



Autism Spectrum Disorders: A Review of the Literature for Health Educators

Maureen K. Johnson and Mary Ruth Carter

ABSTRACT

According to Healthy People 2020, one population confronted with health disparities is that of individuals living with disabilities. Among these individuals are children living with autism spectrum disorders (ASDs). Increasing numbers of children in the United States have been diagnosed with ASDs, a group of developmental disorders for which no specific cause or cure has been conclusively identified. Increasing media exposure as well as legislation addressing ASDs reflects the increasing awareness of ASDs as a significant public health issue. However, whereas ASDs have become an issue of great interest to the general public, the amount of health education literature addressing autism spectrum disorders is extremely limited. This paper provides health educators with a review of literature concerning autism spectrum disorders, specifically its background, prevalence, possible causes, symptoms and diagnostic methods. Furthermore, the potential roles played by health educators in serving individuals (e.g., parents, educators, medical providers) who support children with ASDs is suggested through the application of National Commission for Health Education Credentialing, Inc. responsibilities and competencies for health educators.

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INTRODUCTION

An overarching goal of *Healthy People 2020* is that of eliminating health disparities.¹ People with disabilities must confront a number of health disparities as they are more likely to use alcohol and drugs and are less likely to receive routine oral care, engage in physical exercise and to be overweight or obese.¹ Furthermore, adults with intellectual disorders may experience specific health disparities in the areas of vision and hearing impairments, weight, cardiovascular disease, cancer, psychiatric conditions and oral health.²

Americans living with autism spectrum disorders (ASDs) are among the population facing such health disparities. Research suggests individuals with ASDs may be

vulnerable to co-morbid disorders, specifically anxiety,^{3,4} tic disorders,⁴ depressed mood,^{3,4} epileptiform activity⁵ and motor delay⁶ and attention deficit hyperactivity disorder (ADHD).^{7,8} Furthermore, children with ASDs may demonstrate frequent feeding problems, which may have a significant impact on the quantity and quality of life.⁹

Whether Americans living with ASDs experience health disparities because of the disorder itself or because of behaviors and comorbid diseases related to ASDs, it is evident public health officials and medical providers must address the health needs of this population. Federal and state legislators have also made autism research and policy development a priority as never before, as indicated by the increasing generation of

legislation, funding and research relevant to autism spectrum disorders.¹⁰

However, despite the numerous efforts to understand and address the health needs of autism spectrum disorders, the general public may lack familiarity with the needs of this population. Furthermore, the limited amount of health education research published suggests a lack of familiarity with

Maureen K. Johnson is an assistant professor in the Department of Applied Health Sciences, Arena B-69, Indiana State University, Terre Haute, IN 47809; E-mail: maureen.johnson@indstate.edu. Mary Ruth Carter is LLMSW in Social Work and is a doctoral student in Psychology at Saybrook University in San Francisco, CA 94111.



autism spectrum disorders within the profession of health education. However, due to the increasing numbers of individuals diagnosed with ASDs, it is imperative that health education increase its professional literature relevant to serving individuals with autism spectrum disorders as well as their caregivers. Therefore, the purpose of the current paper is to provide health educators a review of literature concerning autism spectrum disorders. Furthermore, the authors provide recommendations for providing health education to caregivers (e.g., parents, educators, medical providers) of children with ASDs. With an increased awareness of autism spectrum disorders serving as a foundation, health educators play a critical role in providing families and professionals with the information needed to make educated decisions about health care services for children with ASDs.

OVERVIEW OF AUTISM SPECTRUM DISORDERS

According to the U.S. Centers for Disease Control and Prevention (CDC), one in 110 children in the United States are currently being diagnosed with an ASD.¹¹ It is unclear whether this increase is due to an actual increase in number of children with an ASD or if it is due to an increase in diagnoses of the disorder. However, what is apparent are the physical, psychological, social and academic difficulties faced by the population of children living with autism.

Health educators have a responsibility to promote the health of individuals of diverse populations, including those living with developmental disorders. The rising prevalence of autism among children dictates such a need to provide services not only for children living with autism, but also for the parents, teachers and medical providers of these children. As a public health issue with urgent needs but few solutions, the population of individuals with autism spectrum disorders challenges health educators on many levels.

