

## Review

# Healthcare Issues in Children with Developmental Disabilities (Autism)

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### Article information

Received: December 18<sup>th</sup>, 2021; Revised: January 3<sup>rd</sup>, 2022; Accepted: January 7<sup>th</sup>, 2022; Published: January 13<sup>th</sup>, 2022

### Cite this article

Eta VEA. Healthcare issues in children with developmental disabilities (Autism). *Pediatr Neonatal Nurs Open J.* 2022; 8(1): 1-13. doi: [10.17140/PNNOJ-8-134](https://doi.org/10.17140/PNNOJ-8-134)

### ABSTRACT

Developmental disabilities (DDs) refer to a group of conditions that influence the early development of children and cause changes in their normal developmental pattern affecting their physical, language and mental abilities or behavior. Children with DDs just like normally developing children have health issues that need to be addressed. This special group of children especially those having autism frequently suffer from associated conditions such as gastrointestinal disorders, eating and feeding challenges, seizures, sleep disturbances, attention deficit and hyperactivity disorder, and anxiety among others. These health problems affect the health of these children in different ways and extent. Thus, children with DDs need to access healthcare services and receive quality medical care just like their normally developing peers. However, the health needs of children with DDs particularly autism are not being met as required even though this special population are more likely to seek medical care due to their disabilities and associated conditions. Children with autism and other DDs experience disparities in health and healthcare service utilization. Autism is linked to many health conditions such as epilepsy, gastrointestinal problems and other mental disorders. These health problems affect each individual with autism in a unique way negatively affecting his/her existing social interaction and communication impairments. Again, health facilities and medical equipment are not disability-friendly making it difficult for this special group to effectively have access to quality care. In addition, most healthcare providers do not possess adequate knowledge and skills required to make critical decisions regarding this very special group of persons. Furthermore, due to cultural differences certain diagnosis and treatment regarding autism and other developmental disabilities may not be welcomed. The public health sector of all nations has the duty to promote health and prevent diseases for all including persons with disabilities.

### Keywords

Developmental disabilities; Children with autism; Health conditions; Disparities in health; Disparities in healthcare service utilization.

### INTRODUCTION

Developmental disabilities (DDs) refer to a cluster of disorders that affect children early in their lives due to abnormal development. Autism, learning disabilities, visual impairment and down syndrome among others are some examples. These disorders alter children's normal developmental pattern and affect their physical, language and mental abilities or the way they behave.<sup>1</sup> With some disorders such as Down syndrome, the abnormal development may affect both physical and mental abilities of the child. Children with DDs just like the normally developing children have health issues that need to be addressed.

This special group of children especially those having

autism frequently suffer from associated conditions such as gastrointestinal disorders, eating and feeding challenges, seizures, sleep disturbances, attention deficit and hyperactivity disorder (ADHD), and anxiety among others.<sup>2</sup> These health problems affect the health of these individuals in different ways and extent. Thus, children with DDs need to access healthcare services and receive quality medical care just like their normally developing peers.

However, this special population experience major health and healthcare service disparities. Health disparities are differences in health outcomes (which could be avoided) within groups in the population reflecting the behavioral, sociocultural, biological, and environmental factors or social inequalities that exist within the population.<sup>3</sup> Developmental disabilities particularly autism and its

associated co-morbidities influence the health of each individual in unique ways and varied degrees. Literature reveals that adults with disabilities most commonly report fair or poor health conditions compared to their normally developing counterparts (40.3% vs 9.9%). In other words, persons with developmental disabilities experience major health disparities owing to their poor physical and mental health states.

Also, in most cases healthcare providers do not carry out a comprehensive physical examination on many children with developmental disabilities.<sup>4</sup> This may be due to the non-availability of equipment and materials such as weight/height scales, clerking protocols and examining tables among others, adapted to accommodate their varied disabilities. This could have been because of the lack of awareness, poor policy and/or limited resources especially, in resource limited nations like Cameroon.

Disparities in accessing health services, high-quality and safe care for patients with disabilities exist due the lack of adequate systems of care.<sup>5</sup> This issue is a major problem particularly for persons transiting from children to adult healthcare service providers as their healthcare and social needs are not being met. These disparities in unmet healthcare needs of persons with disabilities particularly those with DDs is a glaring example of what must be done to enhance accessibility to healthcare.

For instance, there are few standardized models prescribing the guidelines for caring for this special group such as the adult disability medical healthcare (ADMH) developed for patients with developmental disabilities. This model advocates for the delivery of a complete, compassionate, coordinated and continuous patient- and family-centered care based on evidence, which is accessible to adults with developmental disabilities.<sup>6</sup> Therefore, persons with DDs should be able to access healthcare services that do not only meet their physical health needs but also the psychosocial and mental aspects of their health including health promotion and disease prevention. This paper sought to:

1. To critically examine disparities in health and health services experienced by individuals with developmental disabilities particularly autism.
2. To describe the health conditions frequently associated with autism and their treatment options.
3. To critically examine challenges faced by individuals with disabilities in accessing appropriate medical, dental, and mental health services.

### **DISPARITIES IN HEALTH AND HEALTH SERVICES EXPERIENCED BY CHILDREN WITH AUTISM AND OTHER DEVELOPMENTAL DISABILITIES**

Children with autism experience high rates of morbidity and reduced life expectancy (particularly the disadvantaged) compared to typically developing children.<sup>7</sup> A variety of physical and mental-health problems are commonly associated with autism such as gastrointestinal problems, epilepsy and anxiety among others. Despite the fact that children with autism are affected by varied co-morbidities the healthcare needs of individuals with autism are given little

or no attention.<sup>8</sup> This may be due to inflexible healthcare policy and knowledge gap on the part of healthcare providers.

