The Cerebral Palsy Eye

ISSN: 2408-4891

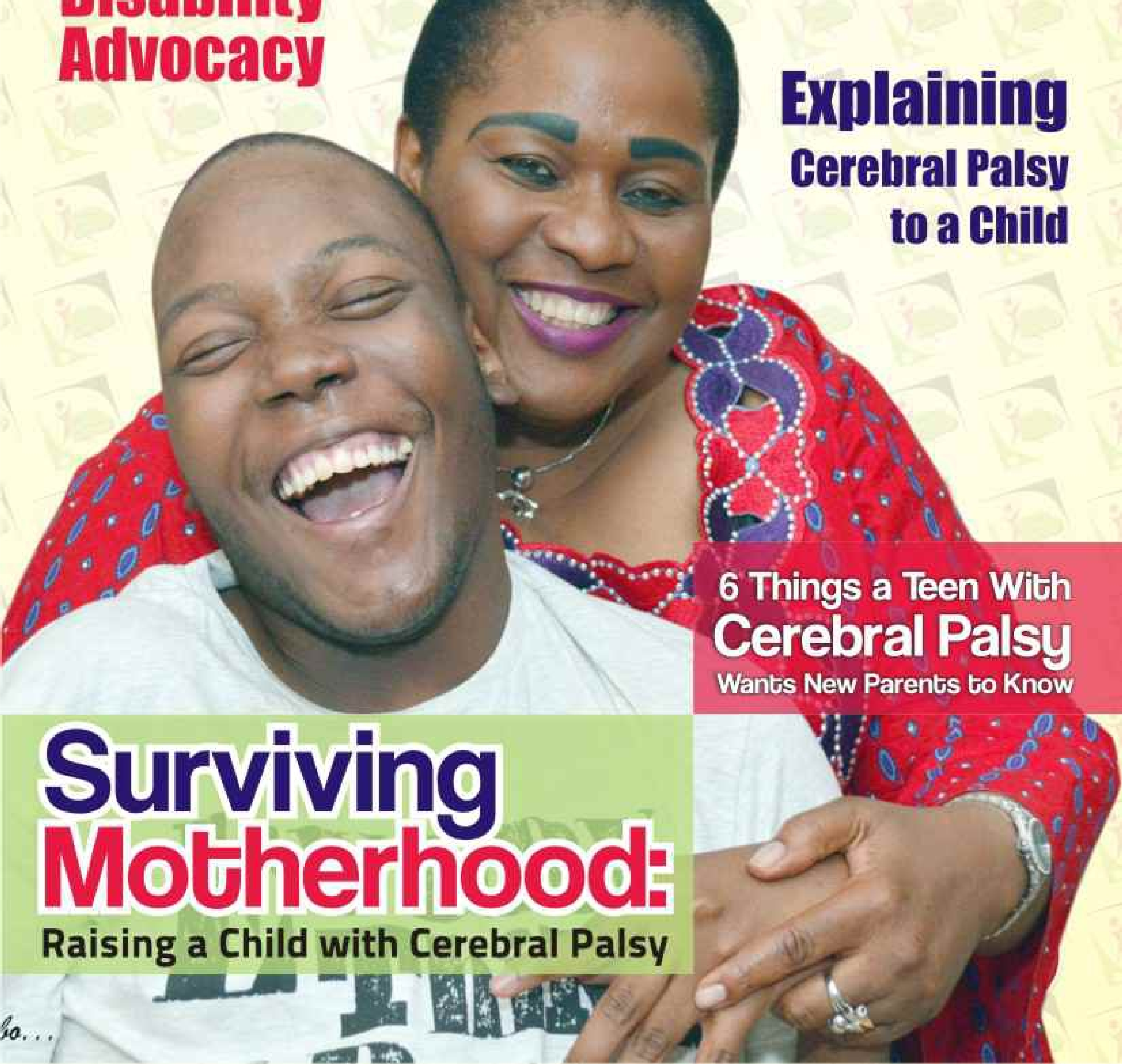
A Publication of Benola A Cerebral Palsy Initiative

Vol. 3/No. 1 August 2016

Cerebral Palsy Defined and its Causes

Disability Advocacy

Explaining Cerebral Palsy to a Child



6 Things a Teen With Cerebral Palsy Wants New Parents to Know

Surviving Motherhood:

Raising a Child with Cerebral Palsy


Summit

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COVER PHOTO:

Olaoluwa and his Mum on his 20th Birthday

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Femi Gbadebo *AVM (Rtd) OFR*
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Welcome to another exciting edition of a magazine that is designed to draw attention to the plight of those amongst us who live with or care for persons living with Cerebral Palsy.

Ideally, this ought to be our third edition for the year 2016 but paucity of funds due to the economic downturn and the consequent effect on donors has made this a very difficult time for Non-Profits. As a result, this is our first edition for the year but we remain undaunted in our work and are optimistic that, with renewed effort at sensitizing the public, we will meet up with the rest of our programs for the year, including the publication of our December edition.

Despite the dwindling resources however, we are pleased to inform you that, through an aggressive advocacy campaign backed by a vibrant program development drive by our Program Planning and Implementation Team (PPIT) and active social media presence, Benola has continued to maintain the leadership positon in the race to change the face of cerebral palsy and disability management both in Nigeria and the rest of Africa.

High points of our activities since our last publication include: Our 3rd Anniversary Celebrations in February and Benola Day 2016 in June, both of which were well received by the public. Others include feature stories in the April edition of the Lagos Business School magazine, "Footprints" and "Mommy Moments" a magazine for nursing mothers. Mention must also be made of those electronic and print media houses who continue to give prominence to stories about CP.

Finally, happy reading and together, let's keep reaching out, touching lives and adding value!

ADVERTISE WITH US

Advertising in "The Cerebral Palsy Eye" which is published three times a year, (April, August and December) is an excellent way to reach a diverse group of decision makers and influential people [both public and private sector] who keenly follow the progress of Benola – A Cerebral Palsy Initiative.

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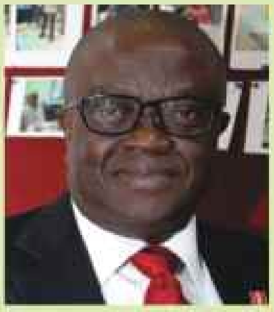

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CEREBRAL PALSY DEFINED

AND THE IMPORTANCE OF UNDERSTANDING ITS CAUSE

Cerebral Palsy is a complicated condition that significantly impacts individuals diagnosed with it. Due to a brain injury sometimes occurring during pregnancy, delivery or post-birth treatment, Cerebral Palsy is a lifelong condition that affects each person differently. Better understanding the root components of CP, including symptoms and the basis for a diagnosis can help you review your child's own health and conditions to understand the challenges faced now or in the future.

Cerebral Palsy can be defined as a condition resulting from a brain malformation or injury causing varying difficulties surrounding body movement, muscle control and coordination, weight, tone, reflexes, body posture, balance and more. It can also be tied to intellectual challenges and varying levels of physical challenges regarding everyday life. Across a wide spectrum, those with Cerebral Palsy may face a minor limp or require full-time assistance; how CP affects the individual depends upon the severity of the condition.

So what is Cerebral Palsy and what can it mean for your child? In short, a lifetime of varying challenges predictably lies ahead. While the injury of the brain does not worsen over the time, symptoms may become more frequent or significant as the individual ages. Early intervention can be an important first step in lessening the severity of certain challenges and helping a child reach their full potential.

Due to the wide variety in those challenges and symptoms that a child with Cerebral Palsy may have to live with, medical costs can quickly pile up. Getting your child the treatment and care that he or she deserves can seem extremely daunting and realizing that your child's CP may have been preventable can be jarring.

Determining the cause of your child's Cerebral Palsy is crucial, not only in terms of better understanding his or her challenges, but also in determining if improper medical decisions contributed to this result. Not all instances of CP were 'just meant to be' or unavoidable. Sadly, instances of improper medical advice, treatment, delivery errors and more can lead to a healthy child living with Cerebral Palsy for the rest of their lives.

