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4 Autism Spectrum Disorders (ASD) and Health Care Services for Underserved Populations

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Key information for local and national policy and law makers

This chapter presents key information related to Autistic Spectrum Disorders (ASD) for the attention of National Policy Members, stakeholders, lawmakers, and healthcare professionals. We set out to encourage the fostering and advocacy for greater health literacy pertinent to ASD. In our opinion, it is of particular importance to advance the knowledge on issues related to prevalence, early symptomatology, diagnostic characteristic etiology, aberrant behaviours, daily living challenges, disorders of verbal and nonverbal communication, schooling adaptation, social pragmatic deficits, and difficulties related to emotional affect. An increased awareness on these topics is paramount as awareness, particularly on early detection of symptoms, can lead to timely assessment and diagnosis. Early detection of ASD signs and early diagnosis through an interdisciplinary management programme contributes to positive therapy outcomes (Koegel & Koegel, 1995; Petinou & Minaidou, 2017; Rapin, et al., 2009; Richard, 1997).

A recent publication by the Centers for Disease Control and Prevention (CDC, 2020) reports significant progress for early ASD screening resulting from rigorous research investigations and systematic ASD awareness campaigns over the past ten years. These efforts have capitalized on the available data and allow the fostering of ASD awareness. Robust advocacy for ASD has been undertaken by the NGO organizations including Autism Speaks (2016) and Ad Council. Increased screening has contributed to the lowering of the age of diagnosis, especially in minority populations and in individuals with diverse cultural and linguistic backgrounds. A recent report by the World Health Organization (WHO, 2019) underscores the importance of implementing integrated services in accordance with the person's individual needs and preferences.

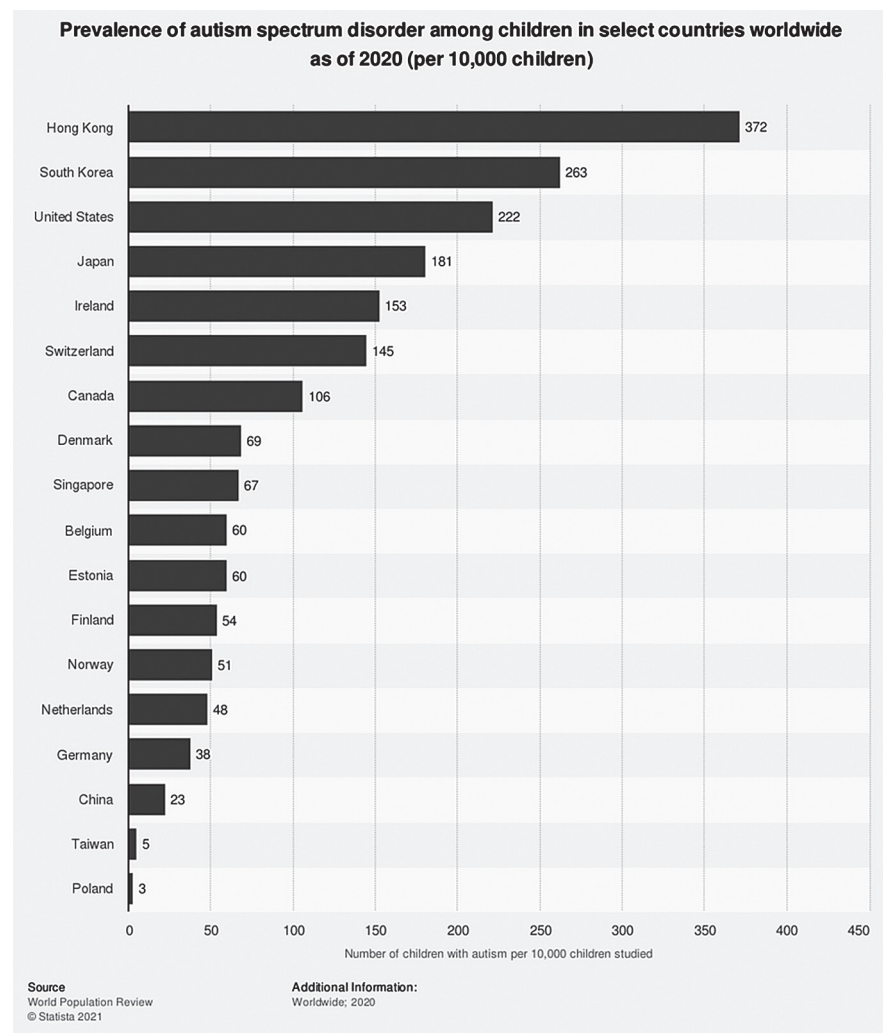
People with ASD do not differ from the rest of the population when it comes to health problems. Nevertheless, their special needs and co-occurring conditions necessitate awareness from politicians supported by committees who can address the societal needs and the level of support to increase the quality of life, access to services, family support and availability to resources of best service provision according to the Declaration of Human Rights (DHR) (United Nations, 1948).