Worthy of note is the fact that as this special population increases in proportion and becoming fully incorporated into the society it is vital to comprehend their health status and disparities in health and healthcare services.<sup>8</sup> This will assist the formulation of physical and mental health promotion and disease prevention frameworks that would provide the unique needs of this special group of individuals. It is important to note that in this paper autism spectrum disorder (ASD) and autism are used interchangeably. The following subsections examine disparities in health and healthcare services experienced by children with autism and present a public health approach to reducing health and health service inequalities among persons with autism and other developmental disabilities.

### **HEALTH DISPARITIES EXPERIENCED BY CHILDREN WITH AUTISM**

Health status and life expectancy vary between children with autism and typically developing children, as well as among children with autism. Literature reveals that persons with ASD experience increased morbidity and early mortality compared to normally developing individuals.<sup>9-11</sup> In addition, literature has clearly documented huge disparities experienced in terms of accessing early diagnosis and support services by persons with autism who are disadvantaged due to their culture, gender, race, and ethnicity among others. This results in even higher disparities in health status and decreased life expectancy experienced by disadvantaged individuals with autism.

Furthermore, disadvantaged persons with autism reported poorer access to healthcare services and increased risk for negative health outcomes compared to typically developing children and children with autism who are not disadvantaged. However, persons with autism who are not disadvantaged have a life expectancy that is averagely 28-years lesser than the normally developing individuals.<sup>12</sup>

Children with autism having comorbid intellectual disabilities (ID) are more prone to physical health problems while those without ID are highly susceptible to mental health disorders as well as unusual suicide rates.<sup>13</sup> Among persons with autism without ID suicide is the greatest cause of premature mortality (they die 12-years earlier). Thus, it can be seen that premature mortality rates are considerably higher among this special group compared to the so-called normal individuals.

Thus, there is absolute need to put in place strategies to promote health and prevent diseases for children with autism. According to the Fundamental Causes Model of contextual health disparities, health disparities provides an insight of the extent to which individuals can potentially avoid risk.<sup>3</sup> In other words, understanding the concept of health disparities directs the putting in place targeted interventions to decrease disparities and improve health outcomes.

In addition to the disparities mentioned it is stated that higher rates of adverse physical health outcomes occur among adults with autism while gastrointestinal disorders, sleep and feeding problems, as well as epilepsy are common in children with ASD.<sup>14</sup> Also, evidence for high rates of cardiovascular problems and mental health conditions including early signs of Parkinsonism have been found in adults with autism. Again, it has been reported that adults with autism are usually affected by visual and hearing impairments, which negatively affect their existing impairments in social interaction and communication.

Finally, there exist disparities in etiology between ASD and other related developmental disorders. Autism is said to be associated either with chromosomal abnormalities, Fragile X, single gene mutations, genetic syndromes, Tuberous Sclerosis and *de novo* copy mutations among others.<sup>3</sup> Also, biological factors such as increased oxidative stress, shortened telomere length, perturbed proteostasis and the malfunctioning of hypothalamic-pituitary-adrenal axis among others may increase the likelihood of developing autism. It is important to mention that little or nothing is known regarding health disparities in ASD among the middle age and older adults. This needs to be taken in to consideration in order to establish accurate health outcomes especially for persons who are moving towards their end of life. This will ensure that children with DDs grow healthily through adulthood.

#### DISPARITIES IN HEALTHCARE SERVICE UTILIZATION

Literature reveals that there exist disparities in healthcare service utilization in relation to cost for persons with disabilities. Up to 15% of individuals with disabilities are unable to access medical care due to cost compared to six percent of individuals in the general population. Despite the fact that children with autism are associated with higher healthcare utilization rates, they experience poorer access to healthcare services and medical homes compared to normally developing children.<sup>15</sup>

In addition, children with ASD experience disparities with respect to accessing early diagnostic and intervention or support services. Even though, autism can be diagnosed as early as 12-months of age most children with autism are usually diagnosed at about four years or later.<sup>16</sup> It is believed that socioeconomic status, race, neighborhood disadvantage and culture play a major role in the disparities in ASD diagnosis. For instance, African American children receive their first autism diagnosis at least one and a half years later than their European American counterparts do.

Similarly, children from households with poor socioeconomic status and/or from high disadvantaged neighborhoods,<sup>17</sup> are also more likely not to be given an autism diagnosis on time. Worse still in resource limited nations Cameroon inclusive, most children with autism are not being diagnosis. In addition, there exist disparities in the availability of and access to autism treatment services. For example, children from poor socioeconomic background have access to fewer hours of autism treatment services, while others particularly from less developed countries such as Cameroon may not even have access to treatment services. This may result in increased adverse physical health outcomes in the lives of this special

group of individuals in the future.<sup>18</sup>

Furthermore, parents of poor socioeconomic status having children with ASD stated poorer access to care for their children; they do not get early and continuous access to care. Again, others have reported disparities in the quality of healthcare and access to general and specialist medical services.<sup>7</sup> Some studies have reported disparities among parents of children with autism in terms of getting referrals as required.

Literature reveals that most often some children with autism do not have access to specialist care especially children from developing nations such as Cameroon, African American and Latino among others. For instance, a study revealed that children with autism from Latino and African American experience lower rates of neurologic screening and scarcely see gastroenterologists, nutritionists, neurologists, psychiatrists and psychologists.<sup>19</sup> The situation is even worse in some African countries like Cameroon where most healthcare provider are not aware of autism and its associated health conditions and the available specialists are only found in urban areas.

