want to do.'* 

'I like cubicle office space for this reason, as opposed to the open floor plan ones because we have our own private space in cubicles.'P10

## FIGURE 1: RESULTS OF THEMATIC ANALYSIS







Additionally data collected through interviews and Focus group discussions was used to formulate The evolution of autistic individuals experiences around stimming behaviours framework the various stages of which are elaborated below.

#### Stage 1: The authentic autistic self

The autistic child enjoys stimming in an authentically autistic way. He or she is not aware of any differences between himself/herself and other children and enjoys stimming openly.

#### **Stage 2: Encountering the other**

The autistic individual encounters neurotypical or non autistic individuals and feels alienated. He or she faces bullying for stimming openly. This affects their self esteem as they become acutely aware of the difference between their behavior and that of neurotypical individuals. The autistic individual blames him/herself for lack of acceptance by neurotypicals. This has the potential to make him/her depressed and anxious.

#### **Stage 3: Donning a mask**

The autistic person internalizes the rejection and makes efforts to fit in with his neurotypical peers. He or she does so by suppressing their stims as stimming behavior is not accepted by neurotypical colleagues. This process leaves the autistic individual exhausted and traumatized

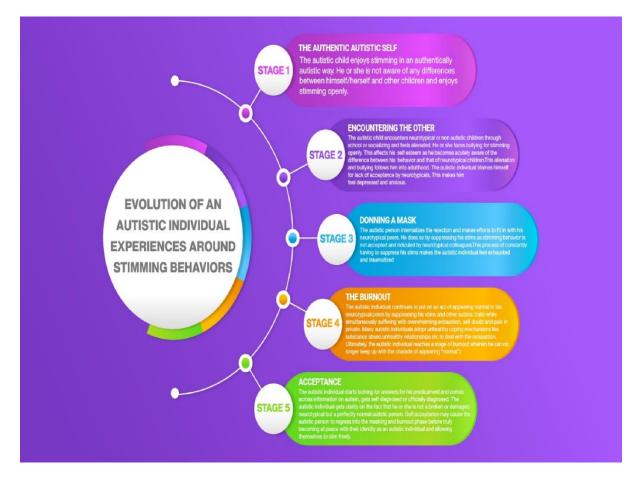
#### **Stage 4: The Burnout**

The autistic individual continues to put on an act of appearing normal to his neurotypical peers by suppressing their stims and other autistic traits while simultaneously suffering with overwhelming exhaustion, self doubt and pain in private. Many autistic individuals adopt unhealthy coping mechanisms like substance abuse, unhealthy relationships etc to deal with the exhaustion.

#### **Stage 5: Acceptance**

The autistic individual comes across information on autism, gets self diagnosed or officially diagnosed. The autistic individual gets clarity on the fact that he or she is not a broken or damaged neurotypical but a perfectly normal autistic person. Self acceptance may cause the autistic person to regress into the masking and burnout phase before truly becoming at peace with their identity as an autistic individual.

# FIGURE 2: EVOLUTION OF AN AUTISTIC INDIVIDUALS EXPERIENCES AROUND STIMMING BEHAVIOURS.



#### 4.5 Results of Objective 3

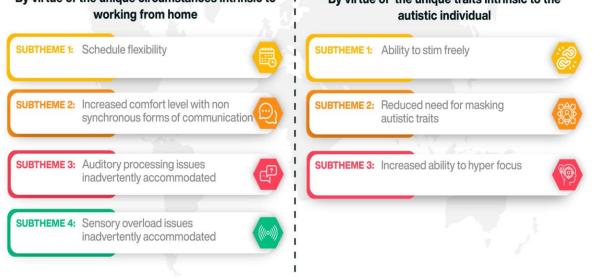
As discussed above, a total of 17 late diagnosed autistic adults (9 males, 8 females), between the ages of 21 and 50 years, participated in the in depth interviews related to their work from home experiences during Covid-19 pandemic in India. Recruitment took place in Delhi , Bombay and Hyderabad. Preliminary analysis of data revealed four Major themes The first theme W.F.H a blessing in disguise included situations intrinsic to the Work from home mandate as well as traits unique to the autistic individual. The second theme included ways to make working from home

more inclusive for autistic employees. The third theme dealt with working from home as an anomalous challenging situation for autistic employees and the Final theme dealt with future outlook of autistic employees on Working from home.

