

## Review

# Early Identification, Assessment and Interventions in Children with Developmental Disabilities: A Review on Autism

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### ABSTRACT

Developmental disabilities are a set of disorders which occur during the child's developmental stages affecting his or her language, physical and mental abilities or behavior. These include autism and other related disorders which all negatively influence the way the child achieves normal developmental milestones. Nurses are expected to work in collaboration with parents and other health care professionals to monitor each child's growth and development during each well-child visit or Infant Welfare Clinics (IWC) as well as during illness episodes. Generally, parents' concerns regarding developmental delays are discussed and the child is followed-up accordingly through developmental screening. A brief test is conducted on the child while the parent/caregiver completes a questionnaire or checklist regarding the child's developmental history. The American Academy of Pediatrics (AAP) recommends that developmental and behavioral screening be conducted for all children during regular IWC or well-child visits at nine, 18 and 30-months. Early diagnosis together with early treatment can make a major difference in a child's life and also decrease the possibility for costly interventions in future. Several programs have been designed to deal with the variety of social and behavioral difficulties associated with autism, focusing on reducing problem behaviors in children with autism. Once an individual is given a confirmed autism diagnosis by a qualified professional, the parents need to seek further information immediately on how to support their child. Early intervention treatment services have been shown to greatly improve a child's development. Thus, diagnosing autism early and instituting treatment and support promptly is mandatory for better prognosis.

### Keywords

Developmental disabilities; Children with autism; Early assessment, Diagnosis and interventions.

### INTRODUCTION

Developmental disabilities are a set of conditions which occur during human development as a result of atypical development that influence typical development affecting the child's language, physical and mental abilities or behavior.<sup>1</sup> Examples include autism and other related disorders which affect the way children are attaining normal developmental milestones. Health care professionals particularly nurses in collaboration with parents have the responsibility to monitor and discuss the child's growth and development. This is expected to be done during each well-child visit or Infant Welfare Clinics (IWC) and during illness episodes. Issues regarding developmental delays and any other concerns the parents might have are discussed and the child is followed-up accordingly through developmental screening. This brief examination tells whether the child is developing normally or if she/he is lagging behind peers with respect to acquiring basic skills as expected for age.

Thus, during growth and development children are supposed to be monitored and then screened to find out whether they are meeting the typical developmental milestones as expected.<sup>2</sup> That is, smiling, babbling, pointing, waving and sharing interests as well as playing, sitting, speaking, and moving among others. During the developmental screening a nurse practitioner (NP) or a physician looks closely at how the child is moving from one stage of development to another. Usually, the child and parents are involved; whereby a brief test is conducted on the child while the parent/caregiver completes a questionnaire or checklist regarding the child's developmental history.

These questionnaires and checklists are standardized tools designed in line with research evidence about developmental and behavioral screening.<sup>3</sup> That is, they take into consideration questions about a child's development with respect to language,

movement, thinking, behavior, and emotions. Developmental screening can also be done by other experts in the healthcare settings as well as in early childhood education, school or community settings. It is worth stating that developmental monitoring is done on a regular basis during the IWC while developmental screening is more formal and is usually performed whenever the child's parents or the physician has a concern (Appendix A).

However, the American Academy of Pediatrics (AAP) recommends that developmental and behavioral screening be conducted for all children during regular IWC or well-child visits at nine, 18 and 30-months. Again, AAP recommends that screening specifically for autism spectrum disorders (ASD) be done for all children at 18 and 24-months during regular well-child visits.<sup>4</sup> If after the screening an area of concern is identified, an official developmental evaluation may be required. This further assessment is conducted in collaboration with other experts to take an in-depth look to identify any deficits or delays so that diagnosis can be made as early as possible and treatment instituted immediately.

Early diagnosis together with early treatment can make a major difference in a child's life and also decrease the possibility for costly interventions in future. It is worth saying that in this paper evaluation and assessment are used interchangeably. This paper sought to:

1. Evaluate and diagnose young children with developmental disabilities particularly autism from an interdisciplinary perspective.
2. Identify and critically examine risk factors and early warning signs of atypical development.
3. Critically examine common assessments and diagnostic approaches such as the diagnostic and statistical manual of mental disorders fourth edition (DSM-IV), International Classification of Diseases-10 (ICD-10), used to identify developmental delays in various fields.
4. Examine different modalities of interventions typical of individuals with developmental disabilities, particularly autism.
5. Explore advances in intervention for children with developmental disabilities.
6. Critically examine factors that contribute to treatment success.

### AN INTERDISCIPLINARY PERSPECTIVE IN THE EVALUATION AND DIAGNOSIS OF YOUNG CHILDREN WITH DEVELOPMENTAL DISABILITIES PARTICULARLY AUTISM

It is worthy of note that a brief screening test does not usually provide a diagnosis of developmental disabilities. However, it tells whether a child is developing normally or if a specialist should conduct a detailed assessment.<sup>5</sup> A formal developmental evaluation is then required, if the screening test suggests an atypical development. This formal assessment gives a critical look at the child's development, typically conducted by a team of well-trained experts. That is, a pediatrician, developmental pediatrician, pathologist, speech-language pathologist, occupational therapist and child psychologist among others (Appendix B). The experts are expected to observe the child, administer a structured test, pose questions to the parents/caregivers and/or request them to complete a check-

list or questionnaire.<sup>6</sup> The outcomes of this formal assessment will tell if the child requires special therapies or early intervention services or both.

It is very important for developmental evaluation to be carried out because many children with developmental delays or behavior concerns are not identified early as required. Thus, by the time they are diagnosed in school, significant delays might have occurred and they must have missed opportunities for treatment. Hence, assessing children for the diagnosis of autism and other related disorders is very vital if these children are expected to do well in educational and other social settings.<sup>4</sup> The following section explains how assessment and diagnosis for autism is made.

