INTRODUCING THERAPEUTIC ROBOTICS FOR AUTISM

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INVESTOR IN PEOPLE

To Zuna, my soulmate!
(Professor Raheel Nawaz)

To Najla Ali, my mother!
(Dr Sara Ali)

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LIST OF ABBREVIATIONS

AAC	Augmentative and Alternative Communication
ABA	Applied Behaviour Analysis
ADL	Activities of Daily Life
ADDM	Autism and Developmental Disabilities Monitoring
ADI-R	Autism Diagnostic Interview-Revised
ADOS	Autism Diagnostic Observation Schedule
ADOS-G	Autism Diagnostic Observation Scheduled – Generic
AI	Artificial Intelligence
ASD	Autism Spectrum Disorder
ASSQ	Autism Spectrum Screening Questionnaire
AT	Assistive Technology
BCI	Brain–Computer Interface
CARS	Childhood Autism Rating Scale
CBT	Cognitive Behavioural Therapy
CDC	Centers for Disease Control and Prevention
CHAT	Checklist for Autism in Toddlers
DSM	Diagnostic and Statistical Manual of Mental Disorders
EEG	Electroencephalogram
ESDM	Early Start Denver Model
GUI	Graphical User Interface
hHRL	hierarchical Human–Robot Learning
HRI	Human–Robot Interaction
LTM	Least-to-Most
ML	Machine Learning
MMR	Measles-Mumps-Rubella
M-CHAT	Modified Checklist for Autism in Toddlers
OT	Occupational Therapy
PC	Personal Computer
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder Not Otherwise Specified
RAAT	Robot-Assisted Autism Therapy

RAT	Robot-Assisted Therapy
SAR	Socially Assistive Robots
SCQ	Social Communication Questionnaire
SDGs	Sustainable Development Goals
SGD	Speech Generating Device
SRS	Social Responsiveness Scale
TEACCH	Treatment and Education of Autistic and Related Communication Handicapped Children
TD	Typically Developed
VR	Virtual Reality
VSD	Visual Scene Display
WOZ	Wizard of Oz
WHO	World Health Organization

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1

INTRODUCTION TO AUTISM – UNIQUELY HUMAN

Autism Spectrum Disorder (ASD) can present significant social, communication and behavioural challenges to those who suffer from it and their carers (e.g. parents and relatives). Considering the sensitivity and significance of ASD, this work will discuss the latest techniques to improve the communication and behaviour of children using Robot-Assisted Therapies (RATs). The work will discuss autism, the prevalence of autism, state-of-the-art and impact of RATs and their associated problems. It will outline robotic interventions which can be carried out at home, making it accessible to carers without the need of a therapist. This review considers the diversity of our audience, hence, the language used is simple, terminologies explained, and practical recommendations are made for carers, therapists, psychologists, roboticists and researchers in the cognitive sciences, Artificial Intelligence (AI) and Human–Robot Interaction (HRI). Although, some work exists in the domain of RATs, scarcely any work exists discussing RAT for children with ASD, their impact, and future policies.

The first chapter of our book will discuss autism itself along with its history, assessment and use of robots for therapy. This includes outlining autism as a clinical condition, its prevalence, scales of assessment, causes and prognosis among children. Following the introduction, the impact of autism on the development and behaviour of children is discussed before connecting it to the clinical findings and therapeutic intervention. Later chapters will discuss RAT for children with ASD and its impact before concluding with some recommendations and policy proposals.

1.1. WHAT IS AUTISM?

ASD is defined as a developmental disability with recurrent deficits in social interaction and the existence of confined, repetitive patterns of behaviours, interests or activities (American Psychiatric Association & Others, 2013). Some common characteristics of ASD are avoiding eye contact, difficulties with emotional regulation or interpreting feelings, and exhibiting a limited range of activities and interests (American Psychiatric Association & Others, 1980). Other most recurring features of ASD are atypical patterns of activities and behaviours, for example, difficulty in transitioning from one activity to another, focussing on minutiae and atypical reactions to stimuli (World Health Organization (WHO), 2022). Epilepsy, depression, anxiety and attention-deficit hyperactivity disorder are some of the commonly co-occurring disorders in individuals with autism. Children with ASD can hide some of their emotional expressions while interacting. They can also miss some important signs of non-verbal communication (e.g. body language and in particular facial emotions) (Moore, 2002). Furthermore, children with autism show limited adaption to change and generalisation of learnt skills (Lahiri, 2020).