Moreover, there are disparities with respect to gender and geographical location.<sup>20</sup> Literature holds that among children with autism having similar clinical and/or health service utilization needs females are more likely to receive psychiatric or emergency department services than their male counterparts are. Talking about geography, it is known that children with autism living in rural areas, especially those with multiple comorbidities, are more likely to travel to urban settings to use emergency department services than those found in urban areas. This is due to the lack of availability of specialist services in rural areas.

#### PUBLIC HEALTH APPROACH TO REDUCING HEALTH AND HEALTH SERVICE INEQUALITIES AMONG PERSONS WITH AUTISM

The Public Health Ministry or Sector of every nation has a vital role to play in promoting, improving and maintaining the health of the general population and ensure equity in health status for everyone including children with disabilities. As mentioned earlier in addition to their disabilities children with developmental disabilities frequently experience other chronic diseases and problems.<sup>21</sup> Hence, the healthcare needs of children with autism is of paramount importance to the public health department since this group within the special population is highly vulnerable but hardly access existing healthcare services. Therefore, it is vital for every nation to meet the delicate health needs of persons with autism especially children. As it is mandatory for them to equally access healthcare services and receive quality care.

This however, requires the putting in place population-based strategies to inform and empower the target group and stakeholders.<sup>6</sup> For instance, organizing health screenings yearly that incorporate practices, which are 'autism friendly' and promoting increased autism awareness among medical professionals, could help meet the comprehensive health needs of children with autism. Also, improving access to healthcare services by reinforcing

health and human services workforce capacity, could go a long way to reduce health disparities for individuals with autism and other developmental disabilities. Persons with developmental disabilities should be included in public health programs, and strategies for emergency preparedness and readiness should equally be put in place taking in to account individuals with disabilities in general. This will ensure that at any point in time issues related to health pertaining to children with developmental disabilities will always be included in health priorities.

Furthermore, data on disability should be regularly gathered and utilized to make decisions regarding public health activities.<sup>13</sup> The following subsections present some of the ways by which the public health sector and related organizations can address health related disparities among persons with developmental disabilities and reduce inequalities.

### **INCORPORATING INDIVIDUALS WITH DISABILITIES IN PUBLIC HEALTH PROGRAMS AND SERVICES**

Despite the Centers for Disease Control and Prevention (CDC) scheme calling on the total inclusion of individuals with disabilities in all programs, the society usually focuses on the disability rather than the unique abilities of these individuals. As a result this special group is often excluded from the usual public health programs and services. This leads to discrimination and isolation which in turn increase unemployment rates among this special population<sup>13</sup> making most of them to live unfulfilling lives. This put individuals with disabilities in a disadvantaged position with great health consequences. Hence, if persons with disabilities are effectively included into health promotion policies and activities it will greatly improve their health and decrease inequalities in health and healthcare services.

### **EMERGENCY PREPAREDNESS AND READINESS TO PROTECT HEALTH AND SAVE LIVES OF PERSONS WITH DISABILITIES**

Persons with disabilities are particularly vulnerable during emergencies and when disasters occur, since they are less likely to escape or be evacuated on time due to their disabilities. Emergency preparedness entails making plans and be ready to arrest and adequately handle the different types and stages of the multiple man-made and/or natural disasters that may occur. This plan that entails system-level responsiveness should consider including at all the stages of preparedness, evacuation, and recovery of every individual with a disability and his/her support systems within the community.<sup>13</sup>

Such emergency preparedness, health protection and live saving plans for persons with disabilities particularly children should also consider plans for modified shelter accommodations within the community.<sup>6</sup> Also, the plan should make provision for the training of individuals with disabilities and families before, during and after disasters. Furthermore, organized planning and commitment is required to better address in particular, the needs of children with disabilities.

### **ACCESS TO HEALTHCARE AND HUMAN SERVICES**

Children with autism have the right to fully access healthcare and healthcare services like the so-called normal or typically developing individuals. Health reforms are available that stipulate exceptional consideration for persons with disabilities including autism and condemns discrimination of any form among this special group.<sup>6</sup> Hence, governments of nations particularly developing and underdeveloped countries need to respect these reforms in order to adequately meet the health needs of persons with disabilities and reduce inequalities in health and access to healthcare services.

Generally, literature reveals that children with disabilities do not have full access to healthcare facilities and services partly because their structures and equipment are not disability friendly. For instance, it was found that in California less than half of the primary healthcare facilities are fully accessible. In addition, these healthcare facilities have limited resources and equipment to accommodate people with disabilities<sup>8</sup>; what more of developing and underdeveloped countries. Since some of the medical equipment and materials employed to conduct complete medical examinations for this special population are not adapted for this special group, the care they receive is obviously limited. Healthcare providers especially nurses need to make their services accessible to all children with disabilities.<sup>22</sup>

The disparities in accessing healthcare and healthcare services can be decreased by making the architecture of every health facility disability friendly and the available equipment and protocols should also accommodate all individuals with disabilities.<sup>13</sup> The specifications should conform to the Architectural and Transportation Barriers Compliance Board (Access Board) standards for defining accessibility of medical equipment established in 2013. This will go a long way to enhance accessibility to care which will in turn ensure a comprehensive and quality care for all persons with disabilities particularly children with autism and other developmental disabilities.