### Evaluation and Diagnosis of Autism

As mentioned earlier regular developmental monitoring and screening are very necessary for all children during well-child visits, and if there are concerns regarding the child's development an evaluation is done to diagnose the condition as soon as possible. Therefore, it is mandatory to discuss how a child can be evaluated and diagnosed with autism. Developmental and behavioral screening are performed to identify and establish the need for a specific intervention and further standardized testing. If the screening indicates the need, the evaluation is conducted by different specialists using a number of specialized assessment tools to assess a mixture of specific behaviors.<sup>5</sup> Physicians, pediatricians, developmental pediatricians, NPs and psychiatrists who diagnosis autism are usually well trained specifically for this purpose. This combination of experts helps to provide multi-disciplinary diagnostic assessments fast enough and suggests appropriate services.<sup>6</sup> The subsequent subsections highlight what is done before, during and after an autism diagnostic assessment.

#### Before the Assessment

Before commencing the evaluation one of the experts, usually the physician asks a few questions regarding the child's development and behavior. He/she may want to know how often the child behaves in a certain way and when this behavior was first manifested. Also, when and how the child reached certain developmental milestones should be made known, the family's medical history and why the parents decided to seek help or whether they were referred is also needed and all documented.<sup>5</sup> Generally,<sup>5</sup> the number of professionals to participate in the assessment is determined based on the child's unique needs and reason(s) for referral (that is whether speech, medical and/or behavioral challenges among others).

#### During the Assessment

Generally, diagnostic testing for autism includes a variety of developmental assessments, physical and neuro-developmental examinations and parent interview. During the diagnostic assessment, the child's parents/caregivers will be required to give information to the clinician regarding their child, including his/her medical history. Also, the child will be observed then reports and previous assessments findings about the child as well as information from school or childcare provider (if available) will be reviewed.<sup>6</sup> Again,

laboratory tests and X-rays may be requested. Furthermore, formal professional assessment tools and criteria is used by qualified and trained professionals to establish a diagnosis. Finally, the diagnostic criteria for ASD as stated in the fifth edition of the DSM will be used to confirm diagnosis and level of severity.

It should be noted that in most countries, only physicians or psychologists are certified to diagnose autism.<sup>7</sup> However, in some societies, NPs who are properly trained may also make autism diagnosis.

In order to diagnose autism early, the NP evaluates all children during well-child visits to identify children at risk for ASD. For every child he/she is expected to:

1. Review the developmental history for risk factors such as polyhydramnios, prematurity, low birth weight, prenatal infections with fever, advanced maternal and paternal age, large discrepancy between maternal and paternal age, among others. and less than 18-months between deliveries.
2. Review family history to find out if there are siblings with ASD or close relatives with developmental or psychiatric diagnoses.
3. Interview parents/caregivers about developmental concerns, observe the child and conduct standardized developmental screening<sup>8</sup> using recommended screening tools.
4. Refer children who screen positive for atypical or delayed development for a more detailed evaluation.

In addition, the NP should assess each child and determine whether they are achieving developmental milestones as required, particularly “joint attention” which the child should start displaying by the age of nine months.<sup>9</sup> Joint attention is the ability of the child to share another person’s interest, usually the mother or draws the mother’s attention to his/her focus/object of interest. That is, the child follows the mother’s gaze to look at the object she is looking at, and looks back at her with shared effect, or looks at an object and then gaze at his or her mother and the object repeatedly to draw her attention to his/her object of interest. The lack of joint attention is a major Red Flag for autism. Other milestones to look for include social smile, response to name and gesture to request needs at two, nine and fifteen months respectively (see the next major section for details). During each well-child visit the NP elicits and assesses how well the child is attaining developmental milestones. For instance, the NP smiles at a two months old child, looks whether the child smiles back and calls the name of a nine months old child from behind and observes if the child will respond, as well as giving an 18-months old child a doll and a comb to comb the doll’s hair while observing the child’s action, among others.

Generally, a team-based approach led by a primary care provider, paediatric specialist, or clinical child psychologist trained to diagnose ASD is recommended to confirm an autism diagnosis.

#### After the Assessment

At the end of the assessment a written diagnostic report containing the full name of the child, date of birth, date of the assessment and a statement clearly stating the conclusion of the evaluation is

signed by the professional (including name and credentials) and handed to the parents. The conclusion should spell out clearly whether or not the child meets the diagnostic criteria for ASD. In addition, the report may contain the name of the clinic and location, the kinds of diagnostic tools used during the assessment, any other diagnoses made and the child’s level of capability and performance. Furthermore, suggestions concerning treatment and other possible steps to take in future are given.<sup>5</sup> It is important to note that this information summarizes the child’s assessment findings and diagnosis which is very vital in planning the child’s treatment program. Again, the report may also include referrals to other specialists for cognitive or academic testing if needed.

Once an individual is given a confirmed autism diagnosis by a qualified professional, the parents/caregivers need to seek further information immediately on how to support their child. Early intervention treatment services have been shown to greatly improve a child’s development as these therapies help children from birth through three-years of age (36-months) to learn important skills. Also, special education services may be required for children age three years and older diagnosed with developmental delay or disability.<sup>6</sup> The services vary and depend on the unique needs of the child. These could either be a therapy to assist the child develop speech, or walk, interact with others, and learn effectively. Such support or special education services are supposed to be provided by the school systems and made available to all children diagnosed with a disability as stipulated by the Individuals with Disabilities Education Act (IDEA).

The IDEA also recommends that children who are younger than three years and are predisposed to developmental delays could qualify for early intervention treatment services whether they have received a formal diagnosis or not. Also, interventions such as speech therapy required for specific signs such as language delays might not need an official diagnosis. It is important to note that though it is extremely important to diagnose a child early and start treatment immediately, intervention started at any age once the individual is identified can still be of help. When parents become worried about their child’s development it can be pretty difficult for them to make the right decision on what to do.<sup>6</sup>

Thus, it is very necessary for parents to be informed of possible centers where they can get help when they have concerns about their child’s development. These centers provide information to parents on where to have their children assessed and locate support services.<sup>5</sup> If available, families are expected to be connected to community-based medical, educational, social and financial resources. To ensure that each individual diagnosed with autism receives best treatment options a comprehensive approach to care is provided by a multidisciplinary team. This is usually made-up of a psychiatrist, NP, developmental-behavioral pediatrician, psychologist, clinical social worker, and clinical counselor.