The only disability in life
is a bad attitude

Cerebral Palsy Diagnosis

The process for diagnosing Cerebral Palsy is not a simple one. CP is a complex condition impacting each person differently; it cannot be overstated the unique, person-specific nature Cerebral Palsy has. Due to associative conditions that may be more pronounced, diagnosing CP may not even be on the radar of parents or doctors due to overlapping symptoms or a lack of awareness. However, getting your child a Cerebral Palsy diagnosis may be a crucial step in not only understanding his or her challenges, but also getting help in limiting how much CP impacts their life today and for decades to come.

The first step (figuratively and, as you can see below, literally) in a Cerebral Palsy diagnosis may, in fact, be your own 'gut feeling' or observations. Missed milestones are often the first red flag a parent may identify when trying to better understand their child and if 'something is wrong.' While challenges associated with Cerebral Palsy may be physical, verbal, mental, etc., parents should take action if they feel their child is not taking on challenges at the rate expected. This does not mean that every child should hit these milestones – children develop in different ways and some may come earlier or later. Instead, diagnosing Cerebral Palsy is sometimes only possible due to parents taking action and scheduling appointments for medical assessment.

This process of taking action can be extensive. The months it can take to schedule appointments, receive assessments, request a second opinion... the process can be exhausting but is essential. We have highlighted a 12-Step Diagnostic Process regarding Cerebral Palsy that highlights, in detail, the various components and requirements associated. Those 12 steps include:

Step 1: Parental Observation

Step 2: Clinical Observations

Step 3: Motor Skill Development Analysis

Step 4: Medical History Review

Step 5: Documenting Associative Conditions, Co-Mitigating Factors, and Ruling-Out Other Conditions

Step 6: Obtaining Test Results

Step 7: Diagnosis

Step 8: Obtaining a Second Opinion

Step 9: Determining Cause

Step 10: Care Team Assembly

Step 11: Care Plan Creation

Step 12: Embracing a Life with Cerebral Palsy

Just from reading the title of each step, you can see that diagnosing Cerebral Palsy requires efforts on the part of a team, rather than just a single doctor or the parents themselves. It is also important to note that a second opinion can be critical; while certain instances of medical malpractice may involve a doctor not wanting to be forthcoming on a Cerebral Palsy diagnosis, other doctors may simply not have the expertise or training to identify and diagnose CP.

Ultimately, your child's Cerebral Palsy diagnosis should come from a medical professional and not a hunch. Getting your child, the medical tests needed to begin ruling out other conditions and determining the severity and cause are critical parts of a Cerebral Palsy diagnosis that can greatly influence your child's potential and future. For more information, please visit our website:

www.benola.org.

Can Cerebral Palsy be prevented or Cured?

Although cerebral palsy is a lifelong disability, there are many interventions that can help reduce its impact on the body and the individual's quality of life. An intervention is a service that aims to improve the condition of cerebral palsy and the day-to-day experience of the person living with it.

Children with cerebral palsy may be supported by a team of professionals including health professionals and community-based support services who work together to help the child and family reach their goals. Through their late teens and early 20s, many young people take increasing responsibility for their own health and wellbeing. Their team may include health professionals and mainstream community providers such as fitness trainers.

CAN CEREBRAL PALSY BE PREVENTED OR CURED?

At present, there is no way to totally prevent or cure cerebral palsy.

Two interventions are now being used to reduce the risk or severity of cerebral palsy:

Magnesium Sulphate – is given to pregnant mothers when they are at risk of very preterm birth. This can help protect babies from the brain injury that leads to cerebral palsy.

Cooling Cap – Newborn babies who have suffered a brain injury due to lack of oxygen before birth (hypoxic ischemic encephalopathy) may be treated with a special cooling cap which aims to reduce the impact of the brain injury.

INTERVENTIONS FOR MOVEMENT ISSUES

Medication

Medical specialists may prescribe medications that assist movement issues. Some medications are taken orally (e.g. diazepam) and others are injected or delivered through surgically implanted pumps (e.g. Baclofen). Many children with cerebral palsy benefit from Botulinum toxin type A injections into muscles affected by spasticity. This intervention is used from about two years of age and is most effective when used in conjunction with therapy.

Surgical procedures

Selective Dorsal Rhizotomy (SDR) is a neurosurgical procedure that is used in a small percentage of children with cerebral palsy to permanently reduce spasticity in their legs.

PHYSIOTHERAPY AND OCCUPATIONAL THERAPY

Physiotherapists and occupational therapists focus on encouraging a person's day-to-day movement skills such as sitting, walking, playing, dressing and toileting. They will use a range of specialist interventions such as movement training and equipment, e.g. walking frames, wheelchairs, supportive seating, footwear and orthotics.

INTERVENTIONS FOR MUSCLE, BONE AND JOINT ISSUES

Surgical procedures

Orthopaedic surgeons correct joint deformities and lengthen muscles. Surgery usually takes place in a child's late primary years or early adolescence to improve walking quality and reduce pain. Paediatric rehabilitation specialists support the management of some of the conditions associated with cerebral palsy, such as spasticity, musculoskeletal issues and growth.

Casts, splints and muscle strengthening

Physiotherapists and occupational therapists may also focus on preventing impairments that might affect movement. They use casts, orthotics and muscle strengthening exercises.

INTERVENTIONS FOR COMMUNICATION ISSUES

Speech pathology

Speech pathologists assess and provide intervention for communication skills. This includes understanding what is being said and learning to use words and sentences. Treatment (intervention) for communication often involves the use of augmentative or alternative communication systems, such as signing, communication boards and speech generating devices.

INTERVENTIONS FOR INTELLECTUAL DISABILITY AND LEARNING DIFFICULTIES

Assessments, special education and learning strategies

Psychologists can provide assessment of a child's learning and development. Special educators work with families to develop a program of interventions to address each child's learning needs. Occupational therapists can facilitate a child's active participation in these learning activities.

Psychologists and occupational therapists can provide assessment and recommend learning strategies to compensate for perceptual difficulties.

INTERVENTIONS FOR EPILEPSY

Medication

Medical specialists may prescribe antiepileptic medication to minimise the number of seizures. They will also guide families on the management of seizures when they do occur.

INTERVENTIONS FOR PAIN MANAGEMENT

Medication

Pain may be treated through medication and by addressing the underlying cause of the pain, e.g. by treating muscle contractures.

Cognitive-behavioural therapy

Psychologists may offer cognitive-behavioural therapy for chronic pain. This process works to help a person change the way they think about pain and, in turn, how they feel and behave about pain.

Massage therapy and hydrotherapy

Temporary relief of pain may be assisted through massage or hydrotherapy.

INTERVENTIONS FOR SLEEP DISORDERS

Medication

Medical specialists may prescribe medication or treat the associated issues that impact on sleep.

Behaviour therapy

Psychologists may assist with behaviour therapy or help families to establish routines to help resolve children's sleep issues.

Sleep systems

For children with postural issues that make sleep difficult, occupational therapists and physiotherapists may prescribe special sleep systems to help children feel more comfortable in bed.

INTERVENTIONS FOR BEHAVIOUR AND EMOTIONAL ISSUES

Behaviour therapy and counselling

Psychologists can offer assessment and support for emotional and behavioural challenges, which may include behaviour therapy and cognitive behaviour therapy. Social workers support people with cerebral palsy and their families in many ways, including strengths-based counselling and mutual aid groupwork.

INTERVENTIONS FOR ISSUES WITH EATING, DIGESTION AND NUTRITION

Medication and surgery

Treatment (intervention) for severe difficulties with digestion, such as gastro-oesophageal reflux (GOR) includes medications or sometimes surgery. If the individual has severely limited eating skills or experiences an unsafe swallow, non-oral feeding may be recommended. This involves a surgically inserted feeding tube to the stomach or the small intestine.

Medical interventions are performed by medical specialists in hospitals.