As previously stated, the purpose of the current paper is to provide health educators with a literature review concerning

autism spectrum disorders. The paper will discuss the current definition of autism as a spectrum disorder, as well as the prevalence, symptoms, potential causes, and diagnosis of ASDs. The final sections of the paper will discuss autism spectrum disorders in the context of the health education profession.

The Evolving Definition of Autism Spectrum Disorders

Until recently, health professionals restricted their definition of autism as a singular disorder with a narrow range of symptoms. However, the American Psychological Association has revised its definition and classification of autism several times. Currently, in the Diagnostic Statistical Manual-V (DSM-V), the American Psychological Association classifies autism and related disorders as a group, or spectrum of disorders, and is thus referred to as an "autism spectrum disorder."¹² ASDs encompass not only what has been traditionally referred to as autism,⁵ but also of developmental disorders that quantitatively and qualitatively vary across the autism spectrum, including Asperger syndrome; Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS); Rett syndrome; and child disintegrative disorder.

Autism

Autism was first identified as an impairment of executive abilities related to dysfunction of the frontal lobe of the brain.¹³ Autistic children were compared to individuals experiencing the effects of frontal lesions; the authors suggested the impaired frontal lobe impacted motivation, communication skills, and "perseverative behavior."¹³ Diagnostic criteria have evolved over the past two decades with an emphasis on impaired communication skills with joint attention and reciprocity impairment.¹⁴ DSM IV-TR criteria include abnormal development in the areas of social interaction, communication skills, and restrictive interests and behaviors.¹⁵⁻¹⁶

Asperger Syndrome

Asperger syndrome is an autism spectrum disorder which is becoming increasingly familiar to the public. The diagnosis

of Asperger syndrome carries with it a great deal of controversy and is characterized by social and communication impairment with no apparent language deficits.¹⁴ Professionals have used the diagnosis of Asperger syndrome to label individuals with persistent social difficulties and poor non-verbal skills. Professionals may also use this diagnosis for children below three years of age when language and communication deficiencies is difficult to evaluate or for those with mild social impairment that does not meet the criteria for other disorders.^{14,17,18} Diagnostic criteria require that an individual does not meet a diagnosis for autism and must show no impairment in cognition or language development during the first years of life.^{16,19-20} Individuals with Asperger syndrome are often misdiagnosed with Attention Deficit Hyperactivity Disorder due to overactivity and difficulty attending to others.¹⁶

Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS)

The third autism spectrum disorder of discussion is pervasive developmental disorder, not otherwise specified (PDD-NOS). A PDD-NOS diagnosis is indicative of an individual who does not meet the full criteria for another PDD diagnoses; however, a combination of symptoms exists which may include social impairment and impaired social reciprocity or stereotyped behaviors.¹⁶ The current diagnostic criteria for PDD-NOS provide an opportunity for clinician interpretation and can lead to overdiagnosis for children with issues such as ADHD.²¹ Volkmar identified several symptoms that could be used to distinguish between PDD-NOS and non-spectrum disorders, including impaired eye gaze, lack of social reciprocity and repetitive use of language when identified before age three.¹⁸ An overall qualitative difference is apparent with children of PDD-NOS when compared with non-spectrum disorder children.²¹

Other Spectrum Disorders

The two remaining autism spectrum disorders are those of childhood disintegrative disorder and Rett syndrome. These diagnoses are extremely rare and are characterized by



normal development, followed by impaired development and regression.^{16,21} Rett syndrome is a genetic disorder which appears within the first four years of life, resulting in deceleration of head growth, regression of motor skills and impaired interest in social interactions.^{16,21} Rett's disorder is exclusively a disorder in females and onset can occur as early as five months of age, distinguishing it from childhood disintegrative disorder.¹⁵ Childhood disintegrative disorder is a regression of skills acquired following at least two years of normal development.^{16,21} This regression may include that of language, as well as behavioral or motor areas of development, including bladder and bowel control.¹⁶

Prevalence of Autism Spectrum Disorders

The diagnosis of ASD disorders has increased considerably in the past fifty years. Zahner and Pauls found prevalence rates of 0.007% to around .02% between 1960 and 1980.²³ According to Rice, a review of parental reports of autism diagnosis among children aged 6 to 8 years identified the average prevalence of ASD diagnosis as 7.5 to 7.6 cases per 1,000 in 2002.²⁴ Kogan and colleagues released prevalence statistics of 1 in 91 which was the result of parent reports of ASD diagnosis among 3- to 17-year-olds for the year 2007.²⁵

