

Current Status of Assistive Technology for AAC for People with Autism Spectrum Disorders in Nepal

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Abstract

This paper is focussed on the current status of usage of assistive technology for augmentative and alternative communication (AAC) for the person with autism spectrum disorder (ASD) in Nepal. ASD is marked by core features including impaired social communication, and restrictive and repetitive behaviours and interest (Diagnostic and Statistical Manual of Mental Disorders 5th Edition: DSM 5). AAC is a specific type of assistive technology that can benefit person with autism (PWA) of all ages by promoting independence, expanding communication and increasing social interactions. The major objective of this paper is to analyse the current status of AAC assistive technology for person with autism (PWA) in Nepal. The paper first analysed the assistive technology in general and then is inclined toward the current status of its development in Nepal. The research methodology of the paper included interviews and discussion sessions. The data were further reviewed based on the reports from the relevant organizations and learning outcomes from different autism related trainings and workshops. The authors visited various organizations related to autism in Nepal, Autism Care Nepal Society (ACNS) and Special School for Disability and Rehabilitation Center (SSDRC) and carried out interviews and discussions and also participated in various autism related training sessions and workshops. The findings of this paper showed that despite the high prevalence rate of autism, there is very less progress in managing ASD in Nepal and that the usage of assistive devices is limited to low tech only.

Keywords – Autism spectrum disorder, assistive technology, ACNS, SSDRC, AAC.

I. INTRODUCTION

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder characterized by deficits in social interaction and communication accompanied by repetitive and

restricted patterns of behaviour and interest [1]. Autism affects how an individual communicates and relates to other people. It is a spectrum disorder which means it has many forms that affect people in a variety of ways and in varying degrees. Each person’s experience with autism presents unique challenges as well as strengths, which define the type of support one needs to lead a fulfilling life.

Although autism can be reliably diagnosed as early as two years of development, most children are diagnosed at much later years [2]. Autism affects all ethnic and socioeconomic groups. Report shows minority groups tend to be diagnosed later and less often [3]. Early intervention provides the best opportunity to support positive developmental outcomes and deliver life-long benefits. However, there is no medical detection for autism.

Autism diagnosis involves three levels of categorization with Level 1: Requiring support; Level 2: Requiring substantial support; and Level 3: Requiring very substantial support [1]. These severity levels are assigned to two domains of autism symptoms which includes impairment in social function and restrictive, repetitive behaviours. Autism diagnosis, including the levels of severity, can help specialists and professionals to provide the right treatment and support.

A. Statistics

According to Centers for Disease Control and Prevention (CDC), 1 in 54 children is diagnosed with ASD with boys four times more likely to be diagnosed than girls [4]. An estimated 1–2% of children worldwide lie on the autism spectrum, with approximately 52 million autistic individuals across the globe.

Figure 1 presents the graphical overview of the rise in the prevalence of autism in the United States of America over the years (2008-2014), as reported by the CDC [5]. The prevalence estimates presented are for four years prior to the reported date (for example, 2018 figures are from 2014). The data shows 1 in 59 children in 2014 had a diagnosis of ASD by the age of 8, which is 15 percent higher compared to 2012.

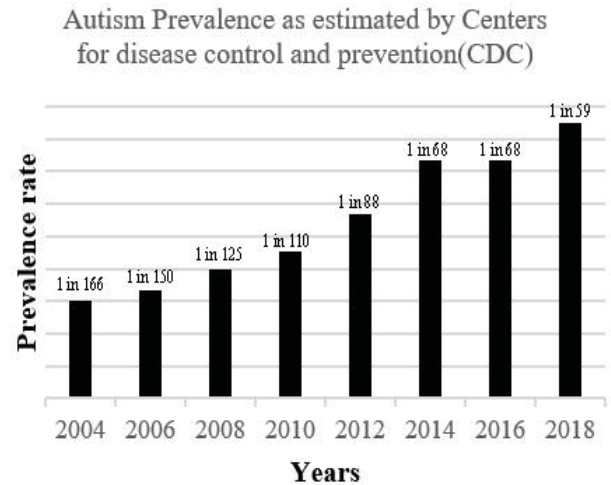


Figure 1 Autism prevalence estimated by CDC

In the context of Nepal, there isn’t exact data regarding the prevalence of ASD. A survey was conducted by Michelle Heys in 2018 [6] using the Nepali- version of an autism screening tool (Autism Quotient-10) in 4098, rural children aged between 9–13 years. Fourteen children scored > 6 out of 10, indicative of elevated autistic symptomatology, of which 13 also screened positive for disability. The study estimated the prevalence of autism at 3 per 1000 (95% confidence interval 2–5 in 1000) children considering that AQ-10 screening tool is as sensitive and specific in the Nepali population as it is in the United Kingdom.