Speech Pathology and Dietary Advice

Speech pathologists provide assessment and treatment (intervention) for eating, drinking and swallowing difficulties. Examples of these are learning to use the muscles of the mouth better, using specially designed utensils and sitting in an optimal position.
Dietitians provide advice on improved and balanced nutrition.

INTERVENTIONS FOR ISSUES WITH SALIVA CONTROL (DRIBBLING AND DROOLING)

Speech pathology

Speech pathologists may suggest various strategies to help people manage saliva loss. These include remembering to wipe their mouth and wearing age-appropriate clothing protection.
They may also recommend special exercises for the face and mouth, which may lead to better ability to control saliva.

Medication

Medical specialists may prescribe medication for saliva control. This is not usually considered a long term treatment option, but can be useful to dry up saliva temporarily. Botulinum Toxin Type A, injected into the salivary glands has also shown to reduce the secretion of saliva. In severe cases of drooling, surgery may be suggested to permanently manage saliva.

INTERVENTIONS FOR HEARING AND VISION IMPAIRMENT

Hearing and Vision impairment are managed as they are for the general population by Opthamologists, Optomitrists, Audiologists and Doctors (GPs). Interventions include corrective eye wear (glasses), contact lenses, hearing aids and in some cases medication or surgery.

Cerebral Palsy is like a Wild ride on a Roller-Coaster

Living with cerebral palsy can be a wild ride, but there are ways to navigate the twists and turns

Cerebral Palsy is a roller coaster.

It's a seemingly unstoppable, out-of-control ride that starts with not knowing how to perform certain functions, followed by either hyper (abnormally high) or hypo (abnormally low) muscle tone. This inability to perform functions then leads to an absence of sensation in the hands and feet, further reducing mobility and function. As you continue to be hurled forward, going up and down on the tracks, your communication and social skills eventually erode. Pretty soon, you are considered disabled.

Parents of children with cerebral palsy are often left in shock by the speed at which their children deteriorate. "What's happening?" they often ask. "And why is it happening?"

The early years

During so-called "normal" development, the nervous system takes the child through the learning process of movement and discovery of the world. At the same time, the parents are unconsciously teaching by example the know-how of every day functions. Children develop the ability to function as they go through each step in the sequence of natural development. Each step prepares the child for the next step. For example, a child starts to move his head first, separating the body's upper and middle part. Then he starts to roll, which prepares his trunk for the act of sitting. Then he tries to sit, followed by going on his knees and then crawling. These sequence of steps eventually leads to the child standing up and walking.

But for a child with CP, learning function independently is difficult since he is missing certain stages of "normal" development. If one side is affected and rotation movement is limited, then this creates a disruption in developmental progression. Since he can't turn his trunk, he can't separate the movements between upper and lower girdle. As a consequence, there is no weight bearing on the arms and legs, which in its turn triggers problems with sensation and muscle tone. Muscle tone can change. It can be hypo, but with inappropriate stimulation it can become hyper.

According to the LIFE program method, we teach the child how to function by taking him through every single step of the function he has to perform. This can be tough, especially in the beginning.

Weight bearing movements normalize muscle tone. And when a child is taught the proper sequence of steps to complete a function, then the brain learns it and it becomes automatic. It's just like learning how to drive a car. We weren't born with the skill, but once we learned and used this skill, it became automatic.

Once function improves, the child starts to discover the world, which leads to improvements in mental and social skills. This, in a nutshell, is the treatment approach to children with cerebral palsy, and it is based on a fundamental and unshakeable philosophy: The sky is the limit.

The teenaged years

As the child gets older, the body goes through the certain changes. This is when we have to be really careful. Because of hormonal change and growth just before and during the teenaged years, we can see increase in the tone, change in the spine curvature (scoliosis), and even deterioration in the function.

For teenagers with CP, the best approach is to maintain normal, independent function while continuing to build new ones. Remember: if they don't use it, they lose it.

CP in adults

As we get older, we tend to move less than we did when we were younger. The same holds true for adults with CP, but with one additional issue: If they don't use it, they'll lose it. Remember? The muscle tone goes hyper, limiting the ability to move and function. This causes the body to compensate and leads to abnormal movements. To avoid this, adults with CP need to maintain functional mobility and improve everyday function.

In addition, it is really important to communicate with treatment provider, since the treatment does not need to be based on exercises but on the person's functional and daily needs. For example, if this person needs to cook and climb the stairs regularly, then the treatment should be focused on maintaining and strengthening the ability to perform these functions.

Finally, as health professionals, caregivers and as family members who simply want to see our loved ones succeed in life, our role is to listen and help children with neurological disorders understand their bodies and learn what they need to do to gain independence in their daily lives.

Explaining Cerebral Palsy to Children

Children are curious and will eventually be asking questions about special needs, either due to a family member or friend having a specific condition or due to encountering someone in a store, on the street, etc. It may catch us off guard, especially if it is directed towards our own children. Being prepared for the questions and the conversation can help lighten the stress and the sense of being overwhelmed. It also benefits the curious child when we can fully answer the questions appropriately.

The first step is to describe what Cerebral Palsy is and how it affects those who have it. For older children, you can start by breaking down the terms cerebral and palsy. You can explain that cerebral involves the brain and that palsy involves a weakness in the way a person moves/positions their body. For a younger child, it is more beneficial to explain how it affects someone. Explain that Cerebral Palsy affects everyone differently, but someone with CP has trouble controlling their muscles (or body parts to simplify it for a young child).

You can also go into the types of Cerebral Palsy. This will emphasize that it affects everyone differently. Here are the 3 main types you can discuss:

SPASTICITY: People with spasticity CP have muscles that are weak and stiff. This is also the most common form.

ATHETOID: This type is when the person is unable to control their body. Body parts may move even when they don't want them to.

ATAXIC: People with Ataxic Cerebral Palsy have shaky movements, making it hard to balance or coordinate movement.

The most important thing you can do is to highlight the abilities that people with Cerebral Palsy have. Children are going to notice the differences and will focus all their attention on that. It is important to encourage the commonality that all children have and point out strengths everyone has. If the child is talking about a certain child, maybe a peer, go ahead and ask your child what the other child is good at. Perhaps they are good at painting or writing. Ask your child what the other child likes to do. Maybe they both like music or playing outside. Spend a good chunk of time finding similarities so your child can find a way to relate.

When explaining Cerebral Palsy to children, they are going to want to know what they can do to help. Tell your child that it is always nice to help, but to ask that child if they need help first. Explain to them that sometimes a person doesn't want or need the help. Let your child know that they can help by just being a good friend. They can make sure no one gets left out and find ways to include the child in games with other children.

This is another great time to talk about bullying with your child. There are a few blog posts dedicated to bullying and these may help you start a conversation on that topic.

Cerebral Palsy may be a confusing topic for children, but it can be simplified by using words they know and understand. An older child may understand a more technical explanation while a younger child may need more examples to relate back to things they know. When explaining Cerebral Palsy, it is important to focus on what people with CP can do to avoid any stereotypes. This can also be a good time to bring up bullying and educate on that topic as well. We hope these tips can help when questions arise and decrease the stress those may feel when having to explain Cerebral Palsy to children. For more information about Cerebral Palsy, please visit our website:

www.benola.org

Surviving Motherhood:

Raising a Child with Cerebral Palsy

Olaoluwa has had a journey which words and pictures can only insufficiently describe. However, the tireless love and support from his family has developed him into the charming, young man that he is today. Though limited in speech and movement, his understanding is in no way limited and his smiles tell stories that light up the room.

HERE'S THEIR STORY....

IT WAS NOBODY'S FAULT

Mrs. Gbadebo...

Nineteen years ago, when I got pregnant with Olaoluwa I went to the best hospital in Kano and I was attended to by the best doctors. However about 6 months into the pregnancy it was discovered that I had too much water in my stomach and the baby had actually tied the cord around his neck. So I had to have an emergency Caesarean Section at 34 weeks and Olaoluwa was brought out with the cord tied around his neck. I was told he didn't cry for about 10 minutes or more and I on the other hand was losing a lot of blood.