It is thought that ASD affects about 7.5 million people globally. A report from the Centers for Disease Control and Prevention (CDC) in 2020 states that around 1 in 54 children are diagnosed with ASD and lack communication skills including verbal, non-verbal and social cues. The reports mentioned that autism is four times more dominant in boys than girls across all races, ethnicities and social groups (Maenner et al., 2020). As mentioned earlier, social and communication skills are significantly affected in children with ASD, which means the condition directly affects the lifestyles of their family members. Direct family members who are carers of children with ASD can find it difficult to acquire a job that can accommodate their responsibilities, affecting their social and economic lifestyle.

Five different types of Pervasive Developmental Disorders (PDDs) are recognised: Autistic Disorder; Asperger's Disorder; Rett's Disorder; Childhood Disintegrative Disorder; and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). Asperger syndrome is closest to autism in terms of symptoms and causes with some differences, for example, no substantial delay in language and cognitive development (Volkmar, State, & Klin, 2009). Autism, Asperger syndrome and PDD-NOS are all referred to as ASD (American Academy of Pediatrics Council on Children With Disabilities, 2007) or autistic disorders (Freitag, 2007), whereas autism is also referred as autistic disorder, childhood autism or infantile autism. The present work will refer to 'autism' as the basic autistic disorder; nonetheless, it is essential

to mention that autism, ASD, and PDD are all used interchangeably in clinical practice (Caronna, Milunsky, & Tager-Flusberg, 2008).

Autism symptoms are identified at an early age; however, it is rarely diagnosed at the initial stages. The first indication usually occurs when a child is at the age of three. Before the symptoms of autism are discussed, it is important to mention that every individual has different needs depending on the level of autism they experience. Some can live an independent life, whereas others may require lifelong care and assistance. With that acknowledgement, we shall discuss the symptoms of autism in detail.

1.1.1. Spectrum of Autism

Often the word 'spectrum' is associated with autism. This refers to the range of symptoms that children with ASD can exhibit, encompassing a wide variety of skills deficits. These varying impairments may include delayed developments, repetitive behaviour such as hand flapping and rocking, high-functioning individuals with active but distinctly odd social approaches, narrowly focussed interests, verbose and pedantic communication (Happé, 1999). Since the spectrum of behaviour is infinite, the distinction between diagnostic categories must be arbitrary (Geschwind, 2009).

1.2. HISTORY OF AUTISM

Eugen Bleuler, who was a psychiatrist, coined the term 'autism' in 1908 to characterise a schizophrenic patient who locked himself from the outside world. The word 'autism' has an interesting epistemology. Autism is derived from the Greek word 'autós,' which is defined as 'morbid self-admiration and seclusion inside oneself' (Bleuler, 1912).

Later in the 1940s, Hans Asperger and Leo Kanner were considered pioneers for their contribution to research in autism, where Kanner studied seriously affected young individuals and Asperger studied highly capable children. They researched these two extreme cases for three decades and their research and ideas are being still used by doctors (Kanner, 1943). Leo Kanner's study group consist of 11 children with the following characteristics:

- Difficulty in social life
- Difficulty in adapting to changes in routine
- Sensitivity to stimuli (especially sound)

- Food resistance and allergies
- Good intellectual potential
- Echolalia (tendency to repeat words).

Hans Asperger group had the same characteristics except the group did not have the problem of Echolalia. He, however, added to the description of these children that they differ in behaviour and motor skills. Afterwards, another psychologist Bruno Bettelheim investigated the effects of therapy sessions conducted on children with autism. He observed that children with autism all had emotionally 'cold' mothers, and later proposed this as his hypothesis. However, the hypothesis was soon rejected by Bernard Rimland, who himself had a child with autism. Autism gained more recognition in the 1970s and 1980s. The Erica Foundation started to provide counselling and education to psychotic children that included autistic children as autism was being misdiagnosed as 'mental retardation' or psychosis. Later the work of Asperger was translated into English, which gained attention among researchers. The work convinced many that it is caused by neurological disorders and other genetic illnesses such as tuberous sclerosis, metabolic disturbances such as Phenylketonuria (PKU), or chromosomal abnormalities such as fragile X syndrome, rather than by parenting. This renewed interest in the domain of autism led to many notable events since this period, including (Parents, 2022):

- In 1980, 'Infantile autism' was included as a condition in the Diagnostic and Statistical Manual of Mental Disorders (DSM) rather than under schizophrenia among children.
- In 1987, the DSM replaced 'infantile autism' with a more extensive definition of 'autism disorder' which included a checklist of diagnostic criteria.
- In 1988, the hit film 'Rain Man' was released which raised popular awareness of the condition. In it, Dustin Hoffman acted as an autistic savant with a photographic memory and an ability to calculate huge numbers in his head.
- In 1991, the US Federal Government classified 'autism' as a special category within Education, leading public schools to recognise the special treatment for children with autism.
- In 1994, Asperger's Syndrome was added to the DSM, including the individuals with high-functioning capability.
- In 1998, a study published in Lancet claimed that the measles-mumps-rubella (MMR) vaccine causes autism which was later debunked.