FIGURE 3: INITIAL TEMPLATES GENERATED USING TEMPLATE ANALYSIS

FIGURE 3a: Working from home during pandemic as a blessing in disguise

### WORKING FROM HOME DURING PANDEMIC AS A BLESSING IN DISGUISE By virtue of the unique circumstances intrinsic to i By virtue of the unique traits intrinsic to the



### MAKING WORKING FROM HOME INCLUSIVE FOR AUTISTIC EMPLOYEES



Figure 3c: Working from home during pandemic as an anomalous challenging situation for

autistic employees

WORKING FROM HOME DURING PANDEMIC AS AN ANOMALOUS CHALLENGING SITUATION FOR AUTISTIC EMPLOYEES



## FUTURE OUTLOOK OF AUTISTIC EMPLOYEES ON WORKING FROM HOME



#### 4.6 Results of objective 4

Two main themes were identified from the semi-structured interview data. 1) Neurodiversity awareness among Indian managers , dealt with Indian managers perception of and (lack of)awareness of Neurodivergence as a phenomenon in human beings. Subthemes included a)Indian managers attitude towards ASD and other neurodivergent conditions b)Indian managers perceptions regarding competence of neurodiverse employees 2) Readiness to employ autistic talent dealt with Indian managers willingness to employ neurodiverse talent. Subthemes included a) reasonable workplace accommodations b)Legal aspect of employing neurodiverse individuals c)Fear of ridicule d)Resistance from neurotypical employees.

#### Theme 1: Neurodiversity awareness among Indian managers

Majority of Indian managers interviewed reportedhaving little to no awareness about the term neurodiverse, although when they were illuminated about its link with autism spectrum disorders, ADHD and dyslexia quite a few of them reported being aware of it. However, awareness of neurodiversity was still only limited to examples of neurodivergent individuals depicted in mainstream Indian cinema.

Subtheme 1: Little awareness and unfavourable attitude

"Oh you mean someone like Ishann Awasthi in Taare Zameen par... I do know a few people who have children like that. I imagine it would be quite tough to bring them up. I wouldn"t wish such an experience on my worst enemy" P07

"India is no country for the disabled. Resources are few, population density is too much." P02

#### Subtheme 2: Apprehension regarding competence of neurodiverse employees

The interviewers made the managers aware of the unique strengths and talents of neurodiverse individuals yet they still expressed disbelief at the competence of neurodiverse employees. *"Well you say they"re great at software testing ...I"d still have my doubts about their abilities until I get to see it for myself" P01* 

P02 who was a manager in a software company revealed that he had met a few employee who fit the definition of ASD and while he acknowledged that they were skilled at their jobs, he expressed apprehensions about their ability to be team players and fit in with their neurotypical colleagues.

"Yeah I have a guy like that in my team...pretty brilliant chap ...spots bugs in codes that would go unnoticed by others, yet he is quite eccentric, not very sociable, always twiddling his thumbs or playing with his shirt buttons. Not very presentable too, definitely not a team player. I don''t see him moving up the ladder anytime soon"P02

"My nephew is mentally disabled or autistic ... whatever you call it. While he is good at numbers and as much as I would like to help him and other kids like him, we simply don"t have the requisite resources or awareness at this point to employ them with other "normal" employees. "P05

#### Theme 2: Apprehension regarding employee-organization fit

#### Subtheme 1: Reasonable workplace accommodations

This subtheme dealt with Indian manager"s readiness to provide workplace accommodations to neurodiverse employees. The employers were ready to provide workplace accommodations to neurodiverse workers as long as it did not involve commitment of extra resources and did not disturb the existing status quo in the organization.

"Allowing him (neurodiverse employee) to work from home some days of the week is possible..can be done but we simply don"t have the infrastructure to give him a separate corner office...besides this might infuriate other employees who might see this as preferential treatment" P01

#### Subtheme 2: Legal aspect of employing neurodiverse individuals

All managers interviewed stated being aware of the persons with disability act in India but only a few were aware of the intricacies of the act. They further expressed apprehensions in employing neurodiverse talent for fear of any legal repercussions.

"Well...as much as I would like to employ a person like that ...I fear not being able to provide him the environment in which he can thrive and then...what if he complains against me or the company...it could become a human rights issue and taint our image"P08

#### Subtheme 3: Fear of ridicule

Owing to the deep stigma associated with autism and other mental disorders in India , managers expressed concern over being the subject of ridicule for employing autistic talent.