### **ACCESSING APPROPRIATE AND TIMELY HEALTHCARE**

Health promotion and disease prevention for children with autism in particular and adults in general are important parts of public health activities. The Westminster Commission on Autism advocated for preventive healthcare for adults with autism supporting the need for the detecting and managing individuals with autism's unmet health needs.<sup>23</sup> It is mandatory to organize autism training that includes staff awareness (nurses in particular), communication and reasonable adjustments with respect to environment and procedures. In addition, behavior management to support children with autism should be taken into consideration. Also of importance is the implementation of the Royal College of General Practitioners (RCGP) Autistic Spectrum Disorder toolkit, which could help make clear a range of modalities such as support in the delivery of reasonable adjustments, access to formal autism training, and clarifying issues of diagnosis and referral pathways.<sup>15</sup> This will go a long way to make primary care practices autism friendly and ensure access to appropriate and timely healthcare.

## STRENGTHENING HEALTH AND HUMAN SERVICES WORKFORCE CAPACITY

Due to the report on the poor health of children with disabilities there is need for capacity building for nurses and other healthcare providers regarding the care of individuals with disabilities. The lack of or limited knowledge and skills regarding the care of children with disabilities among healthcare practitioners act as a major barrier to the provision of competent and suitable healthcare to this special group.<sup>21</sup> Literature reveals inappropriate care rendered to children with disabilities due to inadequate preparedness and lack of knowledge on the part of healthcare providers. As a result, the complex medical and psychosocial needs of children with disabilities are not met. Hence, building the capacity of healthcare providers (especially nurse who are the first to see these children) with respect to disability care is mandatory.

Such training may involve different topics including Public Health Workers and Clinical Care Providers' Awareness on Disability and Life Cycle, and Care for children with Disabilities among others.<sup>24</sup> Empowering healthcare providers with knowledge and skills regarding the care of children with developmental disabilities especially those with autism could go a long way to enhance early diagnosis and intervention for this special population. Approaches to reduce inequalities for children with disabilities are summarized in Appendix.

## HEALTH CONDITIONS FREQUENTLY AFFECTING CHILDREN WITH AUTISM

Autism is the most commonly diagnosed among the developmental disabilities and it presents differently in children affected by the disorder. This is because it is a spectrum disorder which manifests in varied ways and degrees in each individual leading to unique experiences. Thus, no two children with autism are the same therefore, their unique abilities as well as challenges direct the type of support required to meet their needs including their healthcare needs.<sup>25</sup>

Children with autism often face complex and diverse physical and mental health challenges including co-morbidities such as schizophrenia and bipolar disorders, sleep disturbances, seizures, eating and feeding challenges.<sup>26</sup> Also, they frequently experience gastrointestinal problems, epilepsy, obesity, ADHD, anxiety and depression. These are serious conditions that are experienced throughout life and which often impact the health and quality of life of individuals with autism negatively as well as resulting in an increased rate of premature death.<sup>12</sup> These conditions and their treatments are described in the subsection below.

### Gastrointestinal Disorders

Gastrointestinal disorders (GI) are problems that most commonly affect children with autism when compared to their typically developing peers. Literature reveals that children with autism are about eight times more likely to be diagnosed with one or more chronic GI problems than are their typically developing peers.<sup>23</sup> Common examples of GI conditions include recurrent abdominal pain, di-

arrhea, gaseousness, bowel inflammation, gastroesophageal reflux, painful stooling and chronic constipation. Studies have revealed an association between chronic GI issues and increased severity of the behavioral symptoms of autism. These include social withdrawal, repetitive behaviors, hyperactivity and irritability. It is stated that the link is mostly strong among children with autism who are nonverbal and often have problems communicating pain and distress.

It is believed that unhealthy changes in the normal flora (the microbiome) in the intestinal tract cause both behavioral and GI problems in some individuals with autism. Also, it has been shown that the brain could be affected directly by spikes in toxin-producing bacteria in the intestines through the vagus nerve that runs between the digestive tract and the brain.<sup>27</sup> The following paragraphs examine GI problems commonly affecting children with autism.

### CHRONIC CONSTIPATION

Constipation can be defined as difficulties producing bowel motions due to hard stools. According to CDC children with autism are more than 3.5 times likely to be affected by chronic constipation or diarrhea compared to normally developing children.<sup>21</sup> Chronic constipation (lasting two-weeks or more) in patients with autism are mostly linked to insufficient fiber intake and some behavioral medications such as Risperidone. Also, sensory and/or behavioral issues that hamper regular toileting are implicated. Furthermore, metabolic, anatomic, or neurological problems and a sluggish intestinal tract are less common but potentially more serious factors that may predispose a child with autism to chronic constipation.

Constipation is effectively treated using a mixture of medical and behavioral interventions. Medications such as soluble fiber and/or laxatives for example, mineral oil, magnesium hydroxide or sorbitol could be used to manage constipation.<sup>27</sup> On the other hand, behavioral treatment entails modifications in diet for instance, eating more fiber producing foods, avoiding foods that cause constipation as well as instructing the individual to increase fluid intake and make attempts to defecate after each meal by sitting on the toilet pot.

### CHRONIC DIARRHEA

Chronic diarrhea refers to the passing out of frequent watery stools more than three times a day for two or more weeks. Possible medical causes may include immune dysfunction, inflammatory bowel and irritable bowel diseases, intestinal infection. Recently, researchers have reported unusually high-levels of several kinds of toxin-producing Clostridia bacteria among children with autism.<sup>27</sup> It is believed that diarrhea in persons with autism is most often caused by severe constipation. This occurs when hard, impacted stool results in a backup of watery contents which then spill around the hard stool causing abrupt diarrhea.