Incidence and prevalence

The prevalence of ASD reported by the World Health Organization (WHO, 2019) is estimated to be 1:160 individuals, although this represents an average figure. ASD prevalence is higher in males compared to females with a ratio of 4:1. Although global occurrence of ASD is difficult to estimate, the consensus shows a notable increase (Centers for Disease Control and Prevention, 2020), indicating that, during 2016 in the United States alone, around 1 in 54 children presented with a diagnosis of ASD.

Prevalence has been estimated to be 222 per 10,000 children worldwide (Elflein, 2020), as shown in Table 4.1. Notably, there is a scarcity of prevalence data from minority and remote populations. Such observations underscore the need to increase

Table 4.1 Prevalence of Autism Disorders.



screening and identification in underserved and minority populations which may have an impact on prevalence estimates. Despite the variability in documenting the prevalence of ASD across the globe, the median number of diagnosed children across countries is estimated to be 62/10,000 and does not appear to be more prevalent in a given global/geographic area or ethnic group (Gillon et al., 2017).

The WHO resolution on ASD according to the Sixty-Seventh World Health Assembly (2014) presents a plan in relation to a series of comprehensive and coordinated efforts for the management of ASD which has been endorsed by over 60 countries across the globe. This is an encouraging endeavour, in the sense that the resolution seeks to collaborate with member states and stakeholders to strengthen national support and services for individuals with ASD.

The impact of Autistic Spectrum Disorders

Autistic Spectrum Disorders (ASD) refer to a broad range of conditions as an effect of complex neurobiological pathologies resulting in aberrant brain circuitry manifested during infancy (Baron-Cohen, 2011; Petinou & Minaidou, 2017; Tager-Flusberg, 2016; Westby, 2014). A combination of environmental and genetic factors appears to synergize through complicated mechanisms responsible for the development of autism. ASD affects children and families regardless of language background, religion, or socioeconomic status across the globe (Richards, 1991; American Psychiatric Association, 2013; International Classification Disorders-10 [ICD-10], 2019; Gillon et al., 2017). It is characterized by tremendous heterogeneity of symptomatology followed by variable long-term outcomes. Although early symptomatology and clinical characteristic of ASD are evident early in life, e.g., poor eye-gaze and lack of joint attention skills (Baron-Cohen, 1991; Lombardo et al., 2015; Pierce, Marinero, Hazin, McKenna, Barnes, & Malige, 2015), the actual diagnosis often comes much later. Other defining characteristics of ASD involve social-pragmatic difficulties, repetitive behaviours (e.g., repetitive gestures, echolalia), communication difficulties such as speech and nonverbal challenges, difficulty in transition from one activity to the another, fixated obsession to details, and unusual sensory integration (Paul, 2007; World Health Organization, 2019). Furthermore, co-morbid conditions are associated with cognitive, intellectual and learning limitations such as academic and literacy difficulties (American Psychological Association [APA], 2013; Levy, Mandell, & Schultz, 2009).

ASD can be accompanied with additional challenges including medical problems including gastrointestinal complications, feeding and swallowing issues, sensory defensiveness seizures, walking and gait idiosyncrasies and sleep disturbances (Autism Speaks, 2021). This disorder impacts on the typical course of language development, social-emotional-behaviour, adaptive capacity, social-pragmatic skills, play skills, sensory modulation, psychological issues, psychosocial challenges, literacy, and academic abilities manifested across the life span. Early identification can lead to sensitive and supportive management that will form the cornerstone for improved long-term outcomes. This framework will ultimately set intervention goals for the alleviation of aberrant outcomes within a multidisciplinary approach.