"My friends would definitely laugh at me behind my back...they might say stuff like...couldn"t you get anyone better to do the job" P10

"It might make our organization seem incompetent...we are answerable to our stakeholders...employing them seems good from CSR perspective ...but we have to meet our targets at the end of the day, we can"t risk facing embarrassment because of them" P08

Subtheme 4: Fear of resistance from neurotypical employees

Indian managers expressed apprehensions over neurodiverse individual"s ability to blend into the company culture and bond with their neurotypical peers.

"Well like I said...we can"t give preferential treatment to some employs...especially when they look "normal" on the surface. Other employees may not understand ...they would face problems fitting in with the team"P01

"He might get covertly bullied or boycotted by his colleagues ...we won"t be able to help him in such a situation" P06

#### **CHAPTER 5**

#### **CONCLUSION AND DISCUSSION**

#### 5.1 Conclusion

The study aimed at exploring employer and employee perspectives on workplace accommodations required to sustain a neurodiverse workforce in India. In depth interviews covered four different aspects of the study namely neurotypical employer perspectives on employing neurodivergent talent, perspectives of late diagnosed autistic women employees, Stimming as a low cost high efficacy workplace accommodations strategy and finally work from home experiences as an accommodation strategy. The results exhibited that autism awareness is lacking in neurotypical Indian managers, nevertheless, they are willing to provide low cost workplace accommodations like Noise cancellation earphones etc to neurodivergent employees to an extent that their current organizational set up doesn't get upturned. Further, Neurodivergent women have to contend with certain unique challenges that accrue to them by virtue of their gender. This includes being expected to fit into traditional gender roles, expected to shoulder the responsibility of both home and office single handedly. Also, they are vulnerable to sexual abuse and exploitation at the workplace because of failure to understand social cues. Additionally, since they are better able to mask or camouflage their autistic traits they are more likely to be denied workplace accommodations as they are not considered autistic enough, this makes them more susceptible to facing autistic burnout and meltdowns at workplace. In the study on stimming behaviours of autistic employees, it has been found that autistic individuals have very little volitional control

over their stims and the energy it takes them to suppress their stims adversely affects their mental health and productivity levels at the workplace. Lastly ,in the study on work from home experiences of autistic individuals , the overarching theme has been one of optimism to the possibility of working from home as it automatically eliminated many challenges that neurodivergent employees face in neurotypical work environments like sensory overload issues, unspoken rules of social conduct etc. Given the opportunity most autistic individuals will prefer to work from home or in a hybrid work setup for life.

#### 5.2 Practical implications of the study

# 5.2.1 Practical implications of the study on workplace experiences of late-diagnosed autistic women in India

#### Strategies to minimize discomfort for autistic women employees

The study results showed that women struggle with maintaining a traditionally feminine identity at the workplace. For those Indian workplaces where the personal appearance of the employee does not form an integral part of their jobs, autistic women employees should be given leeway to dress and behave in a manner that prioritizes their comfort.

#### Strategies to prevent autistic burnout among autistic women employees

Introduction of the provision of period leave for the entire duration of an autistic woman's menstrual cycle to help them tide over a physically and emotionally draining period in their lives.

Introduction of 32 hour or four day work week for autistic women employees

The study also revealed that autistic women often feel overburdened with handling the responsibility of home and office simultaneously. Thus, facilities like crèches, time and place flexibility, work-from-home, preference in accommodation near the office, etc., may be ensured for autistic women to help them prevent autistic burnout at work, which would go a long way in improving their productivity.

### 5.2.2 Practical implications of the study on stimming behaviors of autistic employees in Indian organizations

The study on stimming behaviours showed that allowing an autistic individual to stim freely at work would not only help alleviate his stress but also help him become more productive at work. In those Indian workplaces where workplace environmental accommodations do not exist to reduce sensory overload on autistic employees, the management and colleagues must accept stimming as an autistic individuals attempt at venting their overwhelming emotions brought on by sensory overload. Allowing an autistic individual to stim freely at work would not only help alleviate his stress but also help him become more productive at work. Thus , Indian managers and colleagues of autistic employees should accept and encourage it instead of ridiculing and judging it.

