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How do we speak? Usage and implications of augmentative and alternative communication (AAC) in young adults with autism spectrum disorder (ASD)

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Abstract

As per the definition of autism by the American Psychological Association (*APA Dictionary of Psychology*, n.d.), autism is typified by challenges in social skills and communication. In this context, awareness of augmentative and alternative communication (AAC) and its usage becomes important for adults with autism to get employed and sustain their jobs. A phenomenological study of how persons with autism communicate and a cross-sectional analysis of the usage of AAC in adults with autism in the age group of 18-25 and its implications through qualitative analysis is proposed. The data collection was through in-depth interviews with the parents of the selected subjects on the ASD spectrum with speech impairments or complex communication needs. The interview questions were formulated based on factors obtained from the related literature, and interviews were carried out in a semi-structured manner. The thematic analysis of the data was conducted. Observation and analysis of communication behaviours of participants at the workplace were also performed by the psychologist. The results portrayed the parents' lack of awareness regarding AACs and the importance of speech therapy. Parents of the subjects were also found to support certain myths about AACs. Besides, the study brings to light the need for transparency in the parent-therapist

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relationship. Parents' lack of awareness regarding AAC, calls for the implementation of sensitization campaigns. Future research should focus on collecting exhaustive data on AAC and its application in the workplace. Employers who hire neurodiverse talent should look at sensitizing the employees to the challenges faced by individuals on the spectrum.

Keywords: Autism, Augmentative and Alternative Communication (AAC), Complex Communication Needs, Awareness

Autism is a neurodevelopmental condition typified by notably impaired social interchange and communication, restricted interests, and iterative behaviours (*Autism Spectrum Disorder*, n.d.) As for communication, some people on the spectrum do not speak at all. Those who use speech may speak intermittently or may practice unreliable speech in which their speech and preferences don't match (Sparrow, 2017) or can have insufficient speech where one cannot converse everything one wishes to (Zisk & Dalton, 2019). They also construe language literally, that is, they pay attention to the meanings of the words instead of discerning the intention of the speaker (Bogdashina, 2005, p.181). Across the autism spectrum, hindrances to pragmatic language skills such as discourse and conversational skills are seen, although there exists heterogeneity in their language capabilities (Tager-Flusberg, 2005).

Disability inclusion in the workplace (Suresh & Dyaram, 2020) is gaining importance in India, and many employers now give importance to diversity in the workplace (Dey, n.d.) and work towards it (Maini & Heera, 2019), thus increasing the possibility of young adults with autism to get employed. Rights of Persons with Disabilities Act 2016 (*Acts | Department of Empowerment of Persons with Disabilities | MSJE | Government of India*, n.d.) also

promotes organisations to employ people with disabilities, and autism is one of the disabilities in the 21 categories, which is considered for disability inclusion.

Communication becomes challenging for one with autism to become employable and sustain employment. In the work environment, communication becomes more challenging as it mostly becomes the communication between a person with autism and a person without autism, where it may not be easy to accept differences in expression. Means to communicate properly becomes critical and affect the employee's productivity as well as personal well-being. At this juncture, it is important to study the possibilities and challenges faced by young adults who are preparing to get employed. This calls for research into how communication happens in young adults with autism and their usage of AAC.

Augmentative and alternative communication (AAC) refers to all how someone can communicate other than talking, where Augmentative means to "add to" and Alternative means "instead of". Different AACs can include pointing to words or images, writing, gestures, drawing, using Information Communication Technology (ICT) for generating voice, or using ICT solutions for communication. One categorisation is based on the usage of technology as no-tech, low-tech, and high-tech, and another one is based on its dependence on any external aid as aided or unaided (Cook & Polgar, 2015). The major features of AAC which need to be considered are availability, affordability, accessibility, portability, and speed (Elsahar et al., 2019). This is generally used to enhance functional communication with persons who don't have any communication problems. Avaz (Sonawane & Varshneya, 2020) and Jellow

(Srinivasan et al., n.d.) are examples of AAC applications that are available in Indian languages also.

Relevant studies are found on the usage of AAC used for communication with children with autism in India (Lal, 2010; Kidwai et al., 2022). Many technical articles based on communication with Information and Communication Technology (ICT) are also available, like the advancement of AAC (Elsahar et al., 2019) and increasing the effectiveness and accuracy of man-machine interaction using multiple modalities (Sreekanth et al., 2016). Relevant articles were not found around communication of young adults with autism who are trying to get employed and thus undergoing life skills training.