#### RISK FACTORS AND EARLY WARNING SIGNS OF ATYPICAL DEVELOPMENT

Children normally develop following a known and predictable pattern which can be described using a continuum of development and most children’s development would appear midway in

the continuum. A child is said to be developing normally if he/she is achieving developmental milestones that is, yardsticks used to monitor each child's development.<sup>7</sup> Developmental milestones are skills such as smiling, laughing, cooing, babbling, saying single words, making phrases and then sentences, sitting, crawling, walking, jumping and following instructions among others. The manner and period during which children acquire certain skills and abilities in the course of development differ from one child to another. Some reach developmental milestones faster than others; some are just on time while others lag behind their peers.

Since there is an expected time-frame to achieve these milestones for normal development it is important to identify risk factors and warning signs of abnormal development. This can go a long way to prevent developmental delays and enhance typical development. It is important to note that there is a difference between developmental delays (when the child achieves skills slowly) and developmental disorders (when the child manifests skills that are abnormal in terms of quality, form and function).<sup>8</sup> However, it is important to identify both early and treatment instituted promptly. Early intervention is known to be effective in helping children with special needs to either catch up or assist them study effectively.

Hence, it is important for parents, teachers and health care providers, especially nurses to know and understand the early warning signs and risk factors for childhood disabilities and delays which can impact normal development. This will enhance normal development and in turn curb the incidence and prevalence of developmental disorders. The following sub-sections present the risk factors and early warning signs of atypical development.

### Risk Factors of Atypical Development

The rates and ways of development differ for different children; little children learn to crawl, talk, or use the toilet at different speeds. But sometimes a child may reach those milestones much later than other kids. There are many reasons why some children may have delays in reaching some developmental milestones or have developmental disabilities. These include prematurity or low birth weight, genetic disorders such as Down syndrome or muscular dystrophy, poor vision, hearing impairment and malnutrition. Also, factors such as personality, health status, life experiences and/or temperament could be the cause of these variances. In addition, physical abuse or neglect,<sup>9</sup> the use of drugs and/or consumption of alcohol during pregnancy and fetal hypoxia during delivery could predispose to developmental delays and disabilities. Again, most developmental disabilities are thought to be associated with a combination of factors such as low birth weight, environmental exposure to drugs or tobacco and high-levels of environmental toxins (that is, lead). Furthermore, maternal infections during pregnancy, stress or neonatal infections, trauma and deficiency in iron, vitamins and proteins are all associated. These are explained in the next paragraph.

Stressful and negative life experiences may actually affect how children's brains develop. Specific, emotionally traumatic life events such as early medical complications which result in medical

interventions, pain, long hospital admissions and discrimination among others may lead to lifelong mental health disorders. Also, numerous stressful life events have been known to affect the shape and size of a child's brain and the connections between the brain cells negatively affecting development, behavior and learning. Furthermore, social and emotional delays are usually associated with cognitive delays and refrigerator mothers or neglectful parenting or early institutional neglect.<sup>10</sup> Cognitive delays are generally associated with serious medical conditions in the prenatal period, genetic problems, exposure to alcohol and lead as well as neglect. Such delays are commonly connected to ASD and related disorders.

### Early Warning Signs of Atypical Development

As earlier mentioned during development some children display behaviors that tend to deviate from the normal range of development. An example is when children display a series of behaviors that are significantly different from their peers. Such abnormal behaviors should be carefully noted and the dates and times at which they emerged, their sequence and quality and how they affect the child's functioning should be recorded.<sup>7</sup> Also, the duration and frequency of behavior(s), type of activity (language, fine motor), the settings and activities in which they occur, interactions with peers and others should all be noted and recorded. Furthermore, areas of weakness and concern should be noted and distinguished from the child's personality.

Some of these abnormal manifestations could be early warning signs of later and more significant disorders which could be resolved and prevent future disorders. Thus, it is necessary to identify children who present signs of atypical development that is those who achieve developmental milestones earlier than expected or attains developmental milestones later than their peers. Particular attention should be placed on children whose development is just a little bit different from the normal that is the "gray area" children because most often they seem to have a typical development.<sup>11</sup> As a result, they may not receive support services early enough to assist them in the areas of development in which they require assistance. Therefore, it is very necessary to closely monitor "gray area" children and pay particular attention to those areas in which they may be developing typically, but lagging a bit behind their peers.

This is very necessary especially in the first five-years of development which are crucial as early identification and prompt intervention will best support growth and development. The following sections explain some warning signs of abnormal development for different types of delays/disabilities at different periods. The early warning signs of speech/language and motor skills development, social and emotional delays, and cognitive delays are presented.

### Early Warning Signs of Atypical Development at Six Months

Children with developmental delays and disabilities manifest differently during development. Hence, every child should be observed for the following early warning signs or "Red Flag":



Concerning speech and language delays it is important to note if the child does not coo or smile, does not try to reproduce sounds and does not respond to loud noises or turn to follow sounds and voices as well as cannot follow objects or people with his/her eyes.<sup>12</sup> For motor skills development, take note if the child has trouble holding head up by age three-months, is unable to reach for and grasp with fingers, or hold objects and bring them to his/her mouth by four months. In addition, note should be taken if by five months the child does not roll over in either direction and cannot sit up without assistance by six-months.