The treatment of diarrhea depends on the cause therefore, to effectively treat diarrhea the cause must be investigated and addressed accordingly. For example, if diarrhea is found to be

caused by food allergies, over consumption of juice, lactose intolerance or celiac disease, changes in diet may treat the diarrhea.<sup>23</sup> Also, depending on the cause medications may be administered or a surgical intervention may be required.

### GASTROESOPHAGEAL REFLUX DISEASE

Gastroesophageal reflux disease (GERD) occurs when the muscle between the esophagus and stomach is weakened allowing partially digested food and liquid mixed with stomach acid to move up out of the stomach. GERD may lead to ulceration of the esophagus and put the child at risk of developing esophageal cancer. Symptoms commonly include sensations of “heartburn”, pain and discomfort in the throat.<sup>7</sup> It is important to note that pain and discomfort may be communicated by persons who are minimally verbal or nonverbal in atypical ways. These include an increased in repetitive behaviors and displaying self-injurious acts such as banging the head against the wall, as well as challenging behaviors. Sometimes, pushing out the jaw or tapping the throat, straining the neck and unusual body postures may be observed.

Also, the individual may experience chronic sore throat, cough, hoarseness, dental erosions, inability to eat and disrupted sleep.<sup>28</sup> In diagnosing GERD a thorough history taking and physical examination is conducted. This assist in eliciting information as to whether the manifestation of the unusual behaviors are initiated or worsened when the patient lies down since the lying position favors reflux of gastric contents. When GERD is severe and chronic specialized tests are ordered in order to identify acid levels and tissue damage in the esophagus.

Tips for relieving the symptoms of GERD include behavioral modifications such as raising the head when sleeping, eating small quantities of food, identifying and avoiding foods that are likely to elicit symptoms, and avoid eating just before going to bed. Medications such as antacids, histamine-2 blockers and protein-pump inhibitors may be administered.<sup>29</sup> For chronic and severe cases of GERD the patient is referred to a specialist.

### EPILEPSY

Epilepsy also known as seizure disorder that affects just one to two percent of typically developing persons is common in about a third of individuals with autism. It is said that one in every four children with autism has seizures.<sup>21</sup> Seizures occur due to lesions or cuts on the brain resulting in unusual electrical activity in the brain. Generally, it begins in either early childhood or adolescence. Occasionally, hyperpyrexia and difficulty sleeping contribute to the occurrence of seizures meanwhile if seizures are not managed or controlled sleep is disrupted. Its signs and symptoms most commonly include unexplained staring spells and confusion, severe headaches and involuntary or unusual movements. Also, the person may experience a brief loss of consciousness and or “blackout” and a body convulsion as well as stiffening of muscles and involuntary jerking of limbs.

Less commonly the individual may experience unexplained changes in abilities or emotions as well as sleepiness or

disrupted sleep which can in turn increase seizures.<sup>25</sup> In addition, there may be regression in normal development as well as inexplicable irritability or aggressiveness. It is important to note that just like autism, epilepsy is equally a spectrum disorder as it varies broadly in severity. Epilepsy in children with autism may begin at any age; however, literature holds that seizures mostly start in the preschool years and also in adolescence. It is usually difficult to diagnose epilepsy because many individuals with autism have difficulty recognizing and reporting their symptoms, and the symptoms do not always manifest outwardly.

Generally, the diagnosis of epilepsy is made using an electroencephalogram (EEG) in order for the individual to be treated properly and prevent brain damage. Several factors are taken into considerations before selecting an anti-epileptic medication. These include where the seizures began in the brain,<sup>29</sup> the kind and extent of seizures and their recorded EEG patterns. Worthy of note is the fact that anti-epileptic medications do not cure epilepsy, but are mostly used to prevent, control or decrease the severity of seizures. Another option is vagus nerve stimulation as well as surgery could be done to remove areas in the brain which produce seizures.

### FEEDING AND EATING PROBLEMS

According to Kanner feeding problems are defining features of autism; about 7 out of 10 children with autism suffer from feeding and eating problems. It is estimated that close to half of this number presents with severe problems.<sup>14</sup> An individual is said to have a feeding and eating problems when he/she does not eat enough, eats a lot or does not eat the right types and proportion of food. Generally, children with autism are very selective that is they eat only a few types of foods usually those with particular colors or textures and at times may display troublesome mealtime behavior. Still others exhibit Pica, which refers to the risky habit of eating nonfood objects for instance, ingesting dangerous and poisonous items or substances including nails, broken glass and pins, as well as swimming pool chlorine tablets and paint chips.<sup>30</sup>

Pica habit can be deadly as it can result in infection, suffocation and perforation of the gastrointestinal tract as well as lead to poisoning.<sup>31</sup> Other health complications related to pica habits are constipation, broken teeth and other dental conditions, bowel obstruction and chronic lead poisoning.

Eating problems may be caused by anxiety, which may be due to an experience such as vomiting or gagging or choking during or after eating a particular food and rigidity (wanting to eat one particular type of food all the time) among others.

On the other hand, an eating disorder such as anorexia nervosa may occur in young women with autism due fear of gaining weight (body image issues). Unlike anorexia nervosa, chronic overeating (bulimia) has also been reported among persons with autism. This may be due to increased appetite that is, a severe side effect of Risperidone (Risperdal) and Aripiprazole (Abilify) used to treat challenging behaviors such as agitation<sup>30</sup> in children and adults with autism. Pica is generally common among children with autism who have intellectual disability.