Very few autism organizations work in Nepal. Of these, the Autism Care Nepal Society (ACNS), founded on April 2, 2008, is Nepal’s only active autism organization run by passionate parents, caring for people with autism [7]. The organization has been providing various kind of services related to autism like counselling, assessment and diagnosis, parent and child training program, therapies, teacher’s training etc. The other establishments are Aarambha pre-primary school and Aakaar vocational unit.

Based on the recent annual report (2075-2076) of ACNS [8], the total number of cases diagnosed at ACNS since its establishment till July of 2019 is 726. The data is shown graphically in Figure 2. Within the fiscal year 2075/76, the total number of autism cases diagnosed at ACNS is 118 with a female to male ration of around 1/8.

Another actively involved organization is a Special School for Disability and Rehabilitation Centre (SSDRC) [9]. It is a non-governmental and non-profit organisation established in October 2010 to support children with ASD from deprived family background to provide special education, therapeutic and related services. Started with two children with autism, the school currently has 45 autistic students with different severity level with age varying from 3 to 25 years. The school is run with the help of 26 staffs. To date, SSDRC has provided different facilities to 280 different autistic individuals. Of them, 36 children were admitted to regular school.

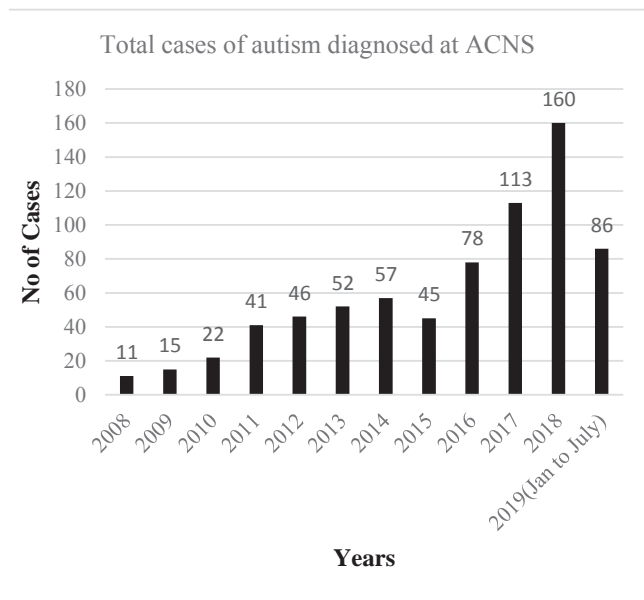


Figure 2 Total cases of autism diagnosed at ACNS

B. Treatment

Autism is a lifelong condition, but early interventions, treatment and therapy can enhance person’s quality of life [10]. Every child or adult with autism has unique strengths and challenges and so there is no generalized approach to autism treatment and intervention [11]. Each autism intervention or treatment plan should be tailored to address the person's specific needs. Intervention can involve behavioural treatments, medicines or both [12]. Many people with autism have additional medical conditions such as sleep disturbance, seizures and gastrointestinal distress [13]. Addressing these conditions can improve attention, learning and related behaviours. Although there is no medication specifically for autism, doctors often diagnose other conditions in autistic people. A

range of medications can help reduce the symptoms like irritability, aggression, obsessive behaviour, hyperactivity, impulsivity, attention deficits, mood changes, anxiety problems [13].

Educational and behavioural therapies can help autistic people, especially younger children [14][15]. These interventions can focus on particular areas that the child is finding challenging. For example, a specialized therapist may aim to improve social and language skills in a classroom, which can help an autistic child maintain conversations with others and develop the skills necessary to live independently. Some forms of therapy will involve family members or others who have regular contact with the child [16]. Participating in therapy can help family members and caregivers understand the condition and learn constructive ways to provide support.

According to the Agency of Healthcare Research and Quality (AHRQ) under the United States Department of Health and Human Services [17], ASD treatments categorized into four groups.

1. Behaviour programs
2. Education and learning programs
3. Medications
4. Other treatments and therapies

C. Assistive technology and AAC

According to the Assistive Technology Act of 2004 [18], an assistive technology device means any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities. Persons with ASD, by definition of their diagnosis, typically have difficulties with expressing themselves through spoken and written language. In severe cases, they may not be speaking at all and fail to understand spoken language, despite no underlying hearing problems. This can even be compounded by motor control issues that make the physical act of speaking difficult [19]. However, it’s incorrect to assume that non-speaking PWAs cannot communicate or speak. As such, assistive devices as means of AAC can play an important role to support and enhance communication for them, regardless of their speech ability.

