SOCIAL-ECONOMICAL ASPECTS OF AUTISM SPECTRUM DISORDERS

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ABSTRACT: *Autism has life-time consequences with a range of impacts on the health, economic wellbeing, social integration and quality of life of individuals with the disorder, and also on their families and potentially the rest of society.*

KEY WORDS: *autism spectrum disorders (ASD), disability, health, economic wellbeing, discrimination, quality of life.*

JEL CLASSIFICATIONS: *I14, J14.*

1. INTRODUCTION

Autistic spectrum disorders are more common than was previously estimated, although there is considerable debate about the extent to which this represents a real underlying increase in prevalence rather than changes in diagnostic criteria or improvements in identification. What is agreed, however, is that there is much greater public awareness of autism today than ever before. The impact of ASDs upon the health, economic and social wellbeing of individuals, their families and the rest of society varies from individual to individual depending on a variety of factors, including age, level of cognition and ability to live independently. While interventions and services currently used to support people with ASDs all impose costs, either to the state or to a charity or to the families of people with ASDs, their availability remains low and unevenly spread, so that the burdens and stresses experienced by families tend to persist.

As well as bearing the practical burdens and perhaps psychological stresses of having a child with an ASD, and facing family disruption and in some cases even breakdown, many parents and families also experience disruption to their employment, constraints on career progression and consequent losses in earnings.

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2. CONCEPTUAL ISSUES

Autism is a neurodevelopmental disorder characterized by difficulties with social interaction and communication, and by restricted and repetitive behavior (Autism Spectrum Disorder, 299.00 (F84.0)). Parents often notice signs during the first three years of their child's life. These signs often develop gradually, though some autistic children experience regression in their communication and social skills after reaching developmental milestones at a normal pace (Stefanatos, 2008).

Autism is associated with a combination of genetic and environmental factors (Chaste & Leboyer, 2012).

Globally, autism is estimated to affect 24.8 million people as of 2015. In the 2000s, the number of autistic people worldwide was estimated at 1–2 per 1,000 people. In the developed countries, about 1.5% of children are diagnosed with ASD as of 2017, from 0.7% in 2000 in the United States. It is diagnosed four to five times more often in males than females. The number of people diagnosed has increased considerably since the 1990s, which may be partly due to increased recognition of the condition (Russell, et al., 2021).

2.1. Social development

Social deficits distinguish autism and the related autism spectrum disorders from other developmental disorders (Rapin & Tuchman, 2008). Autistic people have social impairments and often lack the intuition about others that many people take for granted.

Unusual social development becomes apparent early in childhood. Autistic infants show less attention to social stimuli, smile and look at others less often, and respond less to their own name.

Children with high-functioning autism have more intense and frequent loneliness compared to non-autistic peers, despite the common belief that autistic children prefer to be alone. Making and maintaining friendships often proves to be difficult for autistic people. For them, the quality of friendships, not the number of friends, predicts how lonely they feel. Functional friendships, such as those resulting in invitations to parties, may affect the quality of life more deeply (Burgess & Gutstein, 2007).

2.2. Communication

About one third to half of autistic people do not develop enough natural speech to meet their daily communication needs (Noens, et al., 2006). Differences in communication may be present from the first year of life, and may include delayed onset of babbling, unusual gestures, diminished responsiveness, and vocal patterns that are not synchronized with the caregiver. In the second and third years, autistic children have less frequent and less diverse babbling, consonants, words, and word combinations; their gestures are less often integrated with words. Autistic children are less likely to make requests or share experiences, and are more likely to simply repeat others' words (echolalia) or reverse pronouns. Joint attention seems to be necessary for functional speech, and deficits in joint attention seem to distinguish infants with ASD (Johnson & Myers, 2007). For example, they may look at a pointing hand instead of the pointed-at object, and they consistently fail to point at objects in order to comment on or share an experience. Autistic children may have difficulty with imaginative play and with developing symbols into language (Landa, 2007).

In a pair of studies, high-functioning autistic children aged 8–15 performed equally well as, and as adults better than, individually matched controls at basic language tasks involving vocabulary and spelling. Both autistic groups performed worse than controls at complex language tasks such as figurative language, comprehension, and inference. As people are often sized up initially from their basic language skills, these studies suggest that people speaking to autistic individuals are more likely to overestimate what their audience comprehends.