The CDC estimated autism spectrum disorders affect an average of 1 out of 110 children, or 1% of U.S. children in 2009.¹¹ With limited access to educational diagnoses records at some sites, the surveillance summary provided to the CDC in 2006 reports that for every 1000 children evaluated for autism spectrum disorders, nine are diagnosed with an ASD.²⁶ In 2006, a higher prevalence of autism spectrum disorders have been reported among male children, as the female-to-male ratio ranged from 1:3.2 to 1:7.6.²⁶ Furthermore, the CDC indicated an increase in ASD prevalence in nine out of ten surveillance sites during this evaluation period ranging from a 27% to 95% increase.²⁶

Symptoms of Autism Spectrum Disorders

Common traits of autism spectrum disorders include severe and pervasive im-

pairment in specific areas of development and may include the presence of stereotyped behaviors or interests. Areas of delay may include social reciprocity and communication skills.^{16,27} Autism also includes mental retardation in up to 70% of cases.¹⁵ Children with an ASD diagnosis may have difficulty communicating, difficulty understanding emotions, impairment in nonverbal communication and even sensory issues and/or restricted behaviors and interests.¹⁵ Communication impairments include difficulty in responding to joint attention,²⁸⁻³⁰ inability to share affective states^{14,16,28} and deficiencies in verbal expression.^{14,31,32}

Causes of Autism Spectrum Disorders

Many causes of autism spectrum disorders may be speculative in nature. However, the possible contribution of biological, genetic, neurological, and environmental factors have been widely researched. Recent research has focused on brain biology in ASD individuals. Although measurement of brain mass has been in use for autism research since the 1980s, significant progress has been made due to advancements in technology.³³ Subjects with ASD have been found to have a significant reduction in grey-matter volume in specific areas of the brain, including the medial temporal, fusiform and cerebellar regions.³³

Genetic Factors

There is much debate concerning autism spectrum disorders as genetically determined disorders. Some research asserts that autism spectrum disorders are highly genetic in origin.³⁴ Other research suggests that autism and Asperger syndrome have distinctly different genetic pre-determinants.³⁵ Still other studies report no significant, reliable, or biological indicators of these disorders.³⁶ Researchers seem to agree that ASD has a wide variability in genetic construction which may hinder gene identification.^{37,38} Grigorenko proposed that researchers focus on a "variety of variable genetic causes" rather than one distinct genetic mutation.^{39(p.2)} Researchers have identified "susceptibility genes" for individuals diagnosed with an ASD.⁴⁰ Chromosomal anomalies are found

in 1%-2% of autistic individuals studied.⁴¹

When considering genetic disposition, a biological sibling of a child with an ASD has a 6% to 15% chance of developing the same condition, compared to approximately 0.6% of siblings of children who do not have an ASD.⁴² However, among identical twins, the frequency rises to about 90%.⁴³

Environmental Factors

Infant or prenatal exposure to environmental hazards has been investigated as a risk factor for ASDs. Researchers have investigated infant exposure to measles, mumps and rubella (MMR) vaccinations after a large sustained increase in ASD diagnoses during a period of increased immunizations in the 1980s. Dales, Hammer, and Smith found that MMR vaccinations increased by 10% in 1994; however, ASD prevalence rates increased by 373% during the same time period.⁴⁴

Mercury is just one of many environmental contaminants that may potentially contribute to ASDs through prenatal exposure. The Agency for Toxic Substances and Disease Registry (ATSDR) has identified such contaminants in the "Contaminants of Concern."⁴⁵ In addition to mercury, metals such as cadmium as well as chlorinated solvents such as vinyl chloride, toluene, and diesel particulate matter were suggested as environmental toxins contributing to ASDs.⁴⁶ Maternal second-hand smoke exposure during pregnancy is an additional environmental factor that may be contributing to the development of ASDs.⁴⁷