Augmentative and alternative communication (AAC) is a specific type of assistive technology that can benefit people with autism of all ages by promoting independence, expanding communication, and increasing social interactions. AAC includes all of the ways of sharing ideas and feelings without talking and one often uses all forms of AAC every day like using facial expressions or gestures instead of talking, writing a note and passing it to a friend or co-worker etc. However, people with severe speech or language problems may have to rely on AAC to help them communicate. Some may need it all of the time while others may need it only for longer sentences or to communicate with people they don't know well.

AAC uses a variety of techniques and tools, like board-markers, manual signs, gestures, line drawings, speech-generating devices, eye-gaze etc, to help the individual express their feelings, needs and ideas. It is augmentative when is used as a reinforcement for existing speech, and alternative when is used in place of speech that is absent or not functional. Also, this can be temporary or permanent depending upon whether this has been used during the intensive care only, or is used as some form of AAC throughout the lifetime. [20]

II. Assistive technology as Means of AAC for ASD

Various assistive technologies as means of AAC for ASD have been developed to promote the communicative skills of people with ASD. In recent years publications on the use of assistive technologies including the areas of ASD detection, assessment, diagnosis, intervention, training, learning, environment control, communication, mobility, and access have increased significantly.

The assistive technology for ASD has been broadly categorized into three groups [21]:

1. Low tech assistive technology
2. Mid tech assistive technology
3. High tech assistive technology

Low tech assistive technology are visual support strategies which do not include any type of electronic equipment and are usually low cost and easy to use. These includes dry erase boards, clipboards, 3-ring

binders, manila file folders, photo albums, laminated photographs, highlight tape etc. Mid tech assistive are battery operated devices or the ones using simple electronic devices and often requiring limited advancements in technology. With the growth in the technology, this has become the least common form of technology being used. These include tape recorder, Language Master, overhead projector, timers, calculators, and simple voice output devices.

High tech assistive technology includes high-end electronic equipment and implements complex technological support strategies. These are comparatively of higher cost. These includes video cameras, computers and adaptive hardware, complex voice output devices etc. With the advancement in technology these are gaining higher popularity.

A. Current practices

The use of technology-based interventions for improving ASD core deficits has been growing in popularity, and a variety of technologies such as mobile computing, virtual reality or robotics have been introduced [22]. Virtual reality (VR) based training have also been found to be useful to improve the social skills [23]. A significant increase in social cognitive measures of theory of mind and emotion recognition was observed during a VR based social cognitive intervention, conducted among the eight adults with high functioning autism.

Visual Activity Schedules are often used to help children with ASD cope with the challenges posed by various activities or behaviours during an individual task or throughout the day [24]. For children with autism, they promote independence and predictability, and help with transitioning between activities [25]. There has also been development of virtual reality (VR) to improve the skills of person with ASD. A research has been done where VR is tested for teaching street-crossing skills [26]. During the research, the experimental group which included six children with ASD, showed substantial improvement in their ability to cross the virtual street safely after intervention. Also, by the end of the research, three of them made considerable improvement in their pedestrian behaviour within the protected real-street setting following the VR intervention.

Social Stories are also introduced among the children with ASD to enhance their social skills [27]. Social stories represent short stories describing certain situations, events or activities that follow a set of criteria. They aim to teach children with ASD about certain situations or events, such as dressing up, and also preparing them for new events, such as moving house. Different android applications [28] [39] have been developed to create Visual Activity Schedules [29] and Social Stories [30] to support practitioners working children with ASD.

B. High tech AAC for ASD

High tech AAC for ASD may comprise of computer-based system or mobile application that can be loaded into the devices. One of the major beneficial features of high tech AAC is that they are highly customizable and consequently can provide personalized settings. Next, they are usually adaptable to the needs of user. Currently the mobile applications are gaining popularity due to the fact that they are easily available and are comparatively cheaper. Moreover, various studies showed that these are relatively easy to operate too [31]. Due to the several advantages of using mobile apps as means of high-tech AAC, they are also replacing the low-tech AAC modalities like PECS [32]. Also, mobile apps as means of high tech AAC has helped in greater uptake of AAC with children with ASD [33].

Various researches have been conducted to test the effects of high tech AAC on persons with ASD. Those have demonstrated the positive effects of AAC for children with ASD [34][35][36][37]. However, few papers have also pointed out the need for further research in the area of such interventions involving high tech assistive devices for children with ASD and the potential impact of its long-term effect on their communication skills [38].

C. Current assistive technology for ASD in Nepal

Regarding assistive products in Nepal, as per Nepal's Priority Assistive Product List [40], assistive technology is defined as the application of organized knowledge and skills related to assistive products, including systems and services. Also, it has defined assistive products as any external products (including

devices, equipment, instruments or software), especially produced or generally available, whose primary purpose is to maintain or improve an individual's functioning and independence, thereby promoting their well-being. Assistive products are also used to prevent impairments and secondary health conditions.