This research is based on the concept that AACs may facilitate better communication in the workplace in young adults with ASD. In this context, we propose a phenomenological study on how communication is happening in the present scenario as being experienced by young adults with autism who are getting ready to join organizations and a systematic review of qualitative evidence of their usage of AAC with the following objectives.

Objectives

1. Formulate a questionnaire to conduct the interview based on factors affecting usage and implications of AAC from existing studies.

2. To conduct in-depth interviews on how communication is done and the details of AAC usage with parents of selected subjects in the age group 18- 25.

3. To observe and analyse how the participants are communicating at the workplace.

4. To analyse the requirement of AAC needs at the workplace.

This paper is presented in the following structure. The introduction section contains the definitions of key terms and the state of the art in the relevant topics and the objectives of the study. This is followed by the research methodology, which explains the research design and the results of the study in the subsequent section and concluded with final remarks and future directions. The result of this study may be used to design interventions to create better communication, especially in the workplace for employees with autism.

Research Methodology

A case study analysis of two participants, Ron and Feba (pseudonyms), with ASD and complex communication needs, aged 25 and 26, respectively, who are employed in an IT firm, was conducted. The following steps were followed.

1. Interviews with parents of participants to analyse the case history, communication complexity, and usage of AAC.

2. Observation and analysis of behaviours of the participants from the perspective of the psychologist who supports the participants at the workplace.

Required permissions were obtained from the parents of the participants and the organization for the conduction of the interviews, as well as for using the data for research and publication. A semi-structured interview was conducted with the parents of the participants to analyse the speech complexities of the participants, the challenges they face while

communicating, and the awareness and usage of AACs. AAC Needs Assessment (Tobii Dynavox, 2016) was administered additionally to determine the level of AAC needs. The semi-structured interview mainly looked at identifying the level of awareness the parents had with regard to AACs, the concerns they had over the participants' communication strategies at the workplace, how content they are with the participants' communication skills, and whether they are ready to invest in an AAC device to facilitate the participants' communication.

The interviews with the two parents were audio-recorded and transcribed verbatim. The interview transcripts were thematically analysed and coded for further discussion. The behaviour of the two participants at the workplace was also observed and analysed by the psychologist supporting the participants at the workplace. This observation, too, was transcribed and analysed based on the themes. Based on this analysis, the usage and implications of AAC at the workplace are discussed.

Results and Discussion

National Joint Committee for the Communication Needs of Persons with Severe Disabilities (NJC), a group that deals with research and education surrounding AAC, predicates in the Communication Bill of Rights that everyone has the right to influence their lives through communication (American Speech-Language-Hearing Association, n.d.). When it comes to autism spectrum disorder, communication difficulties persist even after transitioning to adulthood, hindering day-to-day operations (Jennes-Coussens et al., 2006). This research thoroughly studies the parents' perception of their children's communication challenges and their general awareness of augmentative and alternative communication.

Ron's father did not hold back when he was asked whether he felt Ron's communication skills can be bettered.

I don't think one can improve his communication beyond a level at Ron's age, but I don't think it's adequate. If he could at least communicate in sentences and give the right responses, then it could have been considered adequate.

Communication is key in the workplace. The inability to communicate clearly in the office can cause confusion, unintentionally hurt others, or may pass on inaccurate information. Ron mostly answers in one or two phrases to every question directed at him, and this can also be a repetition of the words the question comprises. It becomes all the more challenging when he is asked polar questions because his affirmative responses are not always reliable. Feba, on the other hand, only communicates her needs, whether at home or outside. What she tries to put across with her limited vocabulary needs to be deduced. Feba's parents and siblings are able to do so, but when it comes to the outside world, she struggles to transmit her thoughts or feelings.

While neither parent has ever heard of the term AAC, they have both made use of it in the past. They employed Picture Exchange Communication System (PECS) when Ron and Feba were children, to aid with their communication. They first learned about it when they took their children to speech therapy, and they emulated what they observed at the therapy centre. PECS is highly structured, and continuous usage is essential to maximizing its effectiveness. Anyone can apply PECS, but they must first undergo PECS training (*Picture Exchange Communication System (PECS)*, 2022), which the parents have not. It is claimed that users must always have access to PECS, whether in their community, school, or home (*Picture*

Exchange Communication System (PECS), 2022). However, this was not known to either parent.

