Supporting Persons with Autism Spectrum Disorder in Employment Through Social Connectedness for Promotion of Employee Well-Being: a Study

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Abstract: Employment is one of the key aspirations of adult life for all individuals whether with or without disability as earning provides a boost to one's self confidence and also raises one's productivity, reduces dependence on the family thereby reducing the care giving burden and financial constraints. However, research studies and report suggest that adults with Autism have low employment opportunities and lack support services for successful transitioning from school to work. The present study makes an attempt to understand the changing roles of young adults with Autism owing to the supportive action of social connections at home and work place towards enhancement of employee well-being. The present study was carried out with a sample size of 10 adults with Autism (age range of 18-26 years) and information was obtained on several aspects through in-depth parental interview and non participant observation in the home settings: social connections, family support, work habits and skills and well-being. This study was carried out in 4 major cities: Delhi, Kolkatta, Bangalore and Chennai. Only adults with Autism Spectrum Disorder (ASD) who lived with their parents, attended a structured work setting (supported or sheltered employment or job training center) with little or no disruptive behaviors were included in the study. The respondents were parents of adults with ASD belonging to the middle and upper middle class of society. The findings of the study lend support to the positive impact of social connections and work relationships for adults with Autism thereby helping them cope effectively with the challenges faced at the workplace.

Keywords: Adults with Autism, Autism Spectrum Disorder, Employment, Parents, Social connections, Support, Workplace, Well-being

Introduction: Autism Spectrum Disorder (ASD) though once considered rare has become a common developmental disability with a rising incidence and prevalence (Juneja & Sairam, 2018). *"Employment is a socially normative activity"* and is considered as a key milestone

for gauging the success of transition from adolescence to adulthood. Earning money contributes to raising of one's social esteem and is linked to economic, social and mental well being. For Persons with Disabilities (PWD) one of the major aims of special education and rehabilitation services is gaining meaningful employment for economic development. However it remains a major challenge for persons with disabilities especially those with developmental challenges (Roux et al., 2013). Meaningful work gives a sense of 'self worth' and apart from financial support it also improves one's social connections with community and society. For adults with Developmental Disabilities (DD) face wider gaps in the job market and greater discrimination due to several factors which include low societal expectations, need for long-term and constant support, lack of appropriate accommodations and assistive technologies, low job maintenance, absence of relevant work experience and poor employment opportunities despite several non discriminatory laws and policies framed in this regard (NACBHDD, 2018). Studies and survey reports shed light on key factors for under and un-employment of youths with Autism. Facing job interviews, non supportive work environments, complex social dynamics with co-workers and authoritarian figures, need for flexibility and good communication skills are just a few of many such complex factors. Such studies have identified the key benefits of employment for Autistic adults (Hedley et al., 2017):

- Benefits at the individual level- meaningful employment can have positive impact on the individual's overall wellbeing and Quality of Life (QoL). It is considered financially empowering for the adult with neurological disability and reduces the sense of burden, while developing self belief.

- Benefits at the family level- apart from financial relief, families of such individuals are motivated to see the individual's capacity towards financial and personal independence through better development of adaptive behaviors.

- Benefits at the organizational level- the presence of savant skills in high functioning autistic individuals are often beneficial to the organization, moreover employers ratings of their employees are high in terms of dependability, trustworthiness etc.

- Benefits at the national level- It is seen that increased work participation among adults with Autism has positive impact on nations economy whereas lost employment opportunities increase the welfare costs paid by the government.

The study of the need for humans to belong and feel connected has given rise to the need for studying social belongingness, social connectedness and relationships to investigate human well-being and motivation. Work relationships are critical towards employee well-being as one has to work in close cooperation with co-workers, authority and others at the workplace, follow workplace rules and regulations. Workplace relationships and social connections have been found to impact employee happiness, feelings, stress levels and productivity ultimately affecting health (Kohll, 2018). The Harvard Study of Adult Development which tracked the health, work and lives of a large cohort of male participants (n=729) for several years found that happiness is key to good health and mental well-being. The study pointed out that flourishing is a function of close human bonding with family, friends and society, while