### 5.2.3 Practical implications of study on Work from home experiences of autistic individuals in India

The study called for flexibility alignment according to the needs, strength and motivation of the autistic employees

- A major benefit of working from home for autistic individuals has been that it gave them the freedom to reveal or conceal their autism diagnosis with their non-autistic colleagues. This in turn aided them to avoid being stigmatized by their non-autistic colleagues.
- Schedule flexibility allows employees to adjust their working hours to fit their needs. For example, autistic employees may need to begin their days later to avoid mass transit during rush hour.
- Place flexibility gives employees the choice to work from home, from a satellite office or coworking space, or from anywhere. This benefits autistic employees who struggle with commuting or need a quiet environment to concentrate and supports many other needs.
- Mode flexibility enables employees to work in their most effective mode, whether that is in person, virtually, or in a hybrid model with various ratios of time spent in particular places. For example, an autistic employee with social anxiety might be best accommodated by mostly online work and meetings. Other employees may need inperson work or hybrid environments with a substantial share of in-person work to optimize structure, stimulation, and motivation.
- Continuity flexibility allows employees to take a leave of absence. Most countries provide paid maternity leaves, and paternity leaves are becoming increasingly common. But other types of extended time off such as sabbaticals and leaves for mental health,

caregiving, illness, or education — are also valued by employees. Germany, for example, has a provision for burnout recovery leave that can last several months. Offering continuity flexibility as a proactive measure rather than a reactive last resort for stressedout workers can enhance employee well-being and increase organizational engagement.

Workload flexibility refers to the ability to work full time, part time, or to job share, typically with another part-time employee. This can give people who can't work a traditional full-time schedule due to disabilities the opportunity to be employed. Workload flexibility is possible across all types of occupations and, combined with continuity flexibility, can accommodate a wide range of employee needs.

## 5.2.4 Practical implications of study on Indian managers perspective on employing autistic individuals

Indian managers and employees must be made aware of neurodiversity through organization wide initiative like seminars. Team building and sensitivity training exercises must be performed to encourage empathy towards neurodiverse individuals.

#### 5.3 Policy implications of the study

In the existing RPWD Act, 2016, the list of disabilities has been expanded from 7 to 21 conditions and it now also includes cerebral palsy, dwarfism, muscular dystrophy, acid attack victims, hard of hearing, speech and language disability, specific learning disabilities, autism spectrum disorders, chronic neurological disorders such as multiple sclerosis and Parkinson's disease, blood disorders such as haemophilia, thalassemia, and sickle cell anaemia, and multiple disabilities. The nomenclature mental retardation is replaced by intellectual disability which is defined as "a condition characterized by significant limitation both in intellectual functioning (reasoning, learning, problem-solving) and in adaptive behavior which covers a range of every day social and practical skills including specific learning disabilities and autism spectrum disorders." The Act provides an elaborate definition of mental illness which is "a substantial disorder of thinking, mood, perception, orientation, or memory that grossly impairs judgment, behavior, and capacity to recognize reality or ability to meet the ordinary demands of life but does not include retardation which is a condition of arrested or incomplete development of mind of a person, especially characterized by subnormality of intelligence."

The existing RPWD Act is silent on the needs of non intellectually disabled, late-diagnosed autistic individuals and those autistic individuals who fall in the gifted range of the I.Q spectrum and have low or minimal support needs. Policy initiatives/statutory guidelines should be geared to include such kind of individuals.

Additionally, all government and state level bodies that formulate laws governing autistic individuals should have participation of autistic individuals and their families.

#### 5.3 Recommendations to the industry

- Psychological support for autistic employees working in neurotypical work settings in form of psychologists trained to deal with autistic individuals.
- Nutritional support for autistic women employees in form of dietiticians and meal delivery services

- Physical activity for autistic individuals to help them socialize with autistic peers and improve their physical health which in turn would impact their productivity
- Buddy mentors to help autistic employees socialize with non-autistic employees
- Implementation of Prevention of Sexual Harrasment Act, 2013 at the workplace to safeguard autistic women employees against workplace sexual harassment.

#### 5.4 Limitations of the study

#### 5.4.1 Limitations of study on late-diagnosed autistic women

The study was limited to late-diagnosed autistic women who did not have any intellectual disability ,were verbal and were biologically female. Additionally, data for the study could only be collected from the four major metropolitan cities of Delhi, Bombay , Hyderabad and Chennai due to time and outreach constraints. Lastly, all the study participants held a minimum qualification of a graduate degree. This lead to an exclusion of the views of those late diagnosed autistic Indian women who may not be highly educated.