Anyway to cut the long story short, we had to stay in the hospital for about a month and Olaoluwa was kept in the incubator because not only was he premature, he also had difficulty in breathing.

THE FIRST SIGNS

Mrs. Gbadebo.

About two weeks after he was born, Olaoluwa had a seizure right in the incubator. So they had to shave his hair and administer drip through his skull because having been so small, it was difficult finding any veins. I also noticed that he couldn't suck or swallow very well. If he tried sucking or drinking anything from a bottle, he choked. So even after getting discharged from the hospital, with the different choking and passing out episodes, we kept going in and out of the hospital and by the time he was 4 months, I knew something was wrong. Even though the pediatrician in Kano said that some children outgrow such conditions by the time they turn one, I was still apprehensive especially when at 6 months he wasn't doing the things which his two older brothers had done at that milestone. For example he didn't have neck control and he still couldn't eat well.

THE DISCOVERY

Mrs. Gbadebo...

By December 1996, we moved from Kano to Lagos and following the advice from some friends, I registered Olaoluwa at Lifeline Children's Hospital. After seeing the pediatricians there, I was referred to a neurologist. Tests and scans were carried out and that was the first time I was told that Olaoluwa might have Cerebral Palsy. As expected, the first reaction of a Nigerian mother to such news is 'I reject it, God forbid!' But when there was still no improvement in his condition, we began our quest for a cure by first taking him to Germany. We were there for 6 months and again it was confirmed that Olaoluwa has Cerebral Palsy and that there's no cure. They also prescribed some medications for his seizures, ran some tests, told me about the physiotherapy he has to do all his life and they said that as he continues to grow, I will know the severity of the damage to his brain. So that was the beginning of the journey for us 19 and half years ago.

THE ADJUSTMENTS

Mrs Gbadebo...

For the first time in my life, I had a child who has Cerebral Palsy and we had to make a lot of adjustments such as making room for lots of hospital visitations; both the expected and the emergency visits. There were also the physiotherapy sessions at least three times a week and the financial and psychological adjustments. As he kept growing, his brothers had to help out as well. When he was a baby, it was easier to lift him and do different things or him. But when he became 4, 5 years old, we had to ask one or more people to help us because his brothers had to go to school.

I was a lecturer but I had retired and started doing business at home because I couldn't afford going very far, especially with the Lagos traffic. Even my older sons had to go through changes such as change of school to one closer home and switch from boarding to day school. We all had to make sure we gave him the best that we could.

AVM Gbadebo...
There was a time when my wife couldn't go to the market or get her hair done unless I came home. So there were actually periods when I came home virtually every weekend. because it was so obvious that if I didn't, she wasn't going to leave him with anybody else. This is because the fears we nursed at that time was - 'Can anybody really manage the child as well as we do?' Now, not that I could afford these trips, but we were lucky to have had supportive friends who would put money together for tickets and stuffs like that.

Then as time went on, there was the issue of worrying about her mental state and that of the older children because with a lot of attention being placed on the younger one, their lifestyles became drastically affected - Once the boys came back from school, mommy was already so tired from taking care of so many things. Then to top that up, they also had to do their own share which meant they didn't have a social life per se. They did begin to feel some type of stigma from families who didn't understand. Some families are not keen on their children playing or interacting with a child who has special needs because maybe they think it's contagious.

THE INCLUSION

Mrs.Gbadebo...
Despite all these, we have actually tried to make sure Olaoluwa is a part of our everyday life. If you look round, Olaolu is everywhere and within two minutes of meeting me, you will know about my son so that you don't later think I had been hiding him from you, Another thing I've always believed is that you never know where your help will come from. A lot of people hide such children, but when you are open and honest about your situation, you never know who God will send to you. Maybe you are talking to somebody who knows a neurologist or an expert in the field that your son needs.

Even Olaoluwa's brothers make sure that they tell their friends about him. So when these friends come over everybody plays with Olaolu. They just go upstairs, say 'hi Laolu', speak all the new, youthful jargons and make Laolu smile. When we are having a party, everybody goes upstairs to say hello because he is big now and we can't bring him downstairs all the time. Upstairs, we've made sure he has his bedroom, his sitting room and just simply everything he needs.

I never really wanted him to be far away from us. So, when somebody suggested that we put him in the guest room I refused because there, I wouldn't know what happens to him. The care givers might be abusing him and I would not know. But upstairs before I get to my room, I pass by his room and he sees me. Even when we are climbing the stairs he knows who is coming and begins calling out to the person.

So Olaoluwa is part and parcel of our lives and the first thing anybody knows when they get to this house is that Olaolu is very important to us because we believe that if you show people that someone is important to you, they will treat him the way you also treat him.

AVM Gbadebo...
I want to add that Olaoluwa is upstairs because he's a very unique human being. He developed Scoliosis which is a very serious twisting of the spinal cord and by the time he was 10, 12 years old, he had twisted so badly that his right lung was in danger of collapsing. It took a lot of effort on our part and persuasion of doctors abroad before we finally found a hospital in India that was ready to do the surgery. It's a common surgery in Europe and America but it's only done on children that are verbal because the child should be able to tell you how he feels, if he has pains and so on. But Olaoluwa is not verbal. We do everything for him and so every hospital that went through his files said they won't perform the operation. But the hospital in India carried out the complex, 18 hours operation and the end result is that he has rods in his back which hold his spine cord so that it can be fairly straight.

After that surgery, we just found out that a young man who was taking medication every 2 hours a day suddenly will not take liquids and if he doesn't take liquids, how then do we administer the medication? So he now has a feeding tube through which we administer the medicine.

Putting all this together has made Olaolu a very special, delicate person. If in the process of bringing him down the stairs, you slip and he falls, then maybe we are going to have to find our way to India again. If the care givers mishandle the tube, they could injure him, or pass an infection directly into him. So we now have nurses to manage that. The end result is that it's best to have him upstairs.

NO OVERPAMPERING

AVM Gbadebo...
Before the surgery, I used to exercise Olaoluwa on his stomach. He has very strong hands, though his legs are not really that active. But in the process of making him better, we ended up with a very delicate, young

man. For example once he had stomach tubing we couldn't lay him on his tummy anymore. It was the same thing with moving him upstairs and downstairs because of the rods in his back.But despite these restrictions, we do push him in the way we can; he does his physio regularly, we talk to him and we just do the best we can.

Now there are children who are overpampered even though they are not as delicate as Olaoluwa. Some parents can't stand the sight of their child crawling but really, if that's all the child can do, the best thing is to keep that space and environment clean because by allowing him to crawl, he is exercising a lot of skills and developing himself. So having somebody carry such a child all the time is actually counterproductive.

LETTER TO THE FATHERS...

Mrs. Gbadebo...

I would like to advise men, especially Nigerian men, to be more compassionate. If you want to deny the child, go and have a DNA. !twill tell you if the child is yours or not because most people tend to say, 'we don't know where she got 'this' from!' If the child is yours, you have a moral duty to God and to yourself to take care of that child the way you are taking care of the so called normal ones.

Actually a lot of men are today standing up. During our network meeting, I saw a lot of them - bankers, young and older people - who came with their wives and spoke about their experiences. Two or three of them were actually holding the child because the wife couldn't do the carrying.

This support is necessary because this is not a role for just one person. So as fathers you do what you have to do and then your wife and children will respect you more. Give all the support, be home on time, realize that your situation is different from others who may spend their time clubbing and doing whatever men do. If you have a good job, provide. If you are travelling with the other children, take your special needs child because he/she is part of the family and the more you make sure the siblings love the child, the more the child will bloom.

AND TO THE MOMMIES...

Mrs. Gbadebo...

My advice to mothers without financial support or the support of their husbands is that they have to get closer to God. Even those of us with supportive husbands must get closer to God.