### **Early Warning Signs of Atypical Development at Six-Months to One-Year**

During this stage of development note should be taken of the following warning signs; the child lacks simple problem solving skills that is, cannot find his/her toy even though the child saw the toy actually being hidden.<sup>13</sup> Also, whether a child has difficulties to respond when called to come over and see something interesting, and if she/he keeps on inflicting pain on self for example, by biting the toe or hitting the head against the wall. Again, early warning signs of cognitive developmental delays include inability to wave bye-bye and point to objects or pictures by one year.

Concerning motor skills delays, note when the child has problems with sitting, standing up, reaching for objects, or picking up objects, and does not play games like peek-a-boo. Additionally, is the child unable to crawl or walk, push down with legs when feet are placed on a firm surface/does not bear weight when pulled up to a standing position? Furthermore, the child should be observed to determine whether arms or legs are stiff, or posture is floppy or limp by seven months, and can still not stand even when supported or cannot crawl at one-year.<sup>13</sup> For speech and language delays, if a child at this stage cannot produce any single words such as “mama or dada”, or does not understand words like “bye-bye” or “no”.

Also, it is important to note and report the warning signs related to vision such as the child does not follow moving and falling objects (whether close or far) with both eyes and does not observe movement of the hands. Again, difficulties moving one or both eyes in different directions, crosses eyes frequently, with one or both eyes turning in or out all the time as well as tearing constantly.

### **Early Warning Signs of Atypical Development at Two-Years**

Talking about speech and language delays, the child does not speak up to 15 words, cannot use two-word phrases without repetition and can only imitate speech. Also, the child can only use speech to communicate immediate needs.<sup>12</sup> Other concerns are if the child has a wide vocabulary, but still have problems with articulation or pragmatics. For motor skill developmental delays, the child does not walk by 18-months and can only walk on toes, does not develop a heel-to-toe walking pattern or unable to push a wheeled toy around by two-years. Again, the child may take much longer time than expected to walk and get to his/her destination.

Children having social and emotional developmental de-

lays may display difficulties interacting with other children and/or with adults, this is noticeable before the child begins school. Usually, by three months the child does not smile at people and pays no attention to strangers or seems frightened by strange faces. Also, by seven-months, the child shows no emotional attachment to parents or caregivers, does not derive satisfaction being with people, does not smile unless prompted, and refuses hug. Again, at nine the child does not display back-and-forth sharing of sounds, smiles, or facial expressions as well as does not wave back at people, and cannot point or reach for his/her toy.<sup>10</sup>

Early warning signs of cognitive developmental delays include inability to imitate how common objects such as a pencil, hairbrush, telephone, or spoon are used, by two years the child cannot understand simple instructions such as come, go, give me that pen. Also, the child is unable to imitate words frequently used such as mama, food, eat, drink and so on.<sup>7</sup> In addition, to the early warning signs mentioned above it is important to watch for any loss of skills that the child has already learned.

Furthermore, it is worth noting that the child’s brain is at its most flexible from birth to age five, thus it is very mandatory to get the required assistance and resources early enough if any of the above signs are noticed. This is in order to enable the child learn to his/her maximum potential during this very important phase of development. Earlier intervention on any of the area of disability may certainly result in better outcomes for the child.

### **COMMON ASSESSMENTS AND DIAGNOSTIC APPROACHES USED TO IDENTIFY DEVELOPMENTAL DELAYS AND DISABILITIES IN VARIOUS FIELDS**

Various methods are available for use in assessing and diagnosing developmental delays and disabilities. Also, several instruments are available specifically designed to evaluate and diagnose autism spectrum disorders. Again, it is important to note that several items are needed to evaluate speech and language in children with autism. These include behavioral observation, preverbal language skills or early communicative skills, receptive and expressive language skills, and oromotor functions.<sup>14</sup>

In addition, the assessment could be done officially by the use of norm-referenced or criterion-referenced tests such as preschool language scale—fourth edition (PLS-4) and clinical evaluation of language fundamental-revised (CELF-R). However, educators in settings where there are no resources for a formal assessment could adapt tests or checklists locally and use to assess the related skills. The instruments available for the diagnosis of autism include interview, checklists and observation schedules among others which cover the entire lifespan.<sup>15</sup> For the purpose of this paper the following sub sections describe some of the instruments used for diagnosing autism. The instruments presented in this paper are believed to be the most widely used and can be easily adapted by NPs for use in the assessment and diagnosis of autism in different settings.

#### **Interview**

This includes the Autism Diagnostic Interview-Revised (ADI-R)

tool which is one of the most widely used diagnostic algorithms and a diagnostic tool of choice for many public school systems and psychologists assessing children suspected of being on the spectrum. It involves a comprehensive, structured interview conducted by a trained clinician or psychologist with the child's parents or other caregivers, familiar with the child's developmental history and current behavior of the child. The interview can be used to assess both children and adults, as long as their mental age is above 2-years, 0-months. This comprehensive interview provides a thorough assessment of persons suspected of having autism or other autism spectrum disorders. The ADI-R has proven highly useful for formal diagnosis as well as treatment and educational planning.

It is a semi-structured interview that focuses on the three key symptom domains used to diagnose ASD. These domains are communication, social interaction, and repetitive or stereotyped patterns of behavior.<sup>16</sup> The interview is made up of 93 items and takes about two-hours or more to administer. The items are scored on a scale from 0 (typical behavior or development) to 2 (abnormal behavior/development, or impairment).