The skills and abilities of children with ASD vary from one child to another. While

some individuals present with typical cognitive skills others have severe cognitive challenges which lead to the need for long-term care, support and intervention. The ASD characteristics have a profound influence on the person's everyday living tasks.

ASD also impacts negatively on caregivers, close family members, and friends as the person with ASD faces challenges when it comes to social engagement within the family and societal context. Educating individuals with ASD implies long-term daily living activities and life-long learning. A significant parameter affected by ASD is schooling and education. This aspect calls for assessing each child individually and regularly to inform the preparation of individual rehabilitation and support programmes to address the special needs arising which are likely to change over time. These programmes should lead to the provision of the least restrictive framework for the child in order to successfully manage the long-term process of intervention and progress (Frith, 2008; Richard, 1997).

Key information for health professionals, social workers, community leaders, and educational practitioners

Frequently, individuals with ASD require life-long support in an effort to address the individual's needs. The abilities and needs of ASD individuals are diverse and can change over time. The presence of severe disability requires life-long care and support for both the person with ASD and his/her caregivers. There is a need for countries through respective professional and voluntary organizations, health service centres, and rehabilitation institutes to establish guidelines adhering to the provision of evidence-based practice for managing characteristics, behaviours and development patterns through special training and awareness.

According to WHO (2019), the best care for people with ASD depends on the actions at the national and local community level that foster support, inclusion, and immediate access to all available services. This is a critical issue, as health care professionals can become key members of the interdisciplinary team targeting best service provision for ASD individuals. The WHO resolution on ASD (Sixth-Seventh World Health Assembly, 2014) presents a plan in relation to a series of comprehensive and coordinated efforts for the management of ASD endorsed by more than 60 countries across the globe. This is encouraging in the sense that the resolution seeks to collaborate with member states and stakeholders to strengthen national support and services to individuals with ASD. Successful implementation is dependent on increasing awareness.

Suggestions related to the management of ASD focus on treating unserved and underserved populations to receive early identification and timely diagnosis. With the influx of refugees in different countries across the world, individuals in underserved populations who might be presenting with ASD characteristics face the danger of misdiagnosis or lack of identification (United Nations Refugee Agency, 2019). It is of paramount importance that caregivers, healthcare professions, and all members of interdisciplinary teams acquire, process, and understand newly-developed, evidence-based health information. Such information is related to issues pertinent to the etiology, symptomatology and management of culturally and linguistically diverse individuals

with ASD, particularly in underserved areas (Gillon et al., 2017; Health Resources & Services Administration, 2019). This knowledge will allow these populations the right to access health care for themselves and their families.

How to identify ASD

People with ASD face difficulties with social pragmatic aspects of the communication spectrum and present with challenges in peer interactions (Frith, 2008). Individuals with ASD exhibit restricted interests, engage in repetitive behaviours, use monotonous speech contours and, on many occasions, engage in immediate and/or delayed echolalia (American Psychiatric Association, 2013). Nevertheless, some individuals with ASD exhibit remarkable strengths, including special skills in mathematics, arts, music, and science. Furthermore, children with ASD are known for their strengths regarding memory, e.g., issues related to details or long-term information such as dates, birthdays, and other events. Along these lines, professionals and caregivers need to capitalize on these skills in the effort to develop the best interventions and long-term positive outcomes related to social communication skills and overall learning abilities.

The importance of identification

It is important that social, health and educational practitioners, along with national and local community leaders, be familiar with clinical signs pertinent to identification of ASD. Early identification is a key component to successful management of individuals with ASD across the life span. Timely identification and accurate diagnosis impact tremendously on the long-term outcomes (Paul, Chawarska, Klin, & Volkmar, 2017). A multidisciplinary approach to ASD includes comprehensive assessments on standardized and non-standardized testing protocols supplemented by careful taking of case history and clinical observation. ASD is often in co-morbidity with other neurodevelopmental disorders manifested as psychiatric challenges, intellectual impairment, sensory motor issues, and self-injury (Tager-Flusberg, 2016). Detailed differential diagnosis for ASD allows the identification of other accompanying conditions that may complicate management and warrant attention such as intellectual disability, language impairment, apraxia of speech, motor-kinesthetic deficits, psycho-emotional issues, attention deficits, and/or hyperactivity disorders.