Eating problems may be manifested as hatred or dislikes for certain tastes, textures and strong flavors. This in turn result in extremely limited food habits, which is often due to autism-related hypersensitivities and/or a strong resistance against change. This usually leads to excessive consumption of high-calorie and low-nutrient foods. Chronic overeating may results when the individual is unable to recognize or sense when the stomach is full and/or when eating has becomes a soothing sensory behavior. There are specialized feeding programs that have been developed, which are being implemented by behavioral therapists and nutritionists in some autism clinics. Also, to an extent, some speech, behavioral and occupational therapists can be of help in the management of pica habits.<sup>32</sup>

Medical therapy is employed to treat iron or zinc nutritional deficits, infection as well as infestation with intestinal parasites. On the other hand, behavioral therapies can be effective in reducing pica habits.<sup>33</sup> These include strategies for reinforcing good behaviors such as given rewards to the child (in the form of small food treats) for not putting inedible objects in his/her mouth. Another strategy is to constantly removing the child's attention from the nonfood items to his/her favorite activities as well as continuously blocking the child from any attempts to eat uneatable items.

## OBESITY

Obesity is another condition commonly found in children with autism usually caused by chronic overeating and begins early in lives of children with autism. The child may dislike foods containing vitamins and proteins but concentrates on eating more of high calorie foods. However, some studies have associated the likelihood of being overweight or obese with the number of psychoactive behavioral medicines these children take.<sup>3</sup>

Treatment usually takes into considerations dietary and behavioral measures. Dietary approach to treatment entails introducing healthier food choices while reducing each serving size for breakfast, lunch and supper. At times, if required high-calorie foods are removed from the child's diet while daily exercises in the form of walking and/or riding bicycles is encouraged.<sup>34</sup>

## SLEEP PROBLEMS

Chronic sleep problems frequently occur in children with autism (more than half of children with autism have trouble sleeping). Most persons with autism experience disrupted sleep that is, they have issues with normal sleep patterns.<sup>35</sup> For instance, many adults with autism have problems going to sleep while others wake frequently at night, still some may wake up very early and stay awake throughout the day. Lacking sufficient sleep may actually result in a sleep disorder, which can aggravate abnormal behaviors during the day. Sleep disturbances may also pose difficulty in communicating, increase aggressive and repetitive behaviors, as well as inattention, hyperactivity and irritability. Generally, these reduce the quality of life and hamper learning.

According to research, possible biological causes of sleep

problems in persons with autism include mutations in genes that control the body's sleep-wake cycle called the circadian rhythm. In addition, sleep problems may be worsened by undetected seizures occurring at night disrupting sleep brain patterns.<sup>36</sup> Again, anxiety may affect the ability to fall asleep and remain asleep for long hours at night. In addition to biological causes of sleep problems, reduced levels of melatonin may cause autism-related sleep problems.<sup>37</sup>

Some strategies to help improve sleep for persons with autism and get them back to sleep after waking up at night have been suggested. These strategies include integrating daytime exercises and outdoor activities in a manner that will lead to evening routines that limit screen time before bed. In addition, parents are taught how to create visual schedules that help to establish regular bedtime routines. These strategies have been proven to increased sleep time for individuals with autism as well as reduced anxiety, inattention and challenging behaviors during the day.<sup>38</sup>

## MENTAL HEALTH DISORDERS

Mental health conditions such as ADHD, anxiety and depression among others frequently affect children with autism. Averagely 62% of persons with autism suffer from one or more mental health disorders<sup>14</sup> which can greatly worsen autism's behavioral challenges if not identified and treated.

Usually, autism and ADHD have similar symptoms<sup>39</sup> as such an evaluation by a specialist is required to differentiate between the two disorders and develop a suitable treatment plan for the individual. Generally, treatment may entail ADHD medication as well as behavioral strategies such as the Applied Behavior Analysis (ABA). ABA is a remarkable treatment therapy for individuals with autism,<sup>40</sup> which is widely used by healthcare professionals as well as in many schools, autism centers and clinics.

### Anxiety

Anxiety disorders are mostly diagnosed among persons with autism; about 42% of children and teenagers with autism are affected with one or more anxiety disorders<sup>41</sup> compared to about 3% of children and 15% of adults who develop normally. Persons with autism are particularly affected by social anxiety, which is excessive fear of strangers, crowds and social circumstances. Anxiety can be elicited at different points in time and caused by various activities including past enjoyable events.

For many children with autism anxiety may be triggered by difficulty participating in social activities and significant sensory sensitivities to lights, tastes, smells and loud noises.

### Depression

It is estimated that about seven percent of children and 26% of adults with autism are affected by depression whereas only about two and seven percent of children and adults respectively in the general population are affected. It is worth noting that the rates of depression among individuals with autism increase with age and

intellectual ability.<sup>14</sup> The signs and symptoms of depression may include continuing feelings of sadness, no longer showing interest in his/her desired activities, displaying poor hygienic practices, irritability as well as feeling insignificant and desperate. Severe symptoms of depression are recurrent thoughts of death and/or suicidal tendency.<sup>42</sup>

### CHALLENGES FACED BY INDIVIDUALS WITH DISABILITIES IN ACCESSING APPROPRIATE MEDICAL HEALTH SERVICES

Persons with disabilities face many barriers in accessing and utilizing quality healthcare services. This may be due to the fact that most of the healthcare facilities are costly, sometimes not available and not disability friendly.<sup>43</sup> Also, the challenges are usually due to stigmatization and discrimination which are associated with their impairments and differences in race or ethnicity among others. The challenges range from inaccessible physical environments, the lack of the appropriate healthcare providers who can render adequate care to persons with autism to inflexible policies and procedures, social assumptions and prejudices. Furthermore, it was found that parents of children with autism faced unique challenges in accessing referrals and specialized care services.<sup>44</sup> The following sub-sections describe these challenges and/or the barriers to accessing and receiving quality healthcare by persons with disabilities in general and autism in particular and state World Health Organization (WHO) as well as United Nations (UN's) strategies for reducing the challenges.