Feba's father, when asked what he feels about AAC facilitating her communication, he stated, "If she fully depends on this, I feel she will lose the communication skills she already has." AAC usage appears to improve communication, as per emerging evidence (Happ et al., 2014). There are some evident advantages to using voice output communication tools, like requesting, social or conversational skills, labelling objects, and receptive language, according to Rispoli et al. (2010). However, Feba's father is not quite certain that an AAC would help her communicate better. AACs, in his opinion, will aid in full expression, but they might also have the unintended consequence of diminishing the utilization of already existing communication skills. AACs and their effects were viewed with scepticism by Ron's father as well. He believes that because Ron appreciates technology, he will begin to rely heavily on them to communicate. Recently, Ron has been making the effort to call his parents via phone. His father is content with the improvement, despite the fact that his expression is not fully intact.

Studies have shown how beneficial speech and language therapy is and how little to no development children make without it (Broomfield & Dodd, 2011; Adams et al., 2012). Ron and Feba were both taken to speech therapy for approximately a year, but the course was inconsistent. To get to the therapy centre, both parents claimed that they had to commute a significant distance, and after a while, they did not think it was very productive in terms of the progress Ron and Feba made. Parents did not have direct sessions with therapists to discuss their children's progress, nor did they know what was being worked on. Besides this, despite having little understanding of how the sessions worked, both parents perceived that the

activities were redundant. Another obstacle was the sizeable fee associated with each session, which the parents deemed excessive in the long run. As a result, the parents decided not to take their children to speech therapy afterward. Following a year of irregular attendance, Ron was admitted to a special school where he received continued support with communication, but only occasionally. Feba's father, in lieu, opted for a normal school where only special educators visited twice per week. The speech therapy offered to their children at the start did not entirely appease either of the parents. This demonstrates the significance of family-centered practice, which views the entire family as the client rather than just the child. It prioritizes fostering functional bonds between the family and therapists (Hanna & Rodger, 2002).

An AAC device like Avaz may help Ron communicate clearly, and his father responded approvingly when asked if was ready to put up the money, "If Avaz helps him with his communication, I am definitely ready to invest." The idea of investing in an AAC was welcomed with doubt by both parents at first, but they, later on, suggested their receptiveness. While both parents expressed a willingness to pay up to 10,000 rupees for an AAC, they wanted to be certain that the gadget would significantly help the two participants. The parents' apparent lack of concern for Ron's and Feba's communication problems is especially noteworthy, considering how clear it is from the screening and observation that their communication is far from adequate.

The opportunity to work independently in a cabin with their job mentor is granted to Ron and Feba. Before deciding to provide them with a separate cabin, the company considered factors such as the volume of sensory stimuli, the circumstances in which they would have to interact, etc. However, meaningful employment would be associated with social ties,

community participation, financial self-reliance, and residential living (Trainor et al., 2008), and employers value employees who can maintain good working relationships and communicate effectively (Bryen et al., 2007). Given the complexity of their language, Ron and Feba would have considerable difficulty with any of this. An AAC can, however, pitch in to support their needs. Richardson et al. (2019) conducted research on employed autistic individuals with complex communication needs to demonstrate that AACs can support workplace participation, and it rightly did so. A study by Babb et al. (2018) implies that AACs, in combination with video visual scene displays (photographs of relevant moments in the individual's life that have verbal annotations on them to aid communication), can facilitate the completion of specific occupational tasks as well as workplace communication.

Conclusion

The results make it clear that awareness regarding AACs has to be broadened on several levels. Parents and primary caregivers of individuals on the spectrum need to be informed of how important speech therapy is in assisting an individual with complex communication needs. The role of AACs, which play an important role in facilitating an individual's communication, should also be emphasized. It is also imperative to deal with certain misconceptions surrounding the use of AACs. Both parents seemed to uphold the "myth" that AAC use would debilitate existing communication skills.

Employers, in a research by McNaughton et al. (2003), revealed that employees were hesitant to collaborate with colleagues who utilized AACs. However, a more recent study by Muller (2014) contradicted this finding and claimed that people who use AACs could readily

fit in. This finding can prove to be significant in Ron's and Feba's employment. Once they start using AACs, they will find workplace lives more unchallenging. Even so, sensitization workshops with the objective of creating awareness among employees need to be planned out.

It is always better for a therapist to maintain transparency with the parents. Taking into account the complexity of treatment options and the unavailability of resources, parents of autistic individuals are entitled to receive clear feedback, which is pivotal to a constructive family-therapist relationship (Mulligan et al., 2012). Ron's and Feba's parents' accounts are testaments to the lack of transparency on the side of the therapist, which needs to be brought about.