2.3. Repetitive behavior

Autistic individuals can display many forms of repetitive or restricted behavior, which the Repetitive Behavior Scale-Revised (RBS-R) categorizes as follows:

- <u>Stereotyped behaviors</u>: Repetitive movements, such as hand flapping, head rolling, or body rocking.
- <u>Compulsive behaviors</u>: Time-consuming behaviors intended to reduce the anxiety that an individual feels compelled to perform repeatedly or according to rigid rules, such as placing objects in a specific order, checking things, or handwashing.
- <u>Sameness</u>: Resistance to change; for example, insisting that the furniture not be moved or refusing to be interrupted.
- <u>Ritualistic behavior</u>: Unvarying pattern of daily activities, such as an unchanging menu or a dressing ritual. This is closely associated with sameness and an independent validation has suggested combining the two factors.
- <u>Restricted interests</u>: Interests or fixations that are abnormal in theme or intensity of focus, such as preoccupation with a single television program, toy, or game.
- <u>Self-injury</u>: Behaviors such as eye-poking, <u>skin-picking</u>, hand-biting and head-banging

No single repetitive or self-injurious behavior seems to be specific to autism, but autism appears to have an elevated pattern of occurrence and severity of these behaviors (Bodfish, et al., 2000).

2.4. Other symptoms

Autistic individuals may have symptoms that are independent of the diagnosis, but that can affect the individual or the family. An estimated 0.5% to 10% of individuals with ASD show unusual abilities, ranging from splinter skills such as the memorization of trivia to the extraordinarily rare talents of prodigious autistic savants.

Many individuals with ASD show superior skills in perception and attention, relative to the general population. Sensory abnormalities are found in over 90% of autistic people, and are considered core features by some, although there is no good evidence that sensory symptoms differentiate autism from other developmental disorders (Ben-Sasson, 2009). Selectivity is the most common problem, although eating rituals and food refusal also occur.

3. DIAGNOSIS AND EDUCATION

Diagnosis is based on behavior, not cause or mechanism. Under the DSM-5, autism is characterized by persistent deficits in social communication and interaction across multiple contexts, as well as restricted, repetitive patterns of behavior, interests, or activities. These deficits are present in early childhood, typically before age three, and lead to clinically significant functional impairment. Sample symptoms include lack of social or emotional reciprocity, stereotyped and repetitive use of language and persistent preoccupation with unusual objects (Autism Spectrum Disorder, 299.00 (F84.0)).

Educational interventions often used include applied behavior analysis (ABA), developmental models, structured teaching, speech and language therapy, social skills therapy, and occupational therapy and cognitive behavioral interventions in adults without intellectual disability to reduce depression, anxiety, and obsessive-compulsive disorder. Among these approaches, interventions either treat autistic features comprehensively, or focalize treatment on a specific area of deficit. The quality of research for early intensive behavioral intervention (EIBI) - a treatment procedure incorporating over thirty hours per week of the structured type of ABA that is carried out with very young children - is currently low, and more vigorous research designs with larger sample sizes are needed. Two theoretical frameworks outlined for early childhood intervention include structured and naturalistic ABA interventions, and developmental social pragmatic models (DSP). One interventional strategy utilizes a parent training model, which teaches parents how to implement various ABA and DSP techniques, allowing for parents to disseminate interventions themselves. Various DSP programs have been developed to explicitly deliver intervention systems through at-home parent implementation. Despite the recent development of parent training models, these interventions have demonstrated effectiveness in numerous studies, being evaluated as a probable efficacious mode of treatment (Simpson, et al., 2003).

Early, intensive ABA therapy has demonstrated effectiveness in enhancing communication and adaptive functioning in preschool children; it is also well-established for improving the intellectual performance of that age group. Similarly, a teacher-implemented intervention that utilizes a more naturalistic form of ABA combined with a developmental social pragmatic approach has been found to be beneficial in improving social-communication skills in young children, although there is less evidence in its treatment of global symptoms. Neuropsychological reports are often poorly communicated to educators, resulting in a gap between what a report recommends and what education is provided. It is not known whether treatment programs for children lead to significant improvements after the children grow up, and the limited research on the effectiveness of adult residential programs shows mixed results. The appropriateness of including children with varying severity of autism spectrum disorders in the general education population is a subject of current debate among educators and researchers (Simpson, et al., 2003).

Medications may be used to treat ASD symptoms that interfere with integrating a child into home or school when behavioral treatment fails. They may also be used for associated health problems, such as ADHD or anxiety. More than half of US children diagnosed with ASD are prescribed psychoactive drugs or anticonvulsants, with the most common drug classes being antidepressants, stimulants, and antipsychotics (Sanchack & Thomas, 2016).

4. ANALYSIS OF THE RECENT STUDIES ABROAD ON AUTISM TOPIC

A pooled dataset on children with ASD was drawn from American studies of children with intellectual disabilities and/or mental health problems. From each of these datasets the information on all of those children with autism or those diagnosed as having a pervasive developmental disorder (PDD) was extracted. (Foundation for People with Learning Disabilities).

The aggregate national costs of supporting children with ASD are estimated to be $2.7 billion per annum, of which $1.7 billion is accounted for by children with ASDs and learning disabilities living with their families, $72 million by children with ASDs and learning disabilities living in residential or foster placements, and $1 billion by children with high-functioning ASD living with their families. By age group, it is estimated that only a small cost is accounted for by pre-school children ($3 million), $1.3 billion by those aged 4-11, and $1.4 billion by those aged 12-17. Across all age groups and levels of functioning, 95% of the total national cost for children is accounted for by services, and 5% by family expenses.