Management of ASD caseloads require an interdisciplinary team approach due to the multifaceted and diverse nature of the disorder. Although signs of ASD can be manifested during infancy (e.g., low social affect, lack of eye contact, lack of joint attention, reduced early vocalizations), the actual diagnosis is nearly always executed later in life (Richard, 1997). Characteristics change over time. Consequently, different tools and clinical observation protocols need to be implemented according to the individual's chronological age, and linguistic and cultural background.

What to do when a client has been identified

Once an individual has been identified, the Interdisciplinary Team (IT), which should

include the carers/family members, agrees the best way to manage the child's needs in all areas of development by addressing communication, behavioral and challenges of daily living.

Supporting individuals with ASD

To help and support ASD populations, practitioners need to work closely with family members as well as with all other parties within the interdisciplinary team. It is of paramount importance that, once ASD is diagnosed, caregivers are offered pertinent information related to service availability, appropriate intervention plans for the child with ASD, information on the developmental course of the condition, and other relevant information. When appropriate, caregivers should be encouraged to seek professional advice for themselves for issues such as depression, disappointment, fear, guilt, helplessness, anger, or grief. Addressing emotional issues at an early stage of support contributes to adjustment to this new life-long situation and contributes to gradual healing, improved self-management and acceptance of the facts. Caregiver support needs to be addressed immediately, as ASD is not something the family member will simply 'grow out of'. They need to be made aware that there are a number of intervention programmes that can help children acquire new skills and overcome a wide variety of developmental challenges (Rogers et al., 2014; Volkmar et al., 2014).

Professionals need to be knowledgeable about local resources that are available to meet the child's special needs, from free government services to in-home behavioral therapy and school-based programmes. Emotional stamina allows the caregiver to support the child in an optimum way. It is important for professionals and healthcare professionals to reach out to children with ASD and their families who live in remote areas with limited access to rehabilitation services in order to provide them with the most up-to-date intervention support.

There are a number of suggested approaches for parents and healthcare practitioners (see below). These emphasize the importance of providing structure and safety, finding the most suitable communication channel, designing and implementing a personalized autism treatment plan, and familiarization with the child's culture and linguistic characteristics. It is also important to explore the availability of translators who might be able to assist when: assessing a child and informing parents; reaching out to local communities, such as ASD support groups; accessing early intervention and special education services; and familiarization with the child's rights.

Key recommendations for do's and don'ts (Help Guide ASD, 2021).

- Do educate yourself about ASD through national, international and local organizations. The more you know about ASD the better equipped you will be to make informed decisions about the treatment options and treatment decisions.
- Do become an expert on the child. Know your child. Figure out what triggers your child's challenging or disruptive behaviours. Examine the

circumstances which trigger aberrant behaviours and try to implement troubleshooting strategies to prevent or modify situations that cause difficulties.

- Do encourage multiple means of communication (gesture, pointing, drawing, etc.), especially for those children who are nonverbal.
- Don't wait for a diagnosis. The rehabilitation process should begin immediately. Early intervention is the key to positive outcomes.
- Don't give up. It is impossible to predict the course of ASD, but YOU can make a difference.
- Don't jump to conclusions about what life is going to be like for the child. Like everyone else, people with autism have an entire lifetime to grow and develop their abilities.
- Don't foster false hopes regarding the child's future outcomes.
- Don't be discouraged by the child's slow progress during the course of intervention. Reaching a goal is a long and tedious process requiring persistence.

Key information for professionals working with ASD individuals

There is a need for professionals working with ASD individuals to be able to identify early manifestations of ASD and provide healthcare services to all individuals across the life span. In the context of the island of Cyprus, reaching out and providing services to underserved populations is easier compared to service provision in vast territories such as Australia, due to the relatively short distances and size of the country. Fostering awareness through in-service training programmes either through face-to-face meetings or through distance learning (tele-practice) is important for developing protocols and strategies for effective communication (Health Resources & Service Administration, 2019).