Also, surround yourself with good friends and family because it's a hard journey and I won't lie to you there are many times you will be depressed. My own family have and are still fantastic. My late, elder sister who was a medical doctor was the first person I called when I received the news about Olaoluwa and she was always fantastic. I have a friend who used to come around on Sundays, offering to stay back with Olaolu and the nanny so that we can go to church. Now, that's good support and those are things friends, family and church people can do for you.

In addition, you have to be a pillar and support because if your family constantly see you breaking down, they will not be able to cope. If you need to cry, lock the door and cry. Then clean your face and come back out. If you need a break, don't be shy to ask for one. You can request a friend to come and stay with your child for an hour so that you can go out for a walk or drive. By the time you come back, you'll feel better. Two people might say no, but the next person might say 'Yes, I'd help you.'

Finally, there will be times when you will have to make important decisions as a mother. There was a time when we were away in London and people were suggesting I leave my son behind and return backto Nigeria. But I couldn't do that because I knew I will die and my son who is so used to our love will also die if he suddenly doesn't see us and hear our voices.

YOU ARE NOT ALONE

Mrs. Gbadebo...

Three days ago, we had the first Cerebral Palsy Parents network and were shocked at the number of parents that came out. At such gatherings, you will realize that you are not alone. There are other parents. So don't lock yourself up because the depression that comes with this has made some people go mental or even harm their children. As I said before, surround yourself with good friends, family and associates. Tell as many people as you will start offering to help you. Besides, telling people about what you are going through is also therapeutic. I always tell the younger parents that if I tell 10 people about my situation, 8 will make fun of me or spread the news but that doesn't bother me because the remaining 2 just might be of good help to me.

STOP THE STIGMA

Mrs. Gbadebo...

I will want to appeal to Nigerians that when they see children with special needs or disabilities, they shouldn't ostracize them. Some of these disabilities are not contagious like a cough. These people with disabilities are human beings who also have rights to live. So we must just be kind. Say hello. That's the least you can say if you are the nice one. If you cannot, just walk away but don't just stand and keep staring at the child and the mother. That's why sometimes a lot of mothers don't want to take their children with disabilities out. There was a time we had to take Olaoluwa to the immigration office and everybody just kept looking. Their stares made him jittery because he is not used to seeing so many people. He then started panicking and I started crying. It took a little girl, well she's not little because she was in her 20s, who came to meet me and encouraged me not to mind them but to just do what I came to do. She was an Air force personnel, and she said she will stand with me. She was very kind and very young.

So just be nice. Be kind. You don't have to say anything. If you want to say anything, tell the mother and the mother will encourage the child. It's for reasons like this we started Benola. I've passed through it and I don't want other people going through it. We want people to be aware that there are children who are disabled in Nigeria. There are lots of them and they have to come out. They have started coming out.

ONE FINAL WORD: ONE DAY AT A TIME

Mrs. Gbadebo...

When you first hear the news about a disabled child, you will reject it. Then next, you deny it. When friends and relatives observe the obviously 'wrong', you say, 'no, no, no, there's nothing wrong with my child'. However, if you cut this denial stage short, you can then go on and be angry at God - 'Why me? What did I do wrong? Am I the worst sinner? Look at armed robbers having 'normal' children. What did I do?

After overcoming the anger, you move on to acceptance - 'God what do I do now? Help me. Show me the way.' - and that's when the healing begins.
Note that you don't need to know what the next day holds. You just take it one day at a time. When you are done with today', thank God you have scaled through and then tomorrow morning, pick up your cross and run with it.

Culled from Mommy Moments Magazine

Tuesday, 22nd March 2016, the 6th Regular Meeting of Benola's Project Planning & Implementation Team (PPIT) was held at Peninsula Hotel, Lekki Phase 1, Lagos. Led by Prof Afolabi Lesi, the meeting took far reaching decisions on ways to implement the rest of Benola's Plans for the year 2016.

Way to go Ambassador Uche!

Team Benola joins the world to celebrate the American Cerebral Palsy Awareness Day!

Benola's 3rd Anniversary Visit to Modupe Cole Home/School for the Disabled, earlier today, was a very fulfilling experience. On arrival, we were warmly received by the Assistant Head-Mistress, Mrs Afolayan Taiwo and the PTA Chairman, Mr Babatunde Willoughby, after which about 40 of their articulate residents, led by one of their own popularly called Pastor Muyiwa Durojaye, welcomed us with songs of praise and a prayer for Benola. A conducted tour of their expansive facilities, hostels, classrooms and vocational training institute, followed. The highpoint was the hostels housing over 40 Cerebral Palsy residents with severe limitations including a very healthy looking 63yr old blind, deaf & dumb Chap who has been there for the past 37years. Virtually every resident at Modupe Cole would make a great story but somehow, a 12-year old with CP who was recently found abandoned at an MFM all night prayer really stood out because it was obvious that he earlier been well cared for. To the Management and Staff at Modupe Cole, I say well done for keeping a clean healthy environment and to those who feel life has dealt them the short end of the stick a visit to this unique Home/School in the heart of Lagos may just be what the Dr ordered!

Benola at Modupe Cole

Cross-Section of Participants at Benola's First Quarterly CP Parents Network

CP Parents Network in session

Saturday 13th February 2016, saw the start of a new phase in the quest to fulfil the Benola Vision through the maiden edition of Benola's CP Parents Network held at Peninsula Hotel, Lekki, Lagos. Though limited to a maximum of 20 families, we had 22 parents, most coming from places as far as Ikorodu, Iyana Paja and Redeemed Camp, in attendance. It was also heart warming to find a large number of fathers in attendance. Ages of children ranged from 4yrs to 35yrs and because of the vibrancy of the discussion and active participation of everyone, the event that was scheduled for 11am - 2pm, officially closed at 4pm, after which a few parents staying back for personal consultations. Indeed it was highly fulfilling experience as the parent all indicated interest in partnering with Benola and unanimously called for more of such interactions!

As part of activities marking his birthday, Doyin Sax a budding Saxophonist and Band Leader decided to spend half-day, 9th March 2016, with us at Benola. As the young was one of our first set of volunteers it was an opportunity to review both Benola's progress and the his musical career. A versatile and accomplished musican, Doyin Sax's specialty is Afro Pop but he style based on audience preference covers all gengre of music. Catch him on Thursdays @ The Firewood Restaurant, Bar and Grill, 30 Commercial Avenue, Ozone Cinema Rd, Opp MRS Fuel Station , Sabo, Yaba, from 7pm!

Dateline, Thursday 18th February 2016: An interesting revelation at maiden edition of Benola's Cerebral Palsy Parents Network of 13th February 2016 was the case, as reported by the mother, of a 22yr old with CP who despite his poor writing skills etc was being denied the right to sit for his final school leaving examination as a special student because the examining body (WAEC) only made such provision for the visually impaired, the deaf/dumb and the like, meaning he has going to have to slug it out like everone else. A situation that was sure to leave him at a huge disadvantage. Seeing it as a possible 'human interest story', I floated the idea with a friend and with his help the Editor of This Day Sunday Newspaper, Tokunbo Adedoja, sent his Reporter, Demola Ojo, to interview me for a story!

Mr Samuel Adeoye Olojede, a Talk Show Host with Rockcity 101.9FM visited us at Benola to conduct an interview on my life post retirement and of course, the Benola Vision. Situated in the Rocky city of Abeokuta, capital of Ogun State, Nigeria, Rockcity 101.9FM, a News, Talk Show and Entertainments Radio that started operating 7years ago, is currently listed as one of the top radio stations in South-West Nigeria!

Benola Day 2016 & Olaoluwa's 20th Birthday

Delivering a Paper on Disability Awareness

Interaction with the Media

Wednesday 16th March 2016: I was at the Damian U. M. Azubuike Foundation
4th Series/ Awards/International ICT & Infrastructure Summit, held at Afe Babalola Hall, University of Lagos, where I delivered a paper on, "Information Technology as a veritable tool for Disability Management."