materialistic pursuits like wealth, fame, social status play a negligent role. Brownlow, Werth & Keefe (2018) indicated that employees with Autism are highly susceptible to stress in the workplace due to the stigma associated with their condition. Such attitudes give rise to 'stigmatized identities' and 'emotion work'. This creates the need to include strategies targeting stigma management, peer support, social connections and disability level. It is seen that the population of adolescents with ASD who are transitioning into adulthood is steadily on the rise, though lesser number of adults with ASD venture into regular competitive employment (Krieger et al., 2012), there is a critical need for greater awareness among professionals and parents working towards rehabilitation of Individuals with Autism. A dearth in literature felt in the area of adults with ASD and their successful integration in the mainstream society. creates a huge gap of knowledge. Little is known about their functioning in the home, workplace and leisure activities. Accordingly, the key issues identified for research in this study include: social connections, family support, work habits and skills and well-being. A study on 54 adults with Autism in Delhi found that in the Indian situation such adults lived with their families and although majority stayed at home (41%) or attended a special center (34%), minority (7%) received job coaching while 9% attended a high school. Their skill level was found to be of varying levels ranging from limited independent skills to skills of few adults with ASD who were competitively employed. The findings of the study revealed that persons with Autism (44%) had a daily routine similar to those without Autism such as daily walk, watching TV, doing simple household chores and using computers. These points to the fact that parents of such adults were accommodating them into social spaces and helping them engage with community members. However not all adults with ASD had similar routine. Adults with ASD having low functioning or challenging behaviors were described by their family as 'idle', spent more time indoors in shared family spaces and were often seen to engage themselves in self stimulatory activities. Another major finding from the study was low correlation between stress levels experienced by parents and the nature of daily routine of adults with ASD. The commonly held misconception that parents of such adults are often frustrated and unable to cope with the stress of raising such individuals, was thereby broken to some extent (Daley et al., 2014). Another study tried to examine the employment experiences of young adults with Autism in the United States using the national representative survey of adults aged between 21-25 years receiving special education services. The study findings reported that nearly 53.4% of such adults had worked outside their home, which was quite low compared to adults having other forms of disabilities. Also, such adults received significantly low average wages. Autistic adults having better conversational abilities or functional skills had higher chances of gaining employment. The study concluded that this population experienced challenges in successfully transitioning from school to work and there was need for developing better strategies to aid their transition into adulthood (Roux et al., 2013).

Participant description and characteristics: The adults with ASD chosen for the present study were selected using non probability sampling (convenience sampling) from 4 major Indian cities: Delhi, Kolkatta, Bangalore and Chennai. All selected adults were living with their parents and siblings, majority were nuclear families (n=8) and remaining were staying with extended families (n=2). The families in this study were Hindus and relatively well off

reporting a monthly income between 50,000-80,000 rupees per month. One quarter of mothers were working part time while all fathers were engaged in full time jobs, outside the home. The participating young adults had Autism Spectrum Disorder and were in the age range of 18-26 years (mean age = 21.7 years), all males and were having minimal or no problem behaviors, but needed considerable support in social interactions and personal management skills.

Procedures: Parental interview (in native language) and non-participant observation methods were utilized for collecting data for the present study, with the researcher visiting each family for a period of fifteen days to one month, based on convenience. Informed consent was obtained from each parent and the study protocol was reviewed by five experts in the field of special education. Consent was obtained from participating families at two stages of the study: firstly, during recruitment and sample selection phase and secondly during home visit stage. Separate consent was also obtained from the high functioning autistic adults who were capable of understanding and following the instructions provided. The procedure involved in the study and its benefits were explained to the parents of the adults contacted for the study. At the initial stage, twenty families were contacted for the study out of which fifteen parents showed their willingness for participating in the study. During the course of the study five families dropped out of the study.

Table 1.*Demographic details of the Family (n = 10)*

Variable	n
Geographical Zone	
Delhi	1
Kolkatta	3
Bangalore	3
Chennai	3
Religion	
Hindu	10
Household type	
Nuclear	8
Joint	2
Parental Employment outside home (fulltime/parttime)	
Mother	2
Father	10

Table 2. *Demographic details of Persons with ASD selected for the study*

Diagnosis : Eligibility for study	
Past diagnosis	10
Gender	
Male	10

Age	
18-20	3
21-23	4
24-26	3
Birth order	
Eldest child with siblings/Single child	8
Younger child	2
Siblings	
Adult with Siblings	2
Adult without siblings	8
Employment status	
Not employed	7
Employed (self/sheltered/supported)	3

Findings

i. **Social connections at the workplace:** Detailed information was obtained from one or both parents of the selected adults regarding the daily routine of the adults with ASD- i) engagement in work within home such as household activities such as folding clothes, watering plants, helping elders in household chores, ii) engagement in work outside home (engaging for minimum 3 hours to at least 5 hrs. in meaningful work such as self employment, sheltered employment or supported employment. Using the transcripts and field notes, the following daily routine of the target sample was framed as shown in table-4:

Table 3.