Recent advances in ASD research serve as a springboard for implementing evidence-based practice, developing theory-motivated interventions, and capitalizing on research-based data in understanding etiological underpinnings of ASD including areas of co-morbidity such as speech sound disorders, apraxia of speech, attention deficit-hyperactivity disorder.

Evidence-based approaches for intervention

Evidence-based psychosocial interventions can improve communication and social skills in ASD (Paul, 2007; Rapin et al., 2009). Therapies need to focus on a positive impact on the wellbeing and quality of life and communication abilities of both people with ASD and their caregivers. A plethora of intervention approaches exist for populations with ASD. These approaches vary as according to the severity and type of deficits associated with the disorder. Regardless of the approach, intervention strategies need to adhere to principles of evidence-based practice frameworks (Enderby, 2017).

Therapies should optimize the development of the person's wellbeing, improve communication skills, and improve quality of life. Interventions map onto aspects of behavioral, cognitive, and linguistic frameworks and range from those implementing behaviour modification tasks to developmental approaches adhering to cognitive and linguistic frameworks.

Developmental approaches address social interaction skills by focusing on fostering socially appropriate and meaningful relationships with the caregiver and peers. On parallel lines, behaviour-based approaches in ASD focus on teaching children new behaviours and skills based on structured tasks through the implementation of behaviour modification strategies. An integrated intervention approach appears to be an effective avenue for ameliorating communication deficits in ASD since it draws together characteristics of several effective interventions. Family-based interventions emphasize the notion that family involvement in therapy is paramount when addressing the child's developmental needs. These are designed to provide guidance, training, information and support to family members (Paul, 2007; Richards, 1997). Therapy-based approaches for ASD provide targeted treatment goals by implementing speech therapy activities to address a child's communication and social needs skills, as well as occupational therapy activities to develop daily-living life and physical skills.

It is important that therapy-based interventions for nonverbal individuals with ASD should consider the introduction of augmentative/alternative communication (AAC) support (ASHA, 2020). AAC approaches may employ simple or complex technological systems/devices depending on which approach best meets the cognitive and linguistic level and needs of the individual. The use of technology with individuals with ASD range from stimulating social communication and verbal expression to sheer entertainment. This population is known for its complex learning needs, and many gain great pleasure in playing computer games and in computer-based learning. The interest in technology may be present in this population because many individuals with ASD appear to favour the use of technology (including tablets, computers, and electronic games) for achieving and completing learning goals. Children with ASD are usually motivated by situational circumstances that meet their individual and specific needs and they see as non-threatening. If the environment and context are predictable and structured, it often helps the person with ASD to maintain their routines and behaviours without negatively affecting their zone of comfort. Technology applied in treatment tends to be used mainly for improving social skills, education and thinking skills, but recent applications include more sophisticated technologies. Effectiveness of technological advancements such as virtual agents, artificial intelligence, virtual reality, and augmented reality are being studied and developers feel that these provide a comfortable environment that promotes continued learning for people with ASD (Lacasse, 2017).

Discussion

ASD is a heterogeneous disorder with its characteristics varying on a continuum. Research findings suggest that early identification and early coordinated interdisciplinary intervention can significantly limit the negative impact of ASD in the individual's

social, communicative and academic future. However, ongoing treatment is essential throughout the affected individual's school years, including support in higher learning institutions to meet the ever-growing demands and challenges which they may find themselves dealing with. In addition, many will require ongoing support to gain access to gainful employment and friendship groups and to sustain social emotional health.

Increasing awareness of ASD profiles and signs contribute to early identification and early screening for ASD. Such factors dictate timely interdisciplinary interventions and increase the likelihood of positive outcomes. It is important to keep in mind that healthcare providers, healthcare professionals and educators as members of the interdisciplinary team capitalize on information related to recent advances in ASD (e.g., research findings and evidence-based practice). Furthermore, it is of utmost importance that all members of the intervention/rehabilitation team acquire knowledge of the cultural, linguistic and social profiles of children from diverse backgrounds. Such frameworks form the cornerstone of long-term positive outcomes and better quality of life for both ASD populations and their family circle.

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