#### 5.4.2 Limitations of the study on stimming behaviours

The study was limited to those autistic individuals who were comfortable completing the online interview in English, who had a social media presence and self- identified as being on the autism spectrum. Thus, the study results may not be generalized to Indian autistic adults who do not have a social media presence and are not fluent in English. Additionally, while the use of varied channels of online interviews like Instant messaging, Zoom calls and emails allowed us to have a wider reach , the interviews conducted via Email and Instant messaging were less detailed and did not

allow us to gauge the emotional state of the interviewees. Another major limitation of our study is that it did not include participants who are intellectually disabled or non verbal. Lastly, this study did not include the perceptions of non-autistic managers of autistic employees.

#### 5.4.3 Limitations of the study on work from home experiences of autistic individuals

This study did not include the opinions of autistic individuals working part-time from home. It also excluded the opinions of those autistic individuals who have always worked from home. It also did not include the opinion of autistic entrepreneurs who run their business remotely.

## 5.4.4 Limitations of study on non autistic managers perspectives towards employing a neurodiverse workforce.

The study was limited to non-autistic managers working in a managerial role in Delhi-NCR and Bangalore region only due to time and outreach constraints. Some of the study participants were overtly guarded about their opinions on the subject of the interview as it was considered sensitive and taboo by them, this hindered the interviewers ability to attain elaborate, in-depth answers from them.

#### 5.5 Future Scope of the study

5.5.1 This study has immense future scope for both Autistic Indians and Indian business organizations willing to employ them. In the present study we have explored the workplace experiences of late-diagnosed autistic women in India. Future researches can look into the workplace experiences of autistic women entrepreneurs and autistic women who occupy a managerial position in Indian business organizations.

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- 5.5.2 Further, our study on stimming behaviours was concentrated only on the relevance of stimming behaviours in the lives of autistic individuals in India. Future researches can look into the relevance of stimming behaviours for non-autistic individuals and how it differs from those of autistic individuals.
- 5.5.3 Our study on work from home experiences of autistic individuals during the covid-19 pandemic in India can be further expanded to include the reintegration experiences of autistic individuals into the traditional 9 to 5 work routine post pandemic. It can also explore how work from home impacts the lives of autistic individuals in normal circumstances as opposed to extraneous circumstances caused by a pandemic.
- 5.5.4 Lastly, our study on perceptions of non-autistic managers towards autistic individuals can be extended to include the perception of autistic individuals towards non-autistic managers and autistic managers to determine how their managerial styles differ from each other and which managerial style is most conducive to an autistic employees.

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#### **APPENDICES**

#### **APPENDIX A**

#### **QUESTIONNAIRES**

# QUESTIONNAIRE ON WORKPLACE EXPERIENCES OF LATE-DIAGNOSED AUTISTIC WOMEN IN INDIA

Dear respondent, We are conducting a research on the experiences of <u>Autistic women at the</u> <u>workplace</u>. We'd love to hear about your insights on the same. We promise to keep the personal information provided by you confidential and use it solely for the purpose of this research. This research will help us in understanding the unique challenges faced by an Autistic women whilst working in a neurotypical environment often dominated by men.

This questionnaire is divided into two sections. Section A consists of a brief psychosocial profile of the individual and section B consists of questions dealing with neurodiversity at the workplace.

#### **SECTION A**

#### **Brief Psychosocial Profile**

Name:	Age:
E-mail address:	
Employer and Job title:	

Q1.How many years have you spent at your current job?

Q2How many years have you spent in your current industry?

Q3What all jobs have you held in your lifetime, please specify if they were in a different industry than the one you are in presently?

Q4 What are your educational qualifications?

Q5. Total Years of employment are?

Q6.When did you first suspect yourself of having an Autism spectrum disorder?

Q7. Did you ever get officially diagnosed as being on the autism spectrum?

Q8. Is there any family history of a learning disorder (such as dyslexia, Attention Deficit hyperactivity disorder etc) in blood relatives? If so, please specify who and what type.

Q9.Do you have any immediate relatives who may be considered exceptionally accomplished in their field of work? If so, please specify.

Q10.Have you ever taken an I.Q test? Did you score above average on it?

#### **SECTION B**

#### **OPEN ENDED QUESTIONS**

Q1.Please tell us a little bit about your childhood and growing up in your family.