Students of Grange School Ikeja

Team Benola at Grange School, Ikeja

AVM Gbadebo with Alibaba, Boye Theseabilities

AVM Gbadebo with Crystal Chigbu, Founder Irede Foundation

The warm up before the Walk

Saturday 9th April 2016, The IREDE Foundation (TIF), a Non-profit Governmental Organisation focused on lending a hand of love, joy and hope to children living with limb loss, held it's annual Awareness Walk, "Out on a Limb" simultaneously in many cities across Nigeria and beyound. I was at the Ikoyi arm of the event, Founded in 2012 by Crystal Chigbu, whose daughter, Irede Beulah Chigbu, was born with a missing tibia and patella of the right leg. It took Crystal and her husband, Zubby, 2years to accept the reality of amputation for Beulah. Today, Beulah, who has mastered the use of her prosthetic leg, is a beautiful child with very positive outlook on life. That experience inspired the birth of TIF, a foundation that in just 4years, has impacted many lives and provided artificial limbs to scores of children across Nigeria, raising awareness about amputation in the developing world.

Delivering a Paper on Developmental Disabilities at Manna Cemtre's Parents Forum

Keynote Speakers with the Manna Centre Team

Guess where I spent my Easter Monday, 28th March 2016 - Delivering a lecture, "Understanding Developmental Disabilities" at a Parents Forum organised by Manna Children Centre (MCC), Lekki Phase One, Lagos, to mark the opening of their new facility. Founded by Modupe Williams, whose over 25 years working experience spanning the finance, health management and the UK NGO sectors, Manna Children Centre (MCC)'s Vision is to provide an educational facility in Lagos state where "Every Child Matters" while their Mission is to deliver the highest possible standards of quality childcare and learning experiences for children with special needs and provide family support and with its team of passionate and experienced carers, MCC is committed to delivering the highest possible standards of quality childcare and learning experiences for children with special educational needs!

AVM Gbadebo with Bunmi Afolabi, Alumni Director LBS and Diane-Abasi, Alumni Office, LBS

Interview Session with the Alumni Director LBS

It was a pleasant supprise in when I received a call , late in November 2015, from Olubunmi Afolabi, the Director Alumni Relations, Lagos Business School and Publisher ofvthe schools bi-annual magazine, 'Footprints', requesting to do a feature on Benola in the April 2016 edition of their magazine. The resultant interview was conducted by a team led by the Director and Dian-Abasi in our office on Friday 22nd January 2016!

AVM Gbadebo with Jimi Disu Live on the Discuss

Sunday 31st January 2016. Had a great time @ 'The Discuss with Jimi Disu' on Classic 97.3FM's Award Winning Sunday Afternoon Chat Show where we covered a wide range of topics from my life in the military, through retirement to managing a chold with Cerebral Palsy for over 19 yrs. Awesome way to spend a Sunday afternoon and wrap up the first Month of the year!

AVM Gbadebo with Rear Admiral Jerry Onubi, former Director Medical Services, Naval and his staff

AVM Gbadebo presenting a copy of The Cerebral Palsy Eye to Rear Admiral Jerry Onubi, former Director Medical Services, Naval

Dateline Tuesday, 19th January 2016: With Rear Admiral Jerry Onubi, Director Medical Services, Naval Headquarters and his staff officers at the conclusion of a meeting to explore areas of possible partnership between the Nigerian Navy and Benola Cerebral Palsy Initiative!

The live recording of the interview

Dayo Jalekun in red and the Mommy Moments Team

Dateline, Thursday,18th February 2016: When my dear friend and Special Needs Mum, Dayo Jalekun, called about a week ago to book an appointment for a lady who wanted to interview my wife for a magazine, little did I know that it was to be a mini documentary for the women's magazine, 'Mommy Moments' published by Dassak & Halizters Concepts who were doing an edition on Special Needs Mums. The team led by Eniola Afolayan with Dayo Jalekun in tow subsequently insisted that I join to add the perspective of a Special Needs Dad & Husband which turned out quite well in the end. I'm certainly looking forwards to seeing the finished work.

Wednesday, 30th March 2016, I paid a courtesy visit to the new Commander of 107 HQ NAF Camp Air Cdre AG Yusuf, Commander. Located on Victoria Island, Lagos the Nigerian Air Force Unit has supported Benola's Programs right from our first Public Presentation in February 2013, with security and free access to their facilities. True to form, the Commander equally pledged his support towards the achievement of Benola's Vision for Cerebral Palsy in Africa!

AVM Gbadebo with Funke Treasure Durodola, GM, Radio One 103.5FM, Obalende, Lagos

AVM Gbadebo with Bunmi Yekini, Producer Health, Radio One , Obalende, Lagos

On Air at Radio One Lagos

Thursday 28th January 2016: True to the promise 2 weeks ago by General Manager, Funke Treasure Durodola, that Radio One' 103.5FM would partner with Benola to raise awareness about Cerebral Palsy, I was with On Air Personality, Fidelis Ebohon and Priducer, Adebukola Lawal, on the Magazine Program, 'This Morning on Radio One' where we discussed Cerebral Palsy. Thereafter, I spent over an hour in the studio Producer Health, Bunmi Yekini and her staff, recording 10 sound bites which the Station will use randomly to support Benola's CP advocacy campaign.

AVM Gbadebo recieving a donation of Wheelchairs from Mr Yemi Osilaja, President, Rotary Club of Lekki and Adeola Adetunji, MD Coca-Cola Nigeria

Saying a word of appreciation for the donation of Wheelchairs by Rotary Clob of Ikoyi, Lagos

On Thursday, 10th March 2016, while at the Kidney Foundation Lecture, I received a call from Mr Yemi Osilaja, President, Rotary Club of Lekki, asking if I could send someone to pick up 4 Wheelchairs for Benola at their Rotary Meeting that evening, the idea of sending one of my staff crossed my mind but when he casually mentioned that their Guest Speaker for the night was non other than Coca-Cola Nigeria's Managing Director, Adeola Adetunji, I changed my mind and later that evening found my way to Cactus Restaurant, Victoria Island, Lagos, venue of the meeting. It turned out to be a brilliant idea because at the I end of the evening I'd had a one-on-one with Mr Adeola Adetunji, listened to an impressive presentation on Coca-Cola worldwide and Nigeria, delivered a 5min talk on Benola's Vision for Cerebral Palsy in Africa and walked away with 4 brand new wheelchairs that are valuable contributions to Benola's Assitive Devices Outreach.

AVM Gbadebo with Christian Jnr of Sterlin Business Network who facilitated Benola's selection as Sterlin Business

28th January 2016, As a follow up to my talk on "Business Opportunities in Disability Management!" at Sterling Business Network's (SBN) Elite Breakfast, Christian Jnr who single handedly started the relationship between SBN & Benola 2yrs ago and has been nurturing it through Social Media Platforms from his base in London, invited me for a meeting at Radisson Blu Anchorage Hotel, VI, Lagos where we had our first one-on-one interaction. At the end Christian reiterated his earlier pledge that SBN had committed partnering with Benola to raise awareness about Cerebral Palsy. His parting words. "Sir, you've got a great Initiative and the only way to keep it growing is to keep on aggressively asking for support!"

AVM Gbadeboo and Brig Gen Ndubuisi networking at an SBN event

Thursday 11th February 2016, true to their promise to support regularly create opportunities for exlosure and fund raise for Benola Cerebral Palsy Initiative, Sterlin Business Network (SBN) Victoria Island Branch, at a Business Networking Cocktail Party made a token presentation to Benola. Certainly one more reason to give a great big shout out to SBN!

Report of Meeting of Families of a Child with CP

The annual meeting of Families with a Child with Cerebral Palsy was held on April 16, 2016 in Open Doors Special Education Centre. It was organised and moderated by Uchenna Madueke, Benola Ambassador and teacher at Open Doors. About 18 parents and children attended the meeting, most of whom came all the way from Vom. Due to petrol scarcity not many came from Jos but two vehicles brought all the Vom families.

The programme started on lively note with children's video songs on a lap top.

After that the children and their families danced to music on the laptop. Uche reminded the parents that we need to have fun with our CP children and we don't always have to be sad and worried.