- In 2000, vaccine producers removed a mercury-based preservative called thimerosal from all routinely given paediatric vaccines.
- In 2009, US CDC started the estimation of autism approach which significantly helped screening and diagnostic techniques.
- In 2013, DSM-5 was presented according to which all subcategories of the condition were placed under a single umbrella diagnosis of ASD.

From 2013 onwards, experts have viewed autism as a continuous spectrum of conditions. There have been no further revisions to the DSM-5.

1.3. PREVALENCE OF AUTISM

The recognition of Autism led to many further studies and the recording of cases by medical practitioners. As a result, in the last few decades, an increasing number of autism cases have been diagnosed. In the 1960s–1970s, the initial investigation in Europe and United States suggests 2–4 cases per 1,000 children (Lotter, 1967; Rutter, 2005). This number increased drastically following the diagnostic criteria of autism in the late 1980s–1990s (Fombonne, 2009; Rice, 2013; Rutter, 2005).

The United States accepted 'ASD' in the category of those who are eligible for receiving special education, significantly increasing the number of children enrolled in the education system under this category. Often children who were misdiagnosed or classified as having an intellectual impairment were now classified as autism through a process known as 'diagnostic substitution', contributing to the rise in ASD cases among children (Maenner et al., 2014). Epidemiological studies also suggest that the development of diagnostic criteria and incorporation of the concept of autism as a spectrum of impairments during the later decades of the twentieth century can be attributed to the rise in prevalence of autism (Fombonne, 2009; King & Bearman, 2009; Rice, 2013). Other factors like increased clinician training, availability of standard screening and diagnostic tools, media awareness and outreach are also recognised as contributing to the increase in the prevalence rate.

The CDC has been tracking autism cases since 1996 and later formed the Autism and Developmental Disabilities Monitoring (ADDM) Network. Since 2010, the ADDM Network has been collecting data on ASD prevalence and its early detection among children aged 4 years. The CDC estimated that there are about 5.5 million adults with ASD in the United States (2.21% of the total population) (CDC, 2022). Data from modelling of state-based populations and parent surveys suggest a significant gender-bias, with more men affected than women [4.3 million male adults (3.62%) compared to 1.1 million female

adults (0.86%)] (CDC, 2022). The prevalence trend of autism reported in the United States is based on four different data types which include:

1. Epidemiologic studies
2. Special education 'child counts'
3. Administrative data on developmental services from the state of California
4. National surveys based on parental reports.

To keep the records at national level, large-scale, nationally represented population-based epidemiologic studies should be undertaken regularly, thereby, employing verified and similar techniques and diagnostic criteria over time.

The ADDM Network tracks the prevalence of ASD at the age of eight years, since at this age they are more likely to have the disorder throughout their childhood. Since 2000, they have monitored ASD in 8-year-old children every two years in various US sites, implementing procedures that have been consistent throughout time and are based on the DSM, 4th Edition diagnostic criteria (American Psychiatric Association & Others, 2013). Furthermore, it has been established through research that the median age at which a formal diagnosis of ASD is declared is 5.2 to 5.7 years (Tribune, 2022). Pharmacological and Interventional therapies have shown promising results for ASD patients besides the traditional education and behavioural therapies. For example, a few people have improved after receiving some interventional treatment, e.g. deep brain stimulation.

Unfortunately, even after so much awareness about autism, it is considered a stigma and therefore under reported or not reported at all in some countries. For example, according to the Pakistan Autism Society, around 400,000 children in Pakistan are diagnosed with ASD. However this number is under-reported because many are reluctant to report a mental disorder (Shattuck, 2006).

1.4. PRELIMINARY ASSESSMENT AND SCREENING OF AUTISM

Initial diagnostics are often done by the parents or carers of children with ASD. About half of the parents are reported to be aware of their child's atypical behaviour when their child is only 18 months and about 4/5th are aware of this behaviour when the child is about 24 months. The usual atypical behaviour among children includes missing the milestone, such as

- no response to their name by the age of 6 months
- no eye-to-eye gaze contact

- absence of babbling by the age of 12 months
- lack of gestures
- non-appearance of a single word by age of 16 months
- no phrases (2 words or more) by the age of 24 months
- lack of general social and language skills.