Multifactorial Contributors

Whereas numerous studies focus on a specific contributing factor in the development of autism spectrum disorders, their authors frequently stress the contribution of multiple factors. The debate concerning the causes or contributory factors of autism spectrum disorders may also be one of "nature vs. nurture." While many researchers point to biological, neurological, or genetic risk factors contributing to autism spectrum disorders, Dawson argues that a primary factor contributing to ASDs is that of limited social interactions. Dawson suggests these



limited social interactions consequently places ASD children at risk for impaired social and linguistic development.⁴³ Some children with ASDs may only demonstrate symptoms under certain conditions or within specific social contexts, suggesting the influence of factors that are not genetic or part of the surrounding physical environment.^{16,17}

Diagnosis of Autism Spectrum Disorders

The increasing prevalence of autism dictates the need for a multitude of quality evaluation methods. One method or assessment instrument is not sufficient for the conclusive diagnosis of an autism spectrum disorder. Because primary care providers (PCP's) are often the first medical professionals to initiate comprehensive evaluation and follow-up treatment, it is essential PCP's are able to utilize appropriate diagnostic techniques at specific stages of the evaluation process. The American Academy of Pediatrics (AAP) addresses proper diagnostic procedures at various stages of evaluation.⁴⁸

First Stage Evaluation

First stage evaluation includes the related activities of screening and surveillance. Screening consists of the detection of symptoms through application of evidence-based testing.¹⁴ Surveillance refers to ongoing data collection relevant to the identification of a disorder by an integrated health system.¹⁴ The AAP urges pediatricians to conduct an initial surveillance among their general population of patients. This initial surveillance should occur during a general preventative visit and include conducting a family history during which a parent is interviewed and information is documented.⁴⁸ Typical interview questions address the parents' observation of their child's communication and behavior. Deficits in these areas (e.g., lack of eye contact, delayed communication) may indicate further evaluation. Another cause for concern is a child with an older sibling with an ASD, as he or she is 10 times more likely to develop an ASD than those children whose older siblings do not have an ASD.⁴⁸

Non-medical care providers (e.g., parents) can assist with the evaluation process by responding to an online diagnostic tool such as the Parents' Evaluation of Developmental Status (PEDS). At the completion of the PEDS, immediate feedback is provided based on the concerns reported by the parents.⁴⁹ The PEDS is no cost to the parents and is only ten questions in length; however, as a broadband diagnostic instrument, it may not be able to discern a specific developmental disorder (e.g., autism) from other developmental, communication and intellectual disabilities.⁴⁹

A second parent report that may be used early in the surveillance process is that of the Autism Diagnostic Interview (ADI). The ADI is a parent report measure that can be utilized between ages four and five.⁵⁰ This tool utilizes parent interview which is structured to examine the child's communication skills, reciprocal social interactions, and restricted and repetitive behaviors. Two tools are utilized for measuring development with nonverbal vs. verbal individuals.⁵⁰

Two established instruments used in the early screening of ASDs are the Checklist for Autism in Toddlers (CHAT)⁵¹ and the Modified Checklist for Autism in Toddlers (M-CHAT).⁵² The CHAT is utilized primarily with the general population;⁵³ however, it can be used within a clinical setting.⁵⁴ The M-CHAT is administered over a period of 18 months to 24 months and has several changes from the original format.⁵² New diagnostic items evaluate sensory and motor abnormalities, imitation, and responding to name.¹⁴ Although the rate of ASD diagnosis through M-CHAT screening and referral is similar to that found in a mental health clinic setting,⁵⁵ the M-CHAT also does not include clinical observation and depends on parent report.¹⁴

Second Stage Evaluation

Based on parent concerns, family history, and the results of the initial screening and surveillance instruments, the pediatrician must make a decision whether or not to refer the child for a more comprehensive evaluation for an ASD. This comprehensive

evaluation is known as the second stage evaluation. There is a wide variety of screening tools utilized for second stage evaluation; however, the current paper will discuss some of the most commonly used tools. Tools such as the Childhood Autism Rating Scale (CARS);⁵⁶ the Autism Diagnostic Observation Schedule;¹⁴ and the Pervasive Developmental Disorders Screening Test II⁵⁷ are utilized to screen for ASDs in young children under four years of age. These screening tools must be used with care as over-diagnosis becomes more common at younger developmental levels.⁵⁸ Several observation based tools exist for diagnosis of pre-school aged children. For children with mild to moderate mental retardation, the CARS is one of the most common tools for diagnosis.⁵⁶ This scale is used to distinguish between individuals with autism and those with other pervasive developmental disorders. The Autism Diagnostic Observation Schedule is also commonly used to distinguish between ASD diagnoses; however, use is most effective with individuals who show some language gains.¹⁴