The ADI-R uses DSM-IV Revised and ICD-10 criteria for autism, incorporated in its diagnostic scoring algorithm. Overall, ADI-R has good psychometric properties with inter-rater reliability in the range of 0.62 to 0.89, adequate convergent validity with other scales such as the childhood autism rating scale (CARS) and autism diagnostic observation schedule (ADOS-G) and good construct validity with DSM-IV and ICD-10 criteria.<sup>17</sup> Key weaknesses of the ADI-R are that, it does not directly involve the child, it relies solely on parent report (the memory of the child's caregivers), it is quite long which needs much time to administer, and by an experienced autism clinician. Also, it was realised that ADI-R could not be used to reliably diagnose Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) or Asperger's Syndrome (AS), however, DSM-5 now diagnose autism as a single disorder with three levels of severity.<sup>18</sup>

### Checklists

Described below are some of the checklists used for diagnosing autism:

**Autism spectrum disorders battery:** The ASD Battery was devised to assist in the diagnosis of the different types of ASD that is autism, PDD-NOS and AS. The ASD Battery is exceptional in that in addition to the diagnostic component, it also has aspects of comorbid psychopathology and challenging behaviors. Again, it contains versions for toddlers that is, baby and infant screen for children with autism traits (BISCUIT); and children, adolescents and adults with intellectual disability.<sup>14</sup> The toddler and adult versions used to diagnose both autism and PDD-NOS, while the child version is employed for the diagnosis of PDD-NOS, and AS. The key drawback of the ASD battery is that it depends only on parent or caregiver's report and therefore, subject to rater biases.

### Modified Checklist for Autism in Toddlers

The modified checklist for autism in toddlers (M-CHAT) is an

example of a diagnostic tool that has been developed to identify autism at an early age. This instrument is the first revision of the checklist for autism in toddlers (CHAT). The M-CHAT is an expanded 23-item version of the CHAT.<sup>17</sup> Like CHAT, M-CHAT is administered to parents and answered as either yes or no and the child is scored as "pass" or "fail". The M-CHAT is used for children in the age range 18-24-months and the test is composed of indicators that indicate signs of severe autism. Examples include "is your child curious about other children?" "Does he/she ever bring objects over to show you something?" It is important to note that a child "fails" the test if two or more of the six critical items are endorsed.

However, if a child "fails" it does not mean the child has an ASD because the M-CHAT was developed as a screening and not a diagnostic instrument. The CHAT and M-CHAT are some of the methodologically sound measures that have correctly detected ASD (either autism or PDD-NOS) at a rate of 83%. The CHAT however, was unable to differentiate between the two levels ASD. Also, the CHAT and M-CHAT have low sensitivity for the original scale and limited follow-up data available for the two revisions.<sup>20</sup> Again, it requires expertise knowledge of ASD and training in order to accurately use the two instruments and may not accurately diagnose before the age of three-years.

### Observation Schedules

These comprise the following:

**Childhood autism rating scale:** The childhood autism rating scale (CARS) was developed in North Carolina to support the adequate screening of children for the treatment and education of autistic and related communication handicapped children (TEACCH) program.<sup>21</sup> The TEACCH program was instituted in the early 1970s by Eric Schopler and colleagues and has been used by many with ASD and their families. This measure is completed by incorporating information from parent or teacher interviews together with direct observation of the child performed by experienced experts.

The CARS consists of 15 independent subscales rated on a scale from 1-4; 1) Relationship with people 2) Copying others 3) Emotional response 4) Gestures 5) Object use 6) Adaptation to change 7) Visual response 8) Listening response 9) Taste, smell, and touch response and use 10) Fear or nervousness 11) Speech 12) Nonverbal communication 13) Activity level 14) Level and consistency of intellectual response 15) General impressions. A score of 1 signifies the behavior of a normally developing child and a score of 4 reveals a "severely abnormal" behavior. A score in the range of 30-35.5 suggests mild autism, while a score of 37-60 reflects severe autism.<sup>17</sup>

A key drawback of the CARS is that it was developed based on DSM-III criteria for autism, and the symptoms it measures do not directly match up with those of the diagnostic and statistical manual of mental health disorders, fourth edition, revised-text (DSM-IV-TR) or DSM-V. Also, the CARS usually exaggerate the number of autistic symptoms in children with severe to profound intellectual disability. Finally, the CARS equally do not differentiate the symptoms of autism from those of the other forms of ASDs.<sup>17</sup>

**Autism diagnostic observation schedule-generic:** The ADOS-G is a semi-structured observation schedule designed to assist in the diagnosis of autism and appraise current functioning.<sup>21</sup> The ADOS-G is employed in the diagnosis of children and adults at different stages of development and language ability levels. It is made up of four modules namely: 1) preverbal/single words, 2) flex phrase speech, 3) fluent speech child/adolescent, and 4) fluent speech adolescent/adult. To assess the child using these modules, he/she is subjected to circumstances that require him/her to do such things as requesting help for example, with dressing; engage in symbolic play; take turns in conversation; perform simple tasks such as brushing the teeth; story telling; discussing tasks that occurred earlier in the assessment, and discussing social and emotional situations.

Each module can be completed in approximately 30-minutes. The ADOS-G has advantage over CARS, because it includes a diagnostic algorithm for diagnosing PDD-NOS which according to DSM-V diagnostic criteria is level two ASD. However, it cannot diagnose AS, level one ASD. Items are scored on a 3-point scale from 0 (typical development) to 2 (explicit evidence of abnormality). It has adequate inter-rater, test-retest and internal reliabilities, and it has been shown to have good construct validity with DSM-IV criteria and good convergent validity with the ADI-R.<sup>12</sup> Research has revealed that employing multiple assessment methods; official assessment, observation and parent report will produce a more valid language profile for a child with an ASD as opposed to utilizing a single assessment technique. Other diagnostic criteria for ASD include:

**i. Diagnostic and statistical manual of mental health disorders:** The DSM is the acronym for diagnostic and statistical manual of mental health disorders which is an official diagnostic guide for diagnosing mental health disorders such as ASD.<sup>22</sup> It is a reference book developed and published by the American Psychiatry Association (APA) as a guide to the various types of mental illnesses and is being revised and updated to new visions. The entry for each disorder includes a definition and a list of signs and symptoms used as diagnostic criteria. The DSM-IV-TR was used as a diagnostic reference that describes and categorizes all known mental illnesses and emotional disorders including ASD. Recently, the DSM-IV-TR has been revised to the DSM-V.