Prompts: Describe your childhood hobbies, your family dynamics and your childhood friendships

Q2. Do you have any peculiar hobbies?How closely does your present work/ job revolve around your peculiar interest?

Q3. What all jobs have you held in your lifetime? What made you leave those jobs?

Q4. What exactly do you do at your job? Describe the favourite and lease favourite aspects of work for you.

Q5. Comment on the gender ratio at your workplace? If you found the gender ratio to be skewed in favour of men, then describe some of the key moments that made you feel out of place in a male dominated workplace.

Q6.What does workplace politics mean to you and how does it affect you?

Q7.What are the major workplace issues you encounter because of your Neurodiversity? (For instance difficulty working in open plan offices because of too much noise, burnout due to facing long commute in rush hour, anxiety when things don't go according to the expected plan) Q8.What are the major workplace issues and challenges that you have encountered being an autistic woman?(It may range from from things like being expected to dress up and behave in a certain manner at work to an inability to fit in with your female colleagues to sexual harassment to abuse to difficulties in balancing personal and professional life) How did you manage to overcome them?

Q9. Do you feel that being an autistic women is more challenging than being an autistic man ? What makes you feel that way?

Q10.If you had the option of requesting your employer for job accommodations then, according to you, what kind of accommodations would be the most beneficial to you?

Q11.Have you divulged your neurodiverse status to your employer? Why or why not? If you already did : what were the positive or negative effects? If you have not divulged it yet then what prevents you from doing so?

Q12.Suppose your employer believed that your social skills issues caused too many problems with your peers and customers to keep you in your position. The employer offered another job comparable in pay scale and responsibilities which would lower the amount of contact you would have with other people, but was not in your primary field of interest. Would you take the offer? Q13.Most of your co-workers are probably NTs (neurotypicals) and thus take comparatively lesser time in adapting to unforeseen , random changes at the workplace thus requiring less effort on your manager's part to acclimatize them to the changes. As a neuro-diverse individual, what do you

feel are your unique strengths that will offset the amount of one-on-one time it takes a manager to provide you with supervision and explanation

Q14 What would your ideal workday and work responsibilities look like?

Q15. Given the choice, would you work for your own self or work for an organization?

Q16. Have you ever had a meltdown at work? Describe the experience. What steps would you take to prevent or regain composure in case of future meltdowns?

Q17. In your opinion, how can the workplace be made more open and accepting of autistic women?

Q18. What role does work or having a professional identity separate from your personal identity play in your life?

# QUESTIONNAIRE ON WORK FROM HOME EXPERIENCES OF AUTISTIC INDIVIDUALS

## **SECTION A**

Brief Psychosocial Profile

Name: \_\_\_\_\_DOB: \_\_/ \_\_/\_

E-mail address:

## A.ASD

Do you have a clinical diagnosis of ASD? (yes/r	10)
Specify age at which you received your	
clinical diagnosis	
Do you have any of the following Co –morbid of	conditions(tick those that apply)
	Attention Deficit/Hyperactivity
	Disorder
	a depressive disorder
	an anxiety disorder
	other, specify
	None

# **B.** Demographics

Age	
Biological sex	Male
	Female
	Intersex
	other/prefer not to say
Employment status	Employed part time
	Freelancer/entrepreneur
	Employed full time
	Unemployed and looking for work
	unable to work because of disability
How many years of form	nal education have you undergone?

Job designation	
Total work experience	
Total work from home	
experience	

#### **SECTION B**

#### **Open Ended Questions**

Key Q1. How did you receive the news of lockdown in year 2020 due to covid 19 pandemic ? PROMPTS: What was your reaction ? Did you experience any anxiety regarding the status of your employment ?Were the sudden changes upsetting for you?

Key Q2. How did the loss of pre covid work routine affect your mental health?

PROMPTS: What steps did you take to manage your mental health? Did you adopt any new self care routines that you plan to sustain even after the pandemic is over?

Key Q3. What specific arrangements did your organization make to help its neurodiverse employees cope better with the sudden changes brought on by the pandemic ?

PROMPTS: Was your manager supportive? Did your organization grant more leaves to deal with the pandemic ? Did your organization enroll the services of a licensed therapist to help employees deal with the mental anguish? Did your organization disburse your salary on time? (please state any other arrangements)

Key Q4. What are the diverse technologies used by you to work from home during the pandemic? Did you face any difficulty in adapting to the new technology?