The annual costs for children with an ASD and a learning disability who are living in residential or foster placements are estimated to be $16,185 (if aged 0-3), $40,578 (aged 4-11) and $62,536 (aged 12-17). For the two older age groups the largest contributors to these totals are the care placements themselves, and special education. For children with an ASD and a learning disability who live with families, the costs are much lower: $585 (if aged 0-3), $23,869 (aged 4-11) and $36,474 (aged 12-17). For the two older age groups the largest contributors to these totals are special education, and health and social care services (including hospital and respite care). The annual costs for children with a high-functioning ASD are $1,683 (if aged 0-3), $21,559 (aged 4-11) and $31,559 (aged 12-17). Again, special education is a major element of the total.

For an adult with high-functioning ASD the annual cost of living in a private household (with or without family) is estimated to be $32,681. A sizeable part of this ($19,785) is the imputed cost of lost employment for the individual with ASD (and hence also lost productivity to the economy). Costs for high-functioning adults in supported living settings or care homes are much higher ($84,703 and $87,299 per annum respectively), and the proportion attributable to lost employment is lower. Not surprisingly, the largest cost element in each case is for accommodation, and this includes the costs of support staff. For adults with an ASD and a learning disability, the mean annual costs (excluding benefits but including lost employment) are calculated to be $36,507 for those living in private households, $87,652 in Supporting People settings, $88,937 in residential care and $97,863 for those living long-term in hospital. For people in private households the largest service cost elements are associated with day care, respite services, and adult education. For people in Supporting People settings and residential care, the largest cost element is accommodation itself.

The research has a number of implications for policymakers, the providers of public services and the families of people with ASD.

Firstly, people with ASD appear to be high users of public services and this research demonstrates, for the first time, the breadth of the impact of this complex set of disorders. Secondly, a high proportion of the overall cost of ASD falls to families, whether in terms of out-of-pocket expenses, lost employment opportunities and income or time spent providing informal care, commonly with considerable psychological impacts. The question raised by these high costs is whether this burden – economic and otherwise – is reasonable for a society to expect of families. Thirdly, the high costs associated with supporting adults with ASD warrant attention because there ought, potentially, to be some scope for reducing them by making more widely available those early interventions that have been shown to alter patterns of behavior. Investment in support to families may prevent children being placed in expensive residential accommodation away from home. Fourthly, , the high costs of lost employment/ productivity for people with ASD and their families stand out. Very few people with autism are in employment and will need specialized support to find and remain in work.

5. COST OF TREATMENTS FOR AUTISM SPECTRUM DISORDERS

Without question, autism research and treatment are big business. Autism impacts multiple aspects of the lives of individuals with autism spectrum disorder (ASD), their families, and the communities in which they live, attend school, and engage socially and vocationally. While researchers around the globe endeavor to determine the etiology of ASD, the reality is that intervention based on the principles of applied behavior analysis (ABA) remains the only evidenced-based treatment for children with ASD. While fidelity and reliability are critical to its effectiveness, bad purveyors of ABA are ubiquitous, triggering government task forces and certificate programs as local, state, and federal governments struggle to regulate a growing multibillion-dollar business.

With an early diagnosis, the optimal intensity of ABA-based therapy may be as much as 35–40 h per week, which is estimated to cost between US$ 40,000 and US$ 60,000 when provided in the home, with some programs costing as much as US$ 100,000 per year. Typically, a child who begins an ABA program at the age of three will require at least 3–5 years of treatment, costing a minimum of US$ 120,000 before the child reaches middle school, and children with ASD often continue ABA treatment programs well into adolescence. These estimates are based on a 35–40-h-per-week program, and ultimately, the annual cost of an ABA treatment program will depend on multiple factors, including the agency providing the services, where the services are provided (home, center, school, or hospital), the experience of the individuals providing treatment, and the number of hours provided per week of 1:1 therapy (Chasson, et al., 2007).

According to a report of special education spending by the Center for Special Education Finance for 1999–2000, special education services cost an average of US$ 12,639 per student. When compared to students receiving general education services, it was estimated that a special education student's expenditures were 2.8 times more per year (Eikeseth, 2009). The cost of behaviorally based educational services is likely to be much higher in school districts that provide ABA-based interventions, such as discrete trial training (DTT), on a 1:1 or 1:2 ratio within the classroom and when additional staff trainings are required.

6. CONCLUSIONS

The diversity of sectors on which autism has an impact show there is clearly a need to coordinate action across different parts of government and society more generally. There is also a need to improve our knowledge on the cost and cost-effectiveness of various supports for children and adults to ensure that decision makers have a stronger evidence base when deciding how best to allocate and spend resources on autism. The time now seems right to develop a national strategy on autism.

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