After the dancing, the Director of Open Doors reported that 6 special wheelchairs were donated recently to Open Doors children with CP through Wheels for the World. This a programme under the Joni and Friends Ministry. She told how Joni was paralysed as a teenager but instead of giving up on life, she has gone ahead to be a blessing to other people with disabilities and their families all over the world. She pointed out that parents whose children are unable to walk should be encouraged by Joni's life because it is not necessary to be to walk to a meaningful and fulfilled life.

Then Uche Madueke led a discussion on importance of schooling for children with CP. The main contributions included complaints by the parents in Vom that the government did not assist them in getting their children into schools and they can't afford to send them without help. One father reported that he went to the Plateau State Disability Rights Commission in Jos. The person he spoke with asked him how many children he had. He reported that he had 10 children. Then the person from the commission with told him that if he valued his child with a disability he should remove one of the children who attend a regular and use the money to send his special needs child to school. A staff of Open Doors told the parent about the achievements of Steven Hawkins who is a great physicist but he is paralyzed and only communication through his eye movements which are recorded on a communication. He said disability opens ways for us to be attuned to the challenges human beings have and how they can creatively overcome.

Finally a parent reported that she is grateful to God for the dramatic improvement in her child and advised all parents to always pray for their child.
The meeting ending with everyone enjoying the masa and zobo provided by Uchenna.

20 Things Every Parent of Kids with Special Needs Should Know

1) You are not alone

There may not be anyone else with the same constellation of symptoms as your child but there are people with similar challenges. Find those people. I have never met anyone with all of these same challenges as my kid but I have a strong network within each separate diagnosis. We have made wonderful friends and have found — and I hope provided — a great deal of support within each of these. I just have to pop onto one of my Facebook groups and I'm immediately reminded, I'm not alone.

2) You too deserve to be cared for

We are placed in a position of caring for others nearly constantly. However, you still need and deserve to be cared for. If that entails asking friends or family to bring a meal by every now and then, or going for a pedicure, or a date night, or whatever else you enjoy doing. Whatever makes you feel special and taken care of, take the time to enjoy it, you are worth it!

3) You aren't perfect–and that's ok!

No one is perfect. We all make mistakes. We can wallow in our goof-ups or move on! Try to shift your thinking, maybe there was a good reason you missed that appointment that you were sure was on Tuesday but apparently was on Monday. Maybe your kiddo had a tough day at school and just needed the night off. Who knows. But beating yourself up isn't going to change the situation, so try to move on.

4) You are a super hero

You may not leap buildings in a single bound or run faster than a speeding bullet but you are a super hero none the less. Everyday you manage situations that a regular parent would think are impossible. You stretch tight muscles, remember pills, inject and infuse medicine. You hold hysterical children during horrendous medical procedures. You deal with tantrums and melt-downs. And most often manage not to have a tantrum or melt-down yourself. You encourage your child to do things doctors told you they would never do but you never gave up hope. You are a therapist, nurse, doctor, friend and confidante. You are no regular parent.

5) Therapy is play

Having sat in on several therapy sessions, I have been frustrated by what I thought was premature discharge from therapy on more than one occasion. Since then I have grown, I have learned and I have come to understand. For children, therapy is play and play is therapy. What I mean is that the best therapists find ways to make my son engage in challenging activities that he otherwise would have balked at, by making it a game that he wanted to play. We took a page from their book and did the same at home.

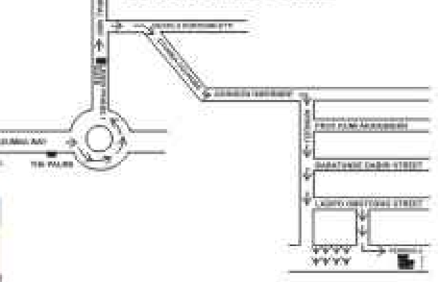
6) Play is therapy

Yes this is different from number five. After discharge from therapy, we sought extra curricular activities for my son that would offer therapeutic benefits. He played sled hockey, runs on a track team, learned to shoot archery and takes swim lessons. All of this is therapy. He's learning, having fun and getting stronger. Win, Win and Win!

7) Make time to enjoy your kids

We super-parents tend to be fairly busy and often over-scheduled. However, while everything on your


PENINSULA HOTEL



calendar is important, it's also important to make time to play, laugh, be silly and just enjoy your kids. Read to them, snuggle with them, engage with them with what's important in their worlds. Make memories outside of hospital walls.

8) You will be obligated to make heart wrenching decisions

You will have to make painful decisions that hurt your heart and leave you questioning everything you thought you knew or understood. Know that you are doing your best – remember number three. I am guilty of agonising over these types of decisions, they can become really overwhelming to me. Talk about your conundrum with others who get it and trust yourself to make the best decision. Make it move on and once it's made, don't re-think it. Easier said than done, but worth a try!

9) You won't always get it right

Many of the choices you are forced to make have no right answer, just the lesser of the hard and painful wrong choices. You will do your best but you won't always get it right, no matter how many sleepless nights you spend agonising over how to handle a situation.

10) Forgive yourself

Yes, you will screw things up sometimes despite the very best of intentions. No amount of torturing yourself will make you feel better, nor will it help you to make better choices. Remember many of the toughest decisions have no right answer.

11) Being a parent is hard. Being a parent to a child with extra needs is extra hard

It can also be extra rewarding. Make us extra passionate. And will almost always make life extra interesting. With the challenges come the rewards. Sometimes you have to search your heart for the rewards but they are there if you look for them.

12) Parenting a child with extra needs is like a marathon

For those folks who are trying to win a marathon, there are no breaks. If you want to stay in the race, you eat, drink and even pee while running. But our marathon will go on for the foreseeable future and beyond. So remember, you don't need to win, just make it to the end. The guy who comes in last place in the marathon, he took breaks, he stood and drank some water, grabbed a quick bite and used the porta-john for his business, then got back on the road. Give yourself those moments – however brief – that are for yourself. Goodness, you might even get to pee in peace every now and then.

13) Don't lose yourself

Don't let being the parent of a special needs child create or reshape your identity. We are many things, being the parent to a child with special needs is part of our identity. But it shouldn't be all of our identity. When you focus all of your life, all of your contacts, all of yourself around your child and their needs, who you are can get lost. Find things in your life you enjoy doing – a glass of wine, a hobby, shopping for yourself.

14) Keep your sense of humor

Certain things get under my skin, we all have our buzz issues, one of mine is people first language. But if you're not careful, you can become overly sensitive to so many things that people start to avoid your company. Many colloquialisms like "I almost had a stroke", or "I nearly had a heart attack" are disconcerting to parents whose children have in fact had a heart attack or a stroke. However, try to remember that people are not making these comments to offend or upset you.

15) Celebrate the little things!

Brag about those accomplishments that might seem small to others but are huge for our kids! Our kids develop on their own clock, they learn many skills late and some they never master. A wiggled toe that couldn't wiggle before, a word, a sentence, a smile, a hug, whatever that milestone may be. Share it with those who love you and your child.

16) Don't let typical parents get you down

I know how hard it is to hear from parents that their child six months younger than yours is walking and yours isn't. Or dealing with the well-meaning stranger who asks why your 2-year-old is scooting around on their butt rather than being up on their feet. Try to remember that these people lack the context that we are constantly embedded in. Explain, teach, be patient, raise awareness amongst those who just don't get it. And remember, typical parents deserve the right to brag too and their pride at their child's accomplishments is not meant as a knock to your amazing kiddo.