Key Q5.Reflect on the distractions faced whilst working in virtual workspaces and strategies used to minimize them.

Key Q6. How did W.F.H affect your collaboration experiences with your colleagues?

PROMPTS: Reflect on your comfort with communication media(synchronous versus non synchronous), experiences with remote networking, navigating changes in meeting dynamics through remote communication tools(experiences with learning to interact without non verbal cues that are present in face to face meetings) Also reflect on the effect these changes had on your stress and exhaustion levels.

Key Q7.In your opinion how can virtual meetings be made more inclusive and accessible for autistic employees ?

PROMPTS: For instance by normalizing keeping video off, having a clear agenda for meeting and providing handouts of meeting related materials in advance, having clear turn taking protocols in meetings to decide when each participant will speak to avoid time-pressured responses, enabling different ways to contribute to a conversation, captioning and sharing meeting records (e.g., recordings, transcripts, notes), and providing sufficient down time between meetings. )

Key Q8. Describe your workspace setup and work routine at home.

PROMPTS: How does it differ from pre pandemic times? How have these differences impacted your productivity levels . work-life balance , mental and emotional well being? Did you have difficulty adjusting to the blurred lines between professional and personal spheres of your life ?

Key Q9. Did you find it easier to create an accessible and distraction free work environment at home as compared to the office?

PROMPTS: How did you work around sensory overload and distraction at home as compared to the workplace? (specify problems faced in both situations and how you managed to work around them)

Key Q10. How was your overall experience of working from home during the pandemic ?

PROMPTS: Did you find it less or more stressful as compared to working in an office setting? Did your productivity levels get increased or decreased ?What other pros and cons did you experience of working from home?

Key Q11. What are the aspects of going back to pre-covid work routines that you find the most anxiety inducing?

PROMPTS : For instance, Dealing with rush hour traffic

#### **QUESTIONNAIRE ON STIMMING BEHAVIORS OF AUTISTIC INDIVIDUALS**

Key Q1.Do you perform any stimming or self stimulatory behavior while at your workplace? Prompt: Describe your stims in detail? Which of these stims do you do perform most frequently at your workplace ? Do you make use of any available material at your workplace as a stimming prop ?

Key Q2. What are the situations at your workplace that trigger you to stim?

Prompt: Give examples of workplace situations that caused you to stim? Reflect on the underlying reasons that caused you to stim during those situations ?

Key Q3. Do you stim openly while in the company of your non-autistic colleagues?

Prompt: How have your colleagues reacted to your stims in past? What impact did their reaction have on your stimming behaviors? If you were forced to suppress your stims due to certain workplace situations or negative reactions from your non-autistic colleagues, how did it affect you ?

Key Q4. Have you ever discussed your need to stim with your non-autistic managers and colleagues ?

Prompt : What was their reaction? Did they try to acknowledge and accommodate your stims ? If yes, then in what ways did your non-autistic managers and colleagues try to accommodate your stims? If you chose not to disclose your need for stimming behaviors to your colleagues then what deterred you from doing so? Key Q5. Imagine yourself being employed in an ideal neurodivergent friendly workplace,

how would you envision your need for stimming being accommodated at such a workplace?

# QUESTIONNAIRE ON NON-AUTISTIC INDIAN MANAGERS PERCEPTION OF AUTISTIC EMPLOYEES

Section A: Psychosocial Profile of Manager

NAME :

AGE :

INDUSTRY:

WORK EXPERIENCE:

#### **Section B: Open Ended Questions**

Q1. What are the kinds of diversity you are aware of at the workplace?

Prompt : when you hear about the term neurodivergence , what comes to your mind ?

*Q2.* Neurodiverse individuals have certain unique skills and talents like superior attention to detail, problem solving skills, ability to think out of the box, software testing etc that make them a source of competitive advantage for business organizations. Yet , due to their atypical brain neurology that makes them hyper aware of sensory stimuli they require certain workplace accommodations like noise cancellation earphones , working from home, dual screens , adjustment of bright lights, private office spaces etc Knowing this, would you be willing to accommodate autistic individuals at your workplace?

Q3. Are you aware about the legality of employing a neurodiverse workers and how you can safeguard the interests of neurodivergent employees ?