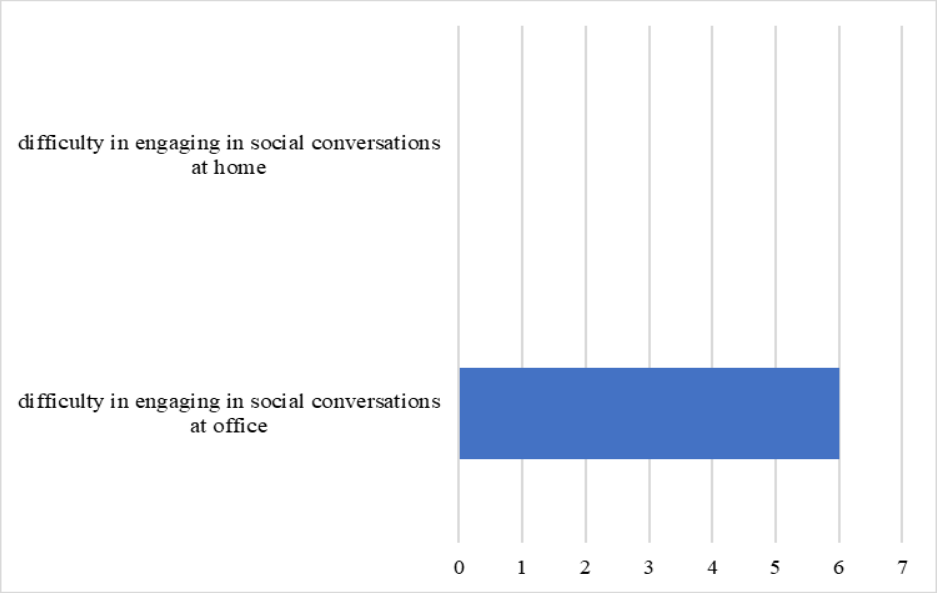
Daily routine activities of Adults with ASD

Activity	n	Percentage (%)
Engages in household chores	5	50%
Sits idle	4	40%
Roams about	1	10%
Goes to job training/ special centre	4	40%
Employed	2	20%

From table 3 it is clearly seen that 50% (n=5) PwASD engage in household chores like washing dishes, watering plants, folding clothes, keeping things in their proper places. However, it was seen that 4 adults with ASD kept idle due to non interest in household activities and in case of two autistic adults, the family refused to give any task to them n the spare time. 10% autistic adults (n=1) preferred to roam about while 4 individuals went to a training center to learn vocational skills. 2 adults with ASD in the sample were full time

employed, one participant was working as an office helper and other participant was engaged in a fruit packing shop.

Figure 1.*Social engagement behaviour of participants.*



From figure 1 it was noticed that 6 males had difficulty in engaging with social conversation at the workplace, however all 10 were easily able to follow the social conservations at home environment, but lacked participation. It was noticed that the Autistic adults were comfortable within the home environment and spent their leisure time engaging in various leisure and recreational activities as seen in table below:

Table 4. ***Recreational and leisure activities for adults with ASD***

Activity	**n**	**Percentage (%)**
Watching TV	8	80%
Playing by self	5	50%
Going for a walk	4	40%
Sitting Idle	2	20%

From the table 4 it is seen that 80% adults engaged in watching Television, while 50% play by self. It is also seen that 40% PWASD go out for walks while 20% (n=2) sit idle, abstaining from social and physical participation in recreational tasks.

Family support: All the interviewed parents were found to be highly supportive of their wards with ASD and despite facing stress and frustration on account of management, they were very happy to see their sons happily engaged in their chosen activity. Family connections in form of sharing eatables, addressing needs of the individual with Autism, listening patiently to their talks, among others are summarized below in the figure:

Figure 2. *Family social connections with Persons with Autism Spectrum Disorder*

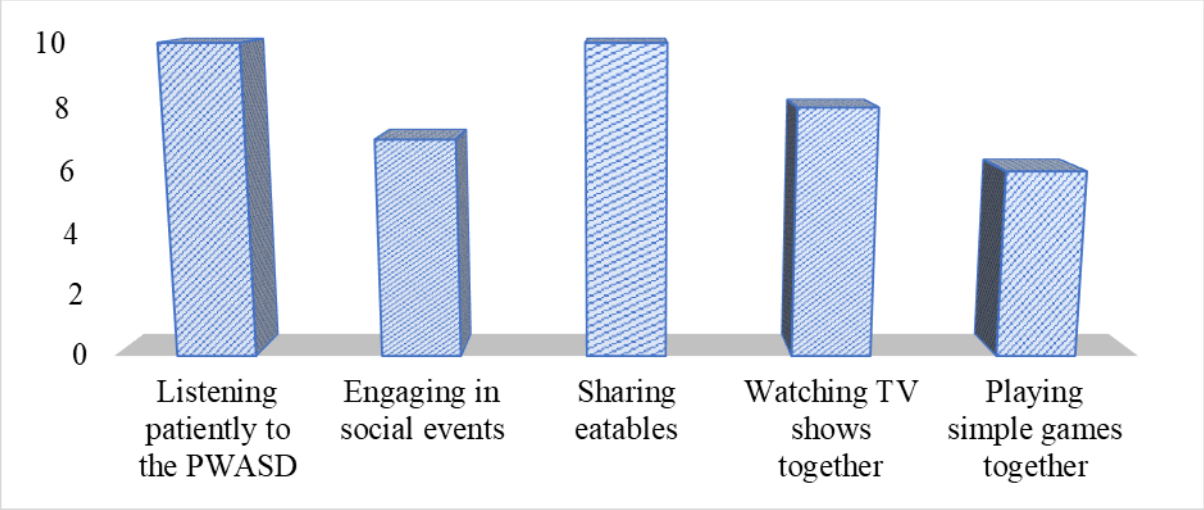


Figure 2 reveals that all families listened patiently to PWASD, also share eatables with them. However it is seen that 6 families fully engage them in social events like family celebrations of festivatls, parties, family trips while 8 families watch TV together but oly 6 families play simple games with the Austistic adults.

ii. **Workplace accommodations for Persons with Autism**: Several agencies such as 'Auticon' are increasingly hiring Individuals with Autism, thereby ensuring that employees have access to colleagues and peers having ASD (Wu, 2019). Such employees can empathize with each other. The workplaces have to be specially designed and adapted for employees with Autism such as:

- Frequent breaks
- Absence of artificial light
- Usage of dim lighting, natural illumination
- Simple instructions
- Fidget Jewelry and Spinners
- Break rooms can be dark rooms, with seating arrangements, soft music and other calming items

The study by Moore et. al. (2005) mentions the use of Virtual Reality (VR) 'avatar' as a technological medium for facial expression recognition and training for persons with ASD, allowing animated sequences in modules: a) emotional expression recognition, c) prediction of expression, c) interpretation of expression. The study concluded that individuals trained using the VR systems were found to communicate with others more effectively. Bharatharaj et. al. (2017) proposed a 'parrot-inspired robot assisted therapy' based on the adapted model rival method in which the nine children were trained during pilot testing stage by analysis of their facial expressions. The findings revealed that children appeared happy while interacting

with the robot and on interviewing parents and other stakeholder it was revealed that the model aided in improvement of the social interaction skills among CwASD.

Discussion and Summary: The study clearly suggests that parents of persons with ASD have accepted their wards with his/her limitations and strive to offer their best services for the happiness and success of their child. However in the absence of employment opportunities, lack of skill training and lack of appropriate transitioning services, the parents find themselves at a loss and end up frustrated and anxious for their wards future. The study found that parental support at home and co-worker support in the workplace played a crucial role in supporting PWASD in job retention and maintenance thereby reducing stress levels and increasing well-being. The recommendations which emerge from this study are: Need for provision of appropriate support services especially human connections, need to understand the unique traits of such individuals, viewing them in a non-stigmatized way especially transition services.

Limitations: The present study has several limitations such as small number of participants and respondents, conveniently selected samples, the families predominantly represent the upper middle class and affluent families who have ready access to several already such as Alexa, android apps etc. another important limitation is that despite lengthy and detailed interviews conducted with parents and careful observations done for the adult with ASD at home, the depth of information obtained is limited and could have been more detailed, there is also a clearly felt absence of interview with the employers or observation at the workplace of the participating adults.

Conclusion: The daily routines followed by adults whether employed or unemployed are seen to be common across the lifespan of an individual irrespective of the region or geographical area. Also, it can be seen that over the past few decades, the role of Assistive Technology, Assistive Devices (AD) and Augmented Reality (AR) have gained an increased foray, acceptance and utility for adults with ASD however, there is need for more research, more support and more acceptance for these devices in terms of accessibility, affordability and awareness. Adults with developmental disabilities require unique support within and outside home, in the workplace, in transportation, in break time etc. This study provided a glimpse into certain available AT and AI solutions for such persons and also parent's views about their wards were positive and encouraging. Employers need to be more sensitized and aware about the changing needs of this target population, in order to effectively cater to their unique demands and also utilize the skill sets of Adults with ASD.

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