The DSM-V has made major changes in categorizing ASD as neurodevelopmental disorders. This categorization defines ASD as a set of disorders which begins in childhood manifesting as impairments in development resulting in deficits in personal, social and academic functioning. According to APA<sup>16</sup> the DSM-V ASD refers to:

**Persistent deficits in social communication and interaction in different contexts, manifesting currently or had manifested in the past as impairments in:** 1. Social-emotional reciprocity evident by atypical social approach and back-and-forth conversation or decreased sharing of interests, emotions/affect or failure to initiate/respond to social interactions. 2. Nonverbal communicative behaviors used for social interaction, evident by poorly integrated verbal and nonverbal communication or abnormalities

in eye contact and body language or deficits in understanding and use of gestures or the absence of facial expressions and nonverbal communication.<sup>22</sup> 3. Building up, sustaining, and understand relationships, displayed as difficulties adjusting behavior to suit various social contexts or in sharing imaginative play or in making friends or total lack of interest in peers.

**Restricted, repetitive patterns of behavior, interests, or activities presenting as or had presented at least two of the following in the past:** 1. Stereotyped or recurring motor movements, use of objects, or speech (for instance, simple motor stereotypes, arranging toys in a row, or flipping objects, echolalia, idiosyncratic phrases); 2. Resistance to change, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior. For example, the child manifests floppy thinking patterns, ritualistic greetings, is strongly attached to same objects or meal every day, or is greatly distressed with minimal changes in activities or in moving from simple to complex activities; 3. Highly limited and fixated interests with unusual intensity or focus; that is, the child is strongly and abnormally attached to strange objects and extremely displays restricted interests.<sup>19</sup>

**In addition:** The impairment prevents the child from communicating effectively, build and sustain relationships, achieve their maximum potential. Also, the symptoms manifest early during development and are not linked to another medical or neurological condition or mental disorder.

**ii. Leiter international performance scale – revised:** The Leiter international performance scale–revised (Leiter-R) is developed specifically for persons having problems with communication and hearing or other types of impairments that involve language. It is a valid measure used to reliably determine non-verbal cognitive, memory and intentional abilities. The non-verbal cognitive abilities do not necessitate the ability to identify, operate, and understand words and numbers, and the scale needs no verbal response from the person being assessed.<sup>14</sup> Hence, it can be completely administered without the use of verbal language and instructions. The Leiter-R subtests are formulated with respect to the child's age and used to determine scores for fluid reasoning and intelligent quotient.

**iii. Intention condition of behavioral enhancement procedures:** The intention condition of behavioral enhancement procedures (UOI) is used to assess the child's ability to understand the intentions of others. During the evaluation the child is made to observe how an experimenter attempts to perform a target action (for example, fitting a key into a lock which the child has never seen being done rightly until completion. After three failed attempts without succeeding, the child is then told come over "*now it's your turn*". The child is expected to understand what the examiner intention was and as a result perform the intended action correctly without repeating the failed action performed by the experimenter.<sup>10</sup>

The child is given a score of zero if he/she is unable to pay attention to the stimulus presented; displays stereotyped and/or sensory manipulation of the object and repeats the failed attempt performed by the examiner among others. The UOI requires the least amount of attention by the child, is easy and quick



to administer, and is also recommended for children presenting with severe symptoms.<sup>11</sup>

**iv. Emotional contagion test:** The emotional contagion test (TCE) is used to assess the emotional contagion, from a quantitative and qualitative perspective, that is the existence or lack of sentimental attunement in the child. This is done by observing the child's behavioral and emotional response with respect to a structured stimulus. The child is presented with four video recordings of a typical individual expressing basic emotions such as happiness, sadness, fear and anger through non-verbal gestures.<sup>23</sup> Each response is given a score of 0 if the child cannot repeat emotional gesture (it is considered absent). On the other hand, if the child repeats the motor pattern of the emotion and behavior the response is considered present and the child may be given a score of 1, 2 or 3.

**v. Behavior rating inventory of executive function – preschool version:** The behavior rating inventory of executive function–preschool version (BRIEF-P) is a questionnaire consisting of 63 distinct items used to measure various areas of executive functions in preschool children from two-years and zero-months to five-years and 11-months in everyday environments.<sup>24</sup> The BRIEF-P is made up of five scales; inhibit, shift, emotion control, Working memory and plan/organize. These five clinical scales are merged to create three large indicators, which are inhibitory self-control (ISCI), flexibility (FI) and emergent metacognition (EMI), one composite score/GEC and two validity scales (inconsistency and negativity). The scores reflect the child's level of functioning as demonstrated by his/her parents' report.

**vi. Short sensory profile:** The short sensory profile (SSP) is a questionnaire derived from the Sensory Profile and is completed by caregivers. The questionnaire comprised 38 items which can be completed in about 10-minutes. The items are divided into domains corresponding to seven different areas, which help to determine how a child with ASD modulates sensory input through sensory systems. Also, these determine which behavioral and emotional responses are associated with sensory processing.<sup>25</sup> The domains assessed include sensitivity to touch, taste, smell, movement, under-responsiveness or seeks sensation, auditory filtering, low energy or weakness and visual or auditory.

**vii. Repetitive behavior scale-revised:** The repetitive behavior scale-revised (RBS-R) is a questionnaire that determines the extent of repetitive behaviors in children with ASD. It is composed of 44 items, on a four-point Likert scale ranging from “absent behavior” to “*ever-present behavior*” and high scores signify regular dysfunctional behaviors.<sup>26</sup> Also it has six behavior subscales that is, stereotyped, self-injurious, compulsive, routine, sameness and restricted.

#### DIFFERENT MODALITIES OF INTERVENTION EMPLOYED IN THE MANAGEMENT OF CHALLENGING BEHAVIORS IN INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES, PARTICULARLY AUTISM

Many programs have been designed to deal with the variety of social and behavioral difficulties associated with autism. The main focus of these programs is to decrease problem behaviors in children with autism and teach them new skills.<sup>24</sup> These individuals are

taught how to act in social situations and/or how to communicate better with other people. Even though autism is a lifelong condition, children with autism may be supported and taught how to become less dependent.