Q4. Do you feel that a neurodiverse employee would be able to blend into your existing organization culture? How would you deal with the challenge of accommodating a neurodivergent worker while at the same time not providing the neurotypical employees similar accommodations.?

## **APPENDIX B**

## **BIO-DATA OF THE AUTHOR**

Name: Ms. Elixir Sagar

**Designation: Research Scholar** 

Institution: Delhi School of Management, Delhi Technological University

# **Educational Qualifications**

Educational	University/College/School	Year	Percentage/cgpa
Qualification			
MBA	Amity Business School,	2014-16	6.24
	Amity University Noida		
BBA	Ideal Institute of	2010-2013	74.33%
	Management and		
	Technology, G.G.S.I.P.U		

## PAPERS PUBLISHED AND UNDER CONSIDERATION FOR PUBLICATION

S.NO	PAPER TITLE	JOURNAL NAME
1.	'I wish they'd just let us be' workplace	Published as ahead of print article
	experiences of Indian autistic individuals	in Autism in Adulthood journal
	around stimming behaviours.	Impact Factor 6.8
		ISSN 2573-9581
		Mary Ann Liebert Publications
		Indexed in:-
		PubMed Central
		• Web of Science: Emerging
		Sources Citation Index <sup>TM</sup>
		(ESCI)
		• Scopus
		• EMBASE/Excerpta
		Medica
		PsycINFO
		• SafetyLit
		• BenchSci

2.	A study exploring the psychological	Published in Journal for ReAttach
	perspective of Indian Managers on	Therapy and Developmental
	employing neurodiverse talent	Diversities, Volume 6 No. 5(s)
		ISSN 2589-7799
		Impact Factor 2.13
		Indexed in:-
		• Scopus
		• EBSCO
		• Crossref
		• Sciopen.com
		• Scope database
		• European Reference Index
		for the Humanities and
		Social Sciences
		• Researchgate
		Sciencegate
3.	Neuroatypicality in the workplace:	Published in Korea Review of
	Leveraging the power of a unique mind	International Studies journal,
		Volume 16, Issue 49 ISSN: 1226-
		4741
		Indexed in ABDC category 'C'

4.	Workplace accommodations to sustain a	Published in Education and society
	neurodiverse workforce in India	journal, Volume 46 Issue 3.
		Indexed in UGC CARE
		ISSN 2278-6864
5.	'India is no country for the Disabled':	Published in Education and society
	Indian managers perspective on	journal, Volume 46, Issue 2.
	employing neurodiverse talent.	Indexed in UGC CARE
		ISSN 2278-6864
6.	Doubly Disadvantaged: workplace	Under review after revision at
	experiences of late-diagnosed autistic	Feminism and Psychology journal
	women in India	Impact Factor 5.4
		ISSN 09593535
		SAGE Publishers
		Indexed in Scopus, SSCI, SCI
7.	'It was a blessing in disguise' Work from	Working paper
	home and reintegration experiences of	
	Indian autistic individuals during and after	
	the covid-19 pandemic in India	

# List of papers presented in national and International conferences

Sr. No.	Title	Place	Publication	ISBN/ISSN No.
1	It was a blessing in	2 <sup>nd</sup> International	Abstract book	ISBN:9788195954605
	disguise ' a study	Pritam Singh		
	on work from	Memorial		
	home experiences	Conference, IIM		
	of late-	Nagpur		
	diagnosed Indian			
	autistic individuals			
	during the Covid-			
	19 pandemic in			
	India.			
2	Doubly	7 <sup>th</sup> International	Abstract Book	E-book of abstracts.
	Disadvantaged:	Communication		
	Workplace	Management		
	experiences of	Conference, Mudra		
	late-diagnosed	Institute of		
	autistic women in	Communications,		
	India.	Ahemedabad		
3	Mindfulness and	6 <sup>th</sup> International	Abstract Book	ISBN: 978-93-89714-12-8
	EFT in managing	Communication		
	stress and	Management		
	improving	Conference		

employee		
productivity		



# **DELHI TECHNOLOGICAL UNIVERSITY**

(Formerly Delhi College of Engineering) Shahbad Daulatpur, Main Bawana Road, Delhi-42

## **PLAGIARISM VERIFICATION**

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Supervisor (s)		
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Department		
		ection. Process and outcome is given
below:		
Software used:	Similarity Index:	, Total Word Count:
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**Candidate's Signature** 

Signature of Supervisor(s)