Forty-five different devices have been categorized under six different heads. It also mentioned the usage of high-tech devices for augmentative and alternative communication (AAC). Besides, it also encourages the use of high-tech devices like smart phones, tablets, personal digital assistants (PDAs) etc for the cognitive and communicative assistance. However, the assistive technology being used in Nepal has been confined to low tech assistive devices.

The frequently used low tech assistive technology includes:

1. Social Stories
2. Social Scripts
3. Turn Taking cards
4. Social Rule cards
5. Sign language
6. Gestures
7. Visual schedules
8. Compartment Object Communicator
9. Paper Communication Cards/Books – pages of symbols organized by topic
10. Picture Exchange Communication System (PECS)
11. E-Tran Frames – the student uses eye-gaze to indicate word or symbol

While low technology systems are convenient and portable, they limit the user's vocabulary, preventing the user from conveying abstract thoughts. Although it offers some limitations, low technology devices are a great starter system for an AAC user and can be created or purchased at minimal cost. The user can also continue to use his/her low technology device even if more complex technologies are introduced.

D. Popular low-tech assistive technology for ASD in Nepal

The most popular low-tech assistive technology and found being used at both ACNS and SSDRC are Signs and gestures, PECS and Visual Schedule.

Signs and Gestures are also referred as no tech assistive technology. Research demonstrates that signs/gestures and the PECS are effective in helping some children with ASD communicate more effectively [41]. Some children with difficulty learning to talk may use their hands to communicate more easily. Children with ASD may be taught signs or gestures similar to “Baby Signs”. For example, a child may learn to bring his fingertips to his mouth to indicate hunger. Signs/gestures are portable, can incorporate an unlimited number of words, and fast-paced as well.

Children with ASD usually respond well to visual information [42]. They can easily learn PECS. PECS makes communication more concrete, visual, and lasting than spoken messages. Further, PECS requires minimal initial communication skills and only simple motor movements. Initially, a child learns to give a picture of a desired object or activity to a communication partner in return for access to that object or activity. Over time, the child learns to use PECS to communicate increasingly complex messages through systematic PECS instruction for a variety of functions (e.g., requesting, protesting, and commenting). Children with ASD may improve spoken language abilities, requesting, joint attention, and problem behaviours.

Since most children with ASD are visual learners, visual schedules can use this strength by adding images to help children with ASD understand language more easily. As a result, children can successfully complete daily activities. ACNS and SSDRC have been using mostly visual schedules to teach the children with ASD.

E. High tech assistive technology for ASD in Nepal

Currently, there is no any high-tech assistive technology for ASD in Nepal. At ACNS, few years back, the team of engineering students developed an android app named, “Beautiful mind” that could aid the children with ASD at ACNS, with support from UNICEF. The android application had parent section and child section, with login system for parents. Within

child section, there were different activities like drawing board, colour fillers etc that were supposed to be engaging for the children. One of the important features of the application was the evaluation graph which could keep track of the time that children spend in specific section and thus could be helpful in knowing the likes and dislikes of the children. However, administrative staffs at ACNS reported that development of this app couldn't reach its full potential as developers were not able to figure out the way to implement it across different devices. Right now, ACNS does not have any such working app.

III. Need of research on high tech assistive technology in Nepal

Both ACNS and SSDRC reported the need of high-tech assistive devices and they also think about building one. But the lack of resources, including human resources and enough budget held them back. Both organizations said that the current trend of low-tech assistive devices could be replaced well by high tech assistive devices and that this will help a lot in managing the cumbersome works such as preparing paper schedules, searching for appropriate pictures, then printing and laminating them. All these works require a good amount of time as well as a lot of waste papers. So, the use of high tech can help manage those. High-tech assistive devices could facilitate both time and waste management.

ACNS and SSDRC also reported that autistic children at their centres seems very inclined towards technology like using smart phones. So, the same interest could be used to ease their lives and get along with social rules.

IV. CONCLUSION

This paper discussed possible assistive devices for people with ASD and the current practice of their usage within Nepal. The findings show two actively involved autism organisation (ACNS and SSDRC) in Nepal have been using low tech assistive devices in their intervention programs. However, the use of high-tech assistive devices is negligible. Since using such high-tech devices could help a lot in easing their life style as well as helping in their learning attitude, it is a prime time to initiate the study and research on these as early as possible. This could be initiated with the literature review of ongoing practices of such devices around the

globe and then modulating those according to the need of people with ASD of Nepal.

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