#### LIMITED AVAILABILITY OF HEALTH SERVICES, IN ACCESSIBLE PHYSICAL ENVIRONMENTS AND EQUIPMENT

Usually, the architectural designs of most health facilities are not disability friendly; they are not well adapted to suit persons with disabilities. As a result, they cannot fully access the structure with their wheelchairs or crutches and circulate freely from one section to another. This prevents persons with disabilities to fully utilize healthcare services resulting in low quality care.<sup>8</sup> It has been documented that most primary care facilities in California do not have accessible healthcare equipment such as weight scales, examination tables, cancer screening equipment and wheelchairs, to move safely and with ease within the health facility.<sup>45</sup>

This is true for almost all healthcare facilities in developing and underdeveloped countries where appropriate health services for persons with disabilities are scarce or very limited. Individuals with disabilities particularly those in rural and remote areas experience high unmet needs for healthcare. In addition, parents of children with developmental disabilities have reported a range of barriers to accessing healthcare services.<sup>46</sup> These include among others the absence of accurate information regarding available services, misconceptions regarding medical care and the aim of treatment, communication and transportation difficulties as well as fear of stigmatization and discrimination.

The absence of appropriate health services and accessible equipment in many outpatient provider offices leads to fewer

preventive investigations, missed diagnoses, and delayed care particularly, for individuals with mobility impairments. For instance, most ladies with mobility difficulties do not access breast and cervical cancer screening examinations because the available equipment are not adapted to accommodate women with disabilities.<sup>6</sup> This unequal access to some health facilities' buildings by persons with disabilities due to narrow doorways, no pavements, inappropriate office and bathroom facilities, and inaccessible parking areas as well as inaccessible medical equipment create barriers to the full access of healthcare facilities.

#### INADEQUATE SKILLS AND KNOWLEDGE OF HEALTH WORKERS AND TREATMENT DECISIONS CHALLENGES

Due to the lack of trained healthcare providers regarding autism parents having children with autism may face major difficulties discussing treatment options with their child's healthcare provider. These challenges may include among others communication difficulties, lack of knowledge on the part of the healthcare provider regarding specific treatments for autism as well as doubts about their role in making treatment recommendations.<sup>8</sup> Persons with disabilities reported that healthcare providers had inadequate skills to meet their needs, and sometimes they were denied care probably due to difficulties to make treatment decisions.

Talking about communication difficulties some parents have reported the lack of involvement/participation in the choice of treatment options for their child, while others mentioned the fact that their child's healthcare provider/physician made only general recommendations or referrals. In order to foster more effective communication between families and healthcare providers/pediatricians tools such as decision making and practice guidelines should be made available for used by the healthcare providers.<sup>47</sup> It is vital for the patient/family and physician to work together and arrive at a treatment plan for their child (shared decision-making). This will obviously enhance healthcare provider-patient/family communication and partnership resulting in quality patient care, compliance and good treatment outcomes and patient satisfaction.

Concerning the lack of knowledge on the part of the healthcare provider, knowledge gaps about the treatment of autism and available community resources have reported by both parents and physicians. Also, uncertainty about the pediatrician's role regarding the care of autism has been reported. With respect to the management, pediatrician are generally not so sure about the treatment options as such they are uncomfortable discussing autism related treatments. As a result, parents miss the opportunity to discuss benefits and risks of treatment options.<sup>47</sup> Therefore, primary healthcare providers need to be provided with treatment/care plans for autism and other developmental disabilities and available resources. These include such tools as the Autism Toolkit and clinical practice guidelines developed by the American Academy of Pediatrics (AAP).

#### INFLEXIBLE POLICIES AND PROHIBITIVE COST

The policy put in place regarding healthcare and disabilities particularly autism may pose a barrier to healthcare service utilization



by this special group. For instance, the assumption that everyone might be able to complete hospital forms unaided, undress and transfer to high examination tables without assistance, and communicate normally may limit full access of hospital facilities by persons with disabilities needing healthcare. Also, a study conducted by Zhang et al<sup>21</sup> reported gaps in access and utilization of healthcare services whereby children with private health insurance had access to less services with more out of pocket expenses compared to children with public insurance coverage.

These expenses are mostly with respect to outpatient services and prescription medications for managing various health conditions including dental care. According to Buescher et al<sup>48</sup> many persons with disabilities are unable to access health services due to cost. Generally, individuals with disabilities in less developed countries do not get the much-needed healthcare due to the cost of transportation and healthcare services.

### SOCIAL ASSUMPTIONS AND PREJUDICES

Generally, it is assumed that persons with developmental disabilities have greater access to healthcare but which is not the case. Literature reveals that 68% of participants in a multinational study assumed that individuals with intellectual disabilities had the same or even better healthcare compared to typically developing children. Meanwhile, persons with developmental disabilities do not receive the needed healthcare easily or on time, and may not receive suitable and adequate healthcare because policy makers turn to neglect or underestimate their health needs.<sup>46</sup>

Also, there exist racial differences in the utilization rates of healthcare services among people with disabilities. Because of cultural differences between the Western world and African there may be conflicting ideas between modern service delivery models and traditional beliefs regarding the diagnosis and treatment of autism and its associated conditions.<sup>49</sup> For instance, in most cultures women are compelled to respect and obey their husbands' instructions including treatment options.