Behavior can be defined as the different kinds of actions and skills (both normal and abnormal) displayed by individuals. It is important to note that behavior can be influenced by one's environment hence, behavior analysts using a scientific approach seeks to understand behavior and how it is affected by the environment. The science of behavior analysis provides guidelines about how behavior works, or how learning occurs. Examples are positive and negative reinforcement which help to maintain and increase the acceptable behavior by respectively using a reward or taking away something unpleasant in response to a stimulus.<sup>27</sup> For example, negative reinforcement can be used to stop tantrums in children with autism.

Another technique is punishment that helps to decrease and extinct poor or abnormal behavior. Over the years, many techniques for increasing good behaviors and decreasing abnormal behaviors have been developed by the field of behavior analysis.<sup>27</sup> The use of these methods and principles to deal with socially important problems and to enhance acceptable behavior change is referred to as applied behavior analysis (ABA). The following paragraphs explains how the ABA has been used in managing children with autism.

The ABA has been used over the years to build useful skills such as looking, listening and imitating, reading, taking the perspective of others and conversing in learners with autism of all ages. Therefore, the ABA principles and techniques assist individuals with autism to learn appropriate behavior and live contented and fruitful lives. The ABA is known widely as a safe and efficient management strategy for autism.<sup>11</sup> Some ABA techniques have proven their effectiveness in enhancing communication and social interaction skills as well as support individuals with autism to care for themselves, succeed at work and fully participate in family and community activities.

Also, ABA techniques are employed in managing some of the challenging behaviors exhibit by children with autism. Again, ABA techniques have been incorporated in to different programs resulting in comprehensive treatment programs for youths and adults with autism helping each individual to learn, achieve and live successfully in their communities.<sup>27</sup> It is important to note that a comprehensive ABA program for learners with autism should:

- Be designed and administered directly by qualified, well-trained professional behavior analysts.
- Determine initial treatment goals through detailed evaluation of each learner's skills as well as learner and family preferences.
- Choose unique goals which are meaningful for the learner and his/her family.
- Make provision for continuing objective measurement of the learner's progress.<sup>28</sup>
- Make provision for the behavior analyst to frequently evaluate the progress data in order to adjust the goals and procedures as



required.

- Provide instruction on developmentally suitable goals in skill areas such as communication, social, self-care, motor, academics, play and leisure.
- Have skills broken down into small parts and/or steps according to the learner's ability and taught from simple such as listening and imitating single sounds to complex such as taking turns in conversations.
- Employ various behavior analytic procedures that is, both adult-directed and learner-initiated in order to enhance learning in different ways.
- Expose the learner to many opportunities both naturally occurring and planned specifically to allow for the acquisition and the daily practice of skills in structure and unstructured situations.
- Make provision for the intervention to be administered consistently for a reasonable number of hours per week.<sup>29</sup>
- Make provision to abundantly reinforce useful skills and socially accepted behaviors using rewards.
- Emphasize on the need for positive social interactions and making learning fun.
- Not reinforce behaviors that are harmful or prevent learning.
- Employ methods to teach varieties of skills in order to enable learners to attain novel skills to use in a variety of settings.
- Emphasize on skills that will permit the individual to gain independence and lead a successful life.
- Train the parents of the learner in order permit them to teach and support skills during routine family activities.
- Organize meetings between family and program staff regularly in order to review progress, plan and make adjustments.<sup>28</sup>

## ADVANCES IN INTERVENTION FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES

Recently, educationists have advocated for an inclusive education for children with developmental disabilities. That is, all regular schools should be modified to accommodate and support children with disabilities in such a way to provide a barrier-free learning environment which will permit all children to achieve their maximum potentials. Also, because no one solution fits all children with disabilities different strategies and interventions should be developed and tried out in order to determine the ones that work best for us and for each learner in our various classrooms. Since it is clear that a child's academic potential cannot be developed in isolation, the social, emotional and physical aspects of development must be considered.<sup>30</sup>

Hence, an ideal and comprehensive support system will include special educators, community-based specialists, and assistive devices at affordable costs, medical assessments and services. In addition, the institution of intervention early enough for successful outcomes have been emphasized.<sup>9</sup> Furthermore, involvement of the parents/family of children with developmental disabilities in the treatment plan has contributed enormously to better treatment outcomes. The following section presents advances that have taken place in the area of early intervention for children with developmental disabilities or delays in the last ten-years.

## Advances in Early Intervention for Children with Developmental Disabilities

Providing comprehensive early intervention services and support for children with developmental disabilities/delays remains a global priority.<sup>31</sup> The early years of every child's life are very vital because during this period children grow very fast and have so much to learn. Children with disabilities and families face special challenges requiring extra help early enough to make a difference in their lives.

The early intervention program (EIP) is a statewide program that provides many different types of early intervention services to infants and toddlers with disabilities and their families. Generally, there exists support for early intervention services in different countries especially in high income nations. According to research parental benefits for participating in early treatment programs are enormous.<sup>31</sup> Parents are able to confidently perform their roles and contribute to their child's development with optimism about the future. A comprehensive early intervention program can at least prevent the significant negative effect in intellectual development that usually happens during early childhood for children with developmental disabilities/delays.

The EIP was first created in New York by Congress in 1986 under the IDEA. The EIP for infants and toddlers with disabilities and their families is made available through the Bureau of Early Intervention and is administered by the New York State Department of Health. The EIP in New York State is found in Article 25 of the Public Health Law and has been in effect since July 1, 1993. According to the State only infants and toddlers who are under three years of age and have a confirmed disability in at least one of the following areas of development that is, physical, cognitive, communication, social-emotional and adaptive are eligible for EIP services.<sup>32</sup> The subsequent subsection describes the EIP services.