Although several approaches are being attempted to facilitate autistic individuals' transition into employment (Pillay & Brownlow, 2016), there is currently minimal understanding of how AACs might assist them therein (Richardson et al., 2019). This recommends that more research on AACs, their usability, and their availability in the workplace needs to be implemented. Future research must look to include more participants and strive to be exhaustive.

References

Acts | Department of Empowerment of Persons with Disabilities | MSJE | Government of India. (n.d.). Retrieved August 26, 2022, from

https://disabilityaffairs.gov.in/content/page/acts.php

Adams, C., Lockton, E., Freed, J., Gaile, J., Earl, G., McBean, K., Nash, M., Green, J., Vail, A., & Law, J. (2012). The Social Communication Intervention Project: a randomized

controlled trial of the effectiveness of speech and language therapy for school-age children who have pragmatic and social communication problems with or without autism spectrum disorder. *International Journal of Language &Amp; Communication Disorders*, *47*(3), 233–244. https://doi.org/10.1111/j.1460-6984.2011.00146.x

American Speech-Language-Hearing Association. (n.d.). *History of the National Joint Committee for the Communication Needs of Persons with Severe Disabilities*. https://www.asha.org/NJC/history

Autism spectrum disorder. (n.d.). Retrieved August 26, 2022, from https://www.apa.org/topics/autism-spectrum-disorder

Broomfield, J., & Dodd, B. (2011). Is speech and language therapy effective for children with primary speech and language impairment? Report of a randomized control trial. *International Journal of Language &Amp; Communication Disorders*, *46*(6), 628–640. https://doi.org/10.1111/j.1460-6984.2011.00039.x

Babb, S., Gormley, J., McNaughton, D., & Light, J. (2018). Enhancing Independent Participation Within Vocational Activities for an Adolescent With ASD Using AAC Video Visual Scene Displays. *Journal of Special Education Technology*, *34*(2), 120–132. https://doi.org/10.1177/0162643418795842

Bryen, D. N., Potts, B. B., & Carey, A. C. (2007). So you want to work? What employers say about job skills, recruitment and hiring employees who rely on AAC. *Augmentative and Alternative Communication*, *23*(2), 126–139. https://doi.org/10.1080/07434610600991175

Cook, A. M., & Polgar, J. M. (2015). Augmentative and Alternative Communication Systems. Assistive Technologies, 411–456. https://doi.org/10.1016/B978-0-323-09631-7.00016-8

Coping with a Crisis When You Have Unreliable or Intermittent Speech — THINKING PERSON'S GUIDE TO AUTISM. (n.d.). Retrieved August 21, 2022, from https://thinkingautismguide.com/2017/11/coping-with-crisis-when-you-have.html

Dey, D. (n.d.). JOURNAL OF CRITICAL REVIEWS Current State of Inclusion of People with Disabilities at Workplaces in India. 7, 2020.

Elsahar, Y., Hu, S., Bouazza-Marouf, K., Kerr, D., & Mansor, A. (2019). Augmentative and Alternative Communication (AAC) Advances: A Review of Configurations for Individuals with a Speech Disability. Sensors 2019, Vol. 19, Page 1911, 19(8), 1911. https://doi.org/10.3390/S19081911

Happ, M. B., Garrett, K. L., Tate, J. A., DiVirgilio, D., Houze, M. P., Demirci, J. R., George, E., & Sereika, S. M. (2014). Effect of a multi-level intervention on nurse–patient communication in the intensive care unit: Results of the SPEACS trial. *Heart &Amp; Lung*, *43*(2), 89–98.

Hanna, K., & Rodger, S. (2002). Towards family-centred practice in paediatric occupational therapy: A review of the literature on parent-therapist collaboration. *Australian Occupational Therapy Journal*, *49*(1), 14–24. https://doi.org/10.1046/j.0045-0766.2001.00273.x

Jennes-Coussens, M., Magill-Evans, J. and Koning, C. (2006). The quality of life of young

men with Asperger syndrome: A brief report. Autism, 10(4), 403–414.

https://doi.org/10.1177/1362361306064432

Kidwai, J., Brumberg, J., & Gatts, J. (2022). Aphasia and high-tech communication support:

a survey of SLPs in USA and India. Https://Doi.Org/10.1080/17483107.2022.2109072,