Also, there may be role conflict as mothers are charged with the responsibility of caring for all their children and other family members making it difficult for them to meet up with their commitment to cater for a child with developmental disability. These may pose barriers to the effective utilization of available healthcare services.<sup>49</sup>

### WHO AND UN'S STRATEGIES FOR IMPROVING ACCESS TO HEALTH SERVICES FOR PEOPLE WITH DISABILITY

Disability is a public health issue hence, nations should consider taking actions towards including disability as a priority in the health sector, develop and implement strategies to reduce challenges faced by persons with disabilities in accessing healthcare.<sup>45</sup> This may include strategies to attain equity for people with disability such as improving access to effective health services and cross-sectorial public health interventions, such as good source of drinking water, proper sanitation and hygiene services, as well as maximum protection during disasters.<sup>50</sup>

Also, existing policies and services should be evaluated and put in place strategies to enable disability inclusion in the health sector establishing healthcare standards related to care of children with disabilities especially in resource poor settings and decrease health inequalities. In addition, services such as health promotion, disease prevention, treatment, rehabilitation and palliative health services should be made very affordable and accessible to all persons with disabilities.

Furthermore, the environment of health facilities should be modified and adjusted to facilitate access by all persons with disabilities.<sup>13</sup> For instance, modifying the physical layout of health facilities to provide effective access for people with mobility problems as well as ensuring their easy access to all public health information.

Above all, healthcare providers should be empowered with the necessary knowledge and skills to meet the individual needs of persons with disabilities both in the hospital and community settings using evidence-based guidelines for assessment and treatment. All these strategies together with the inclusion of individuals with disability in healthcare surveillance could help achieve highest attainable standard of health for this special population.<sup>6</sup> Below is presented WHO and UN's strategies for decreasing the barriers and improving access to healthcare by persons with disability. In a bid to enhance access to health services for people with disabilities WHO does the following among others:

- Intensifies awareness on disability matters, and encourages the inclusion of disability as a component in national health policies and programs among Member States.
- Develop and implement normative tools and guidelines to strengthen healthcare for all including persons with disabilities.
- Capacity building for health policymakers and service providers regarding provision of care, supporting and protecting the rights and dignity of persons with disability.
- Facilitates the collection of disability-related data and information, and dissemination.
- Encourages the implementation of strategies aimed at educating persons with disabilities about their own health conditions, health promotion and disease prevention activities.

### UNITED NATIONS DISABILITY INCLUSIVE STRATEGY

In order to promote sustainable and transformative progress on disability inclusion through all pillars of the work of the United Nations, the UN Secretary-General launched the UN Disability Inclusion Strategy (UNDIS) in June 2019. This strategy compels all UN agencies to make sure that disability is constantly and systematically mainstreamed into all facets of work.<sup>22</sup> WHO and UN are working to systematically integrate disability in all programmatic areas, including at the country-level.

### CONCLUSION

The health needs of children with developmental disabilities particularly autism are not being met as required even though this special population are more likely to seek medical care due to their

disabilities and associated conditions. Children with autism and other developmental disabilities experience disparities in health and healthcare service utilization. Autism is linked to many health conditions such as epilepsy, gastrointestinal problems and other mental disorders. These health problems affect each individual with autism in a unique way negatively affecting his/her existing social interaction and communication impairments. Again, health facilities and medical equipment are not disability friendly making it difficult for this special group to effectively have access to quality care. In addition, most healthcare providers do not possess adequate knowledge and skills required to make critical decisions regarding this very special group of persons.

Furthermore, due to cultural differences certain diagnosis and treatment regarding autism and other developmental disabilities may not be welcomed. These among others create barriers to the effective provision and utilization of healthcare services by children with disabilities in general and those with developmental disabilities in particular. The public health sector of all nations has the duty to promote health and prevent diseases for all including children with disabilities. This can be done by developing and implementing strategies to include persons with disabilities in all aspects of work as suggested by the UN and WHO. If this is done it will go a long way to reduce disparities in health and barriers to health service utilization especially for children with autism. This will in turn decrease stigmatization, discrimination and enhance the delivery of quality and holistic care to persons with disabilities particularly children with autism and related disorders.

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APPENDIX

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**A Summary of the Various Means by Which Public Health Sectors of Nations Could Reduce Health and Health Service Inequalities among Children with Autism and other Developmental Disabilities**

The Public Health Sectors of each nation should:

- Include disability in crisis prevention and disaster risk reduction and risk assessments, recovery and post-conflict and post-disaster recovery planning.
- Institute policies and strategies to enable individuals with disabilities to effectively participate in health related decision making.
- Ensure conflict and disaster assessments collect disaggregated data on people with disabilities and prioritize needs of persons with disabilities in all UNDP recovery programs.
- Assist in capacity building of persons with disabilities and of their organizations to raise their awareness and foster collaboration between local, national and international organizations working on disability.
- Support local authorities to put in place strategies to maintain pertinent information regarding the location and diversity of disability and implement specific awareness and information campaigns for people with disabilities during and after disasters.
- Encourage full access to basic services.

Adapted from United Nations Development Program (UNDP).<sup>25</sup>