Pervasive Developmental Disorders Screening Test II (PDDST-II) is a parent report screening method developed by Siegel and colleagues.⁵⁷ This tool utilizes two stages of evaluation which begin within a primary care setting.⁵⁷ Stage 2 was developed for use within a clinical setting as part of an assessment system.⁵⁷ Due to an initial study of the PDDST-II conducted on individuals referred for ASD evaluation who received a diagnosis of ASD or other developmental disorder, sensitivity of this measure remains unclear. Furthermore, the use of the PDDST II on the general population has not been adequately studied.¹⁴

HEALTH EDUCATION AND AUTISM SPECTRUM DISORDERS

The previous sections of the current paper have provided health educators with an overview of autism spectrum disorders. However, the purpose of the remaining sections is to discuss autism spectrum disorders in the context of health education research and practice. Although health education



literature concerning autism spectrum disorders is limited, literature from several health professions may provide a foundation upon which we may expand our knowledge and skills.

Whereas autism spectrum disorders are frequently discussed in social and educational contexts, they have posed a challenge to health professionals as well. One focus group, conducted by Carbone, Behl, Azor, and Murphy, identified limitations for health professionals.⁵⁹ Participating physicians reported that they were limited in their knowledge of autism resources and found that family members were often more knowledgeable about services and their children's needs than the physicians themselves.⁵⁹ Physicians reported that due to lack of family financial resources, parents relied on sources outside of the medical profession, including internet sources, other families affected by ASD, and the media.⁵⁹ Furthermore, while pediatricians report a desire to improve services for children with ASDs, they identify a lack of time, training and resources as barriers to improving treatment for children with ASD.⁵⁹

As with Carbone et al.'s study, a lack of awareness, time, training and resources may also be contributing to health educators' difficulty in meeting the needs of individuals with autism spectrum disorders. Individuals with ASDs have specific health needs, but they may need to seek health education resources and services from professionals who are not health educators.

Although the cause or causes of autism spectrum disorders has not been conclusively determined, it can be concluded there is a significant lack of health education research and literature focusing on ASDs. While health educators may directly serve the population of children with ASDs, the remainder of the current paper focuses on health educators' roles in serving individuals who are provide care and support for children with ASDs, specifically families, educators, and medical providers. In meeting the needs of these individuals, health educators should apply the entry-level responsibilities and competencies for health educators

established by the National Commission for Health Education Credentialing, Inc. (NCHEC).⁶⁰

Assess Needs, Assets and Capacity for Health Education

The first responsibility of the health educator is to "assess needs, assets and capacity for health education."⁶⁰ This responsibility speaks to health educators' role in facilitating the identification and screening processes.⁶⁰ In clinical, community, and educational settings, health educators may assist with first-stage screening efforts by conducting seminars with caregivers concerning reliable screening tools for ASDs (e.g., M-CHAT). Also, health educators can investigate epidemiological databases store data which describe the incidence and prevalence of ASDs. Health educators in all settings should become familiar with the autism prevalence for their communities and assist in data collection efforts if no such data are available. Furthermore, to assist caregivers of children with ASDs, health educators should become more familiar with the health concerns and disparities that may be present among families caring for a child with an ASD (e.g., access to medical care). Finally, prior to planning new programs and services for parents, educators, and medical providers of children with ASDs, health educators must identify existing programs and resources that have previously met the needs of these caregivers.⁶⁰

Plan Health Education

The second responsibility of health educators is to "plan health education."⁶⁰ Literature from various professions may be valuable in the planning of health education programs and curricula for individuals supporting children with ASDs. Based on the results of assessment in the previous section of the current paper, appropriate goals and objectives must be established for the population.⁶⁰ In the school setting, health educators may assist educators, administrators, and school medical personnel in establishing goals and objectives for initiatives designed to promote wellness of children with ASDs. In the community settings, health educators may collaborate with various organizations

within the communities (e.g., social services, not-for-profit, clinical). Community health educators should make every effort to collaborate with those organizations that serve children with ASDs and other developmental disorders.⁶⁰