Failure to achieve any of these milestones is a key indicator of potential ASD and parents should proceed with further evaluation of autism. By the age of 18 months, half of the parents of children with ASD are aware of their child's atypical behaviours, and about four-fifths are aware by the age of 24 months (Landa, 2008). The usual behaviour of a child includes missing the milestone; no response to the name by the age of 6 months, no eye-to-eye gaze contact, absence of babbling by the age of 12 months, no gestures, non-appearance of a single word by age of 16 months or no phrases (2 words) by the age of 24 months, lack of social and language skills. Failure to achieve any of the mentioned milestones is the key indicator that parents should proceed with further evaluation for autism. A delay in evaluation or non-early diagnosis can have long-term effects. The trend for screening the child for autism varies in different parts of the world. For example, in Japan, the screening of all children is done at 18 and 24 months whereas in the UK only children whose parents or doctors find early signs of autism are screened.

There are different screening tools available for rating autism. The Checklist for Autism in Toddlers (CHAT), Modified Checklist for Autism in Toddlers (M-CHAT) and the Early Screening of Autistic Traits Questionnaire are a few of the early screening tools available (Landa, 2008). However, these tools do not distinguish autism from other developmental disorders. For this purpose, wideband screening tools should be used that may or may not include genetic screening, depending upon the case (Lintas & Persico, 2009).

1.5. SCALES FOR AUTISM ASSESSMENT

As outlined, Autism can be characterised by the difficulty in forming social bonds, maintaining social contact and atypical interest profile. This behaviour leads to the use of repetitive language, which results in delayed language acquisition and development of language (Dumont-Mathieu & Fein, 2005). This restricted children's ability to imitate and participate in play after having stereotyped body movements and usual association with objects (American Psychiatric Association & Others, 2013). Even though the mentioned

characteristics are usually obvious to observers, there remains a need for quantifiable measures through which assessments of the disorder's severity can be obtained. To achieve a quantifiable measure, different scales and measures are available, e.g. Childhood Autism Rating Scale (CARS), Social Responsiveness Scale (SRS), Autism Diagnostic Observation Scheduled – Generic (ADOS-G), Autism Diagnostic Interview-Revised (ADI-R), and Social Communication Questionnaire (SCQ).

The scales are designed to obtain detailed feedback from either carers or parents, which is then used to quantify the level of severity of the autism. For example, the SRS scale is based on 65 questions in the form of a questionnaire, where each response is ranged from 'Not True' to 'Almost Always True'. The given questionnaire is filled by carers or parents of children between the age group of 4 and 8 years (Constantino et al., 2003). This test has strong psychometric qualities and cross-cultural validity in the assessment of autism, helping to quantify the severity of autism-related symptoms (Rutter, Bailey, & Lord, 2003).

The SCQ test is similar to SRS and has 40 questions. The questions required binary responses from parents and carers who have detailed information about their children's developmental behaviour. The available versions of SCQ are 'Current' and 'Lifetime'. The SCQ score can be used to discriminate ASD from non-ASD individuals (Rutter, Bailey, et al., 2003). The ADI-R scale consists of 93 items through input from caregivers in the form of a semi-structured interview. The scale can be applied to individuals with a mental age above 18 months. Some questions in SCQ are adapted from ADI (Lord et al., 1997).The most simple and relevant scale is CARS, which was developed by Schopler, Reichler, and Renner (1988). It consists of a 15-item questionnaire, which uses a 4-point Likert scale to score the behaviour of an individual ranging from 1, which represents no evidence of autism, to 4, which represents severe autism. This is generally used for children above 2 years. The 14 categories within this test deal with the behaviour associated with autism, while the 15th category is used to rate the general symptoms of autism in the individual (Chlebowski, Green, Barton, & Fein, 2010).

Another important scale is the high-functioning Autism Spectrum Screening Questionnaire (ASSQ), which consists of 27 items used for evaluating symptoms that distinguish between Asperger syndrome and other high-functioning ASDs. The questionnaire uses a 3-point rating scale, where 0 is used to denote 'normalcy', 1 for 'abnormality' and 2 for 'substantial abnormality'. The awarded score from this scale can be between 0 and 54. The scale, however, does not work with the individuals with low-functioning autism, i.e. the ones with moderate-severe mental retardation. An updated, extended version of ASSQ (ASSQ-REV) also exists particularly for screening the female phenotype of ASD (Kopp & Gillberg, 2011).