1–10. https://doi.org/10.1080/17483107.2022.2109072

Lal, R. (2010). Effect of alternative and augmentative communication on language and social

behavior of children with autism. Educational Research and Reviews, 5(3), 119–125.

http://www.academicjournals.org/ERR

Maini, A., & Heera, S. (2019). Exploring Disability Inclusion in Organizations through

Managerial Lens: Https://Doi.Org/10.1177/0972262919840193, 23(2), 144–151.

https://doi.org/10.1177/0972262919840193

Picture Exchange Communication System (PECS). (2022, May 11). Integrated

Treatment Services. https://www.integratedtreatmentservices.co.uk/our-

approaches/speech-therapy-approaches/picture-exchange-communication-system-

pecs/

McNaughton, D., Light, J., & Gulla, S. (2003). Opening up a 'whole new world': Employer

and co-worker perspectives on working with individuals who use augmentative and

alternative communication. Augmentative and Alternative Communication, 19, 235-

253.

Muller, K. (2014). *A Look at Employment for Adults Who Use Augmentative and Alternative Communication* [MA thesis]. University of Kansas.

Mulligan, J., MacCulloch, R., Good, B., & Nicholas, D. B. (2012). Transparency, Hope, and Empowerment: A Model for Partnering With Parents of a Child With Autism Spectrum Disorder at Diagnosis and Beyond. *Social Work in Mental Health*, *10*(4), 311–330. https://doi.org/10.1080/15332985.2012.664487

Pillay, Y., & Brownlow, C. (2017). Predictors of successful employment outcomes for adolescents with autism spectrum disorders: A systematic literature review. Review Journal of Autism and Developmental Disorders, 4, 1–11. doi:10.1007/s40489-016-0092-y

Richardson, L., McCoy, A., & McNaughton, D. (2019). "He's worth the extra work": The employment experiences of adults with ASD who use augmentative and alternative communication (AAC) as reported by adults with ASD, family members, and employers. *Work*, *62*(2), 205–219. https://doi.org/10.3233/wor-192856

Rispoli, M., Franco, J., Van Der Meer, L., Lang, R. and Camargo, S. 2010, The use of speech generating devices in communication interventions for individuals with developmental disabilities: a review of the literature. *Developmental Neurorehabilitation*, 13, 276–293.

Sonawane, J. V., & Varshneya, H. (2020). AVAZ application (trial version) - A voice for the nonverbal children with autism spectrum disorder: A pilot study. The Indian Journal of Occupational Therapy, 52(1), 8. https://doi.org/10.4103/IJOTH.IJOTH_2_20

Sreekanth, N. S., Varghese, N., Pradeepkumar, C. H., Vaishali, P., Ganga Prasad, R., Supriya, N. P., & Narayanan, N. K. (2016). Multimodal Interface for Effective Man Machine Interaction. Media Convergence Handbook - Vol. 2, 261–281. https://doi.org/10.1007/978-3-642-54487-3_14

Srinivasan, S., Poovaiah, R., Sen, A., Srinivasan, S., Poovaiah, Á. R., & Sen, A. (n.d.). Insights from User Testing of Jellow: A Communication Aid for Children with Developmental Disabilities. 1. https://doi.org/10.1007/978-981-10-3518-0_79

Suresh, V., & Dyaram, L. (2020). Towards a confluence: disability inclusion and organizational change. Journal of Indian Business Research, 12(4), 625–644. https://doi.org/10.1108/JIBR-03-2019-0068

Tager-Flusberg, H. (2005). Designing studies to investigate the relationships between genes, environments, and developmental language disorders. *Applied Psycholinguistics*, *26*, 29–39. https://doi.org/10.1017.S0142716405050046

Tobii Dynavox (2016). *Augmentative and Alternative Communication Needs Assessment*. http://download.mytobiidynavox.com/MyTobiiDynavox/AAC%20Needs%20Assessment.pdf

Trainor, A. A., Carter, E. W., Owens, L. A., & Swedeen, B. (2008). Special Educators' Perceptions of Summer Employment and Community Participation Opportunities for Youth With Disabilities. *Career Development for Exceptional Individuals*, *31*(3), 144–153. https://doi.org/10.1177/0885728808323717

Zisk, A. H., & Dalton, E. (2019). Augmentative and Alternative Communication for

Speaking Autistic Adults: Overview and Recommendations. *Autism in Adulthood*, *1*(2),

93–100. https://doi.org/10.1089/aut.2018.0007