Implement Health Education

The third responsibility of health educators is to "implement health education."⁶⁰ With the responsibility of implementation, health educators are charged with the execution or carrying out of any plan of action previously developed to assist individuals who serve children with ASDs. A critical part of implementation includes educating participants about the characteristics and specific health needs of the population they serve (children with ASDs). Whether employed in a school, community, or clinical setting, health educators must adequately train individuals involved in implementation of the intervention or program. Individuals involved with such an intervention must become familiar with the need for the intervention, as well as its goals, objectives, and protocol. Involving members of the target population (e.g., teachers of children with ASDs) in both the planning and implementation process may give these participants a feeling of ownership in the intervention.

Conduct Evaluation and Research Related to Health Education

The fourth responsibility of health educators is to "conduct evaluation and research related to health education."⁶⁰ Health educators in school, community and clinical settings can participate in the evaluation of interventions or programs targeting individuals who serve children with ASDs. The evaluation process is essential for determining the effectiveness of such interventions or programs. Regardless of the setting, health educators must conduct a review of literature to determine appropriate design for research and evaluation process, to investigate existing instruments used for evaluation, and to explore appropriate data analysis methods.⁶⁰ If an appropriate instrument is not available to evaluate interventions or programs for individuals serving children with ASDs,



health educators may need to collaborate with other professionals to develop a valid and reliable instrument.⁶⁰

Administer and Manage Health Education

The fifth responsibility of a health educator is to, “administer and manage health education.”⁶⁰ This responsibility speaks to the health educator’s role as a manager and coordinator of resources and personnel. This responsibility may be most applicable to health educators employed in community-based settings or clinical settings that employ professionals who serve children with ASDs. Community health educators may assume administrative functions such as the recruitment and training of volunteers as well as the acquisition of funding through grants and donations to support the mission and goals of the organization (e.g., Autism Speaks).⁶⁰ Within this responsibility, health educators should have managerial and leadership skills to most effectively meet the needs of families and professionals who support children with ASDs residing within the community. In all settings, health educators must demonstrate the alignment of proposed intervention or program with the existing mission and value statements of the setting of employment.⁶⁰ Furthermore, health educators must be mindful of the institution’s budget in the proposal of such interventions and programs.⁶⁰

Serve as a Health Education

Resource Person

The sixth responsibility of health educators is to “serve as a health education resource person.” Regardless of the setting of employment, health educators should be familiar with credible sources of information concerning autism spectrum disorders (e.g., CDC, Autism Speaks). Furthermore, health educators should be able to acquire resources and provide education and training for parents, teachers, medical professionals and any individuals or groups who assume a caretaker role with children who have ASDs.⁶⁰ Finally, health educators may assume a consultative role to organizations such as Autism Speaks, who may seek health education and training regarding the health needs of children with ASDs as well as their caretakers.⁶⁰

Communicate and Advocate for Health and Health Education

The seventh responsibility of health educators is to “communicate and advocate for health and health education.”⁶⁰ Within this area of responsibility, health educators should be familiar with both mass communication strategies and public policy.⁶⁰ Health educators must identify and analyze existing educational media addressing autism spectrum disorders. If existing media do not meet the needs of the individuals or organizations who care for and support children with ASDs, health educators may need to develop new health education media addressing ASDs (e.g., a video educating parents about motivating children with ASD’s to increase their physical activity levels). Media tools can be of a small scale (e.g., parent newsletters in the schools) or of a larger scale (e.g., radio, television and the Internet). In terms of public policy regarding ASDs, health educators should be familiar with ASD positions and policies supported by local elected officials.⁶⁰ Subsequently, health educators should organize an advocacy campaign, which may be as simple as writing letters to elected officials, requesting the support of legislation providing for the allocation of funding to ASD initiatives.

We hope that this paper will increase health educators’ awareness of ASDs, specifically the prevalence, causes, symptoms and diagnostic measures. While medical researchers continue to investigate the causes of ASDs, parents, educators and healthcare providers of children with ASD’s require services that cannot be delayed. Health educators can take a unique and vital role in meeting the needs of these caregivers through the application of the Responsibilities and Competencies of Health Educators. Through the fulfillment of our professional responsibilities to a population affected by autism spectrum disorders, we can demonstrate our commitment to promotion of health for all.

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