### Early Intervention Services

The EIP provides a range of therapeutic and support services to infants and toddlers with confirmed disability or established developmental delay and their families.<sup>33</sup>

These include:

- Family education and counseling, home visits, and parent support groups.
- Special instruction and vision services.
- Speech pathology and audiology services.
- Occupational and physical therapists services.
- Psychological and social work services.
- Service coordination.
- Nursing and nutrition services.
- Assistive technology devices and services.
- Vision services.

The EIP also consists of the child's individual records which include all written materials gathered or incorporated in the EIP. These include all information collected for the child's refer-

ral to the EIP, screening, assessment reports and summaries, parent assessment and other records concerning the child and family. In addition, it composed of progress notes about the child's and family's services prepared by early intervention service providers and any complaints filed by the family among others.<sup>34</sup> It is worthy of note that all information collected is kept confidential by the Early Intervention Official and evaluators, service providers and coordinators. Parents must give their written consent before any information collected about their child can be released.

Furthermore, varieties of home-based and school-based treatments and interventions for children with autism have been developed over the years. These include behavior and communication therapies which have been developed to handle the range of language, social and behavioral difficulties related to autism. Some of these programs are designed to decrease challenging behaviors and to teach new skills while others are used to teach children how to behave in social situations and communicate better with others. These therapies allow children with autism to function well in life.<sup>32</sup>

Successful educational therapies designed for children with autism usually composed of a team of specialists including special educators and a range of activities to enhance behavior, social and communication skills.<sup>11</sup> Intensive and well-structured, individualized behavioral interventions administered to preschool children produce good results. It has been revealed that no medication can treat the major signs of autism; however, some medications can assist in managing them. Examples are antidepressants used to control anxiety, and antipsychotic drugs used occasionally to manage severe behavioral crisis.

#### **FACTORS THAT CONTRIBUTE TO TREATMENT SUCCESS FOR CHILDREN WITH AUTISM**

Different types of therapies have been shown to improve the lives of children with developmental disabilities especially autism.<sup>35</sup> Some interventions help to modify behavior such as ABA, some assist in developing thought processes and creativity for example Floortime, while others help the child to express thoughts and ideas either using speech or non-verbally. However, it is important to note that no single intervention works for all children and children's needs change over time which necessitates the incorporation of other treatment options.<sup>32</sup> Therefore, most children improve best when different therapies are combined or used in a sequence. Several factors can be associated with the successful outcomes for autism treatment and this is usually determined by the degree of improvement in quality of life.

The associated factors which include early diagnosis and treatment, the severity of presenting symptoms, parental involvement and proper determination of individual goals by well-trained experts,<sup>28</sup> among others are both child- and therapy- centered. It is worth noting that treatment, therapy and intervention are used interchangeably in this write up. The subsequent paragraphs explain some of the reasons why an autism therapy is more likely to be successful.

Talking about the factors related to the individual, an in-

tervention would be successful if the child has mild traits at the time of diagnosis and treatment is instituted early that is, between the ages of two and three.<sup>28</sup> This is the period when children are beginning to interact more with others and learn from their environment. An effective therapy and high-level of support especially from family members and the school authorities at this stage will enhance skills development and reduce autistic symptoms. For instance, early interventions and other supports can lead to improved social communication and interaction with others, joint attention and play skills which in turn enhance the child's language and cognition.

To talk of therapy centered-factors ABA programs for learners with autism that are designed and supervised by qualified behavior analysts who are experienced in providing ABA treatment for autism are most likely to be successful.<sup>34</sup>

Other factors include:

- The collective effort of all stake holders; educationists, pediatricians, psychologists and NPs among others.
- Frequent evaluation of treatment plan and client's progress by well-trained experts.

#### **CONCLUSION**

Diagnosing autism early and instituting treatment and support promptly is mandatory for better prognosis. The diagnosis and treatment of autism and related developmental disabilities require a multidimensional approach and a collaborative effort of all stake holders. Generally, nurses and other health professionals with the aid of parent reports are expected to identify children with autism during routine well-child visits that is, before they begin school. Different standardized diagnostic tools are available and should not be used in isolation but in combination with other tests. In addition, each child's behavior should be carefully observed in a clinical setting by well-trained experts in order to better comprehend the child's unique communicative and social interaction difficulties. This should clearly define the child's development profile, and directs individualized interventions and support. Furthermore, it is recommended that interventions should be designed, implemented and supervised by qualified and experienced professionals in order to guarantee the success of treatments.

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APPENDICES

Appendix A

<i>Differences between Developmental Monitoring and Screening</i>		
Indicator	Developmental Monitoring	Developmental Screening
Who monitors?	Parents/other caregivers/nurse	Healthcare provider/ early childhood teacher/other trained provider
Looking for what?	Developmental milestones	Developmental milestones
When?	From birth to 5 years	Developmental Screening at 9, 18, 30-months of age Autism Screening at 18 and 24-months of age
Why?	To help you: <ul style="list-style-type: none"> <li>• Understand changes occurring in your child</li> <li>• Talk about your child's progress with doctors and childcare providers</li> <li>• Learn what to expect next</li> <li>• Identify any delay early</li> </ul>	To find out: If your child needs more help with development, which is not always apparent to doctors, childcare providers, or parents If more developmental evaluation are necessary
How will this be done?	With ease, with the use free checklists	Using an official, validated screening tool
<i>Source: Adapted From National Center on Birth Defects and Developmental Disabilities<sup>a</sup></i>		

Appendix B

<i>Developmental Evaluation</i>	
What is it?	A more in-depth evaluation of a child's development
Why performed?	To identify and diagnose developmental delays and conditions To find out if your child needs specific treatment and whether he/she
Who evaluates?	A developmental pediatrician, child psychologist, nurse practitioner or other trained provider
When?	Whenever there is a concern during development
How?	By conducting a detailed examination using formal assessment tools, observation, and checklists completed by parents and other caregivers.
<i>Source: Adapted From National Center on Birth Defects and Developmental Disabilities<sup>a</sup></i>	

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