17) Don't compare

This is another challenging one folks, but worth the work. All kids are different, typical or with extra challenges and they will grow and develop at their own pace. If a developmental milestone isn't met as you think it should be, certainly talk to your child's

contd. on page 27

REFLECTIONS

It takes an open minded individual to look beyond a disability, and see, that ability has so much more to offer, than the limitations society tries to place upon them **- *Robert M. Hensel.***

CROSSWORD PUZZLE

-by Bolatito Role

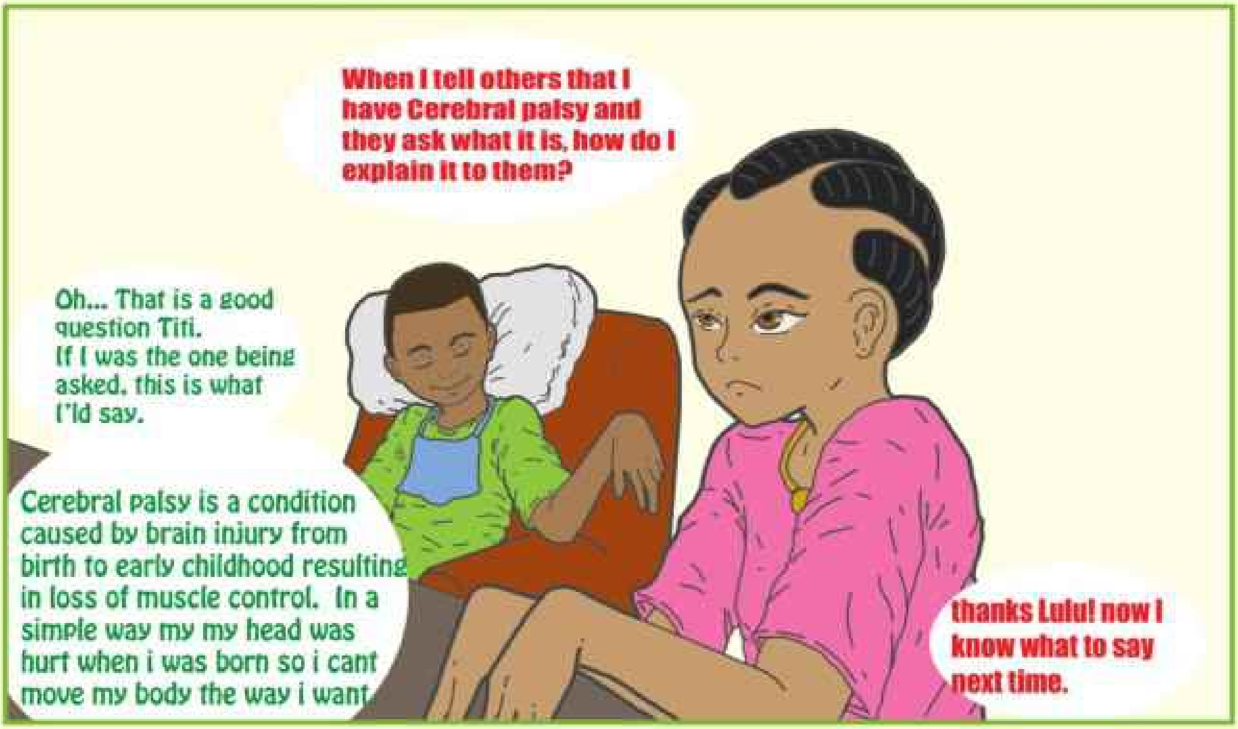
A	S	G	A	C	H	E	A	B	S
F	D	R	J	L	I	M	N	D	R
L	K	A	B	O	J	U	X	V	D
I	N	V	I	S	I	B	L	E	E
Q	B	I	N	R	G	N	Z	K	A
Y	P	S	I	U	F	X	T	L	F
C	A	T	A	T	O	N	I	C	Y
A	S	P	E	R	G	E	R	N	U

1. **GRAVIS**
2. **INVISIBLE**
3. **ADD**
4. **DEAF**
5. **ACHE**
6. **CATATONIC**
7. **ASPERGER**
8. **JOINT**

"I thank God for my handicaps, for through them I have found myself, my work and my God **- *Helen Keller***

A Word from Lulu

by: ***Rotimi Gbadebo***



doctor. Comparing, siblings, cousins, kids in the daycare class, or even comparing kids within the same disability type rarely serves to make you feel better. Your child is unique, and will have their own individual strengths and challenges.

18) You don't have to be "THAT" parent

You know the one who clearly spent 10 hours creating the amazing snack shaped like an animal with licorice whiskers. The one who sends adorable treat bags for every holiday. The one who finds the coolest gifts for the teachers every year. And whose child is always dressed in the cutest outfits that somehow never get dirty. If that's the mum you are led to be, more power to you! However, I have found that there are always enough of those mom's in my kid's classes to keep them in cute snacks and treat bags. Since I have bigger fish to fry, I let them have all the glory!

19) Make time for your marriage.

Marriage is hard work, period. Parenting is hard work, period. Parenting a child with special needs, is especially hard work, period! For those of you who are married or in a relationship, make time for that relationship away from your children.

20) Trust your instincts

You know your children best. Doctors, teachers, therapists are all fantastic resources but if you don't feel like you're being heard, or your child's needs are being met, it's very reasonable to get a second opinion. Don't be afraid to fight for your child and their needs. While the professionals are experts in their areas, you are the expert on your child.

Source: cpsn.org.au

Non-Profit Management Consultant and Contractor

In their publication, "Forces for Good: The Six Practices of High-Impact Nonprofits", Leslie Crutchfield and Heather McLeod who spent four years surveying thousands of nonprofit CEOs, conducting hundreds of interviews, and studying 12 high-impact nonprofits to uncover their secrets to success, came up with six practices that high-impact nonprofits use to achieve extraordinary impact. Mainly that these nonprofits:

- Work with government and advocate for policy change
- Harness market forces and see business as a powerful partner
- Convert individual supporters into evangelists for the cause
- Build and nurture nonprofit networks, treating other groups as allies
- Adapt to the changing environment
- Share leadership, empowering others to be forces for good

In addition, they noted that high-impact nonprofits also master the basics needed to sustain their impact which include but is not limited to:

- Attracting and retaining great people
- Finding sustainable sources of funding
- Investing in their infrastructure and capacity.

If you think their findings are still true, Benola will like your comments on know how you see these playing out in your nonprofit and if there are any other practices you would like to see added to this list, please forward your thoughts to us at: info@benola.org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DISABILITY ADVOCACY

What is Advocacy?
Disability advocacy is acting, speaking or writing to promote, protect and defend the human rights of people with disability.

Disability advocates may advocate for themselves, another person, or a group of people with disability. They work through issues that have an adverse impact on rights for an individual or group, or on a society-wide level. Advocates may be paid or operate on a voluntary basis.

Types of disability advocacy commonly referred to are:
Self-Advocacy - undertaken by someone with disability who speaks up and represents themselves. Support and training for self-advocacy is available through community-based groups.

Individual Advocacy - a one-on-one approach, undertaken by a professional advocate, relative, friend or volunteer, to prevent or address instances of unfair treatment or abuse.

Group Advocacy - advocating for a group of people with disability, such as a group of people living in shared accommodation.

Citizen Advocacy - where community volunteers advocate for a person with a disability, such as an intellectual disability, over the long-term, supported by a Citizen Advocacy organization.

Systemic Advocacy - working for long-term social changes to ensure the collective rights and interests of people with disability are served through legislation, policies and practices.

Legal Advocacy – provide legal representation in the justice system, pursue positive changes to legislation and assist people with disability to understand their legal rights.

What disability advocates do
Disability advocacy may include:

- Providing information to people with disability about their human rights and identifying instances of discrimination
- Assisting people with disability to uphold their rights by speaking with and writing to people and organisations to raise awareness of problems and seek solutions
- Helping people with disability negotiate complaints processes or legal action to enforce their human rights
- Writing submissions and lobbying government to make changes that promote and protect the rights of people with disability
- Campaigning for social change by speaking to the media to raise awareness and highlight situations where people with disability are treated unfairly

Disability advocates often require a variety of skills, including:

- Disability awareness, how to communicate with and support people with different disabilities
- Understanding laws, legal instruments and jurisdictions
- Understanding processes within oversight and complaints handling bodies
- Applying a human rights approach to advocacy
- Negotiation skills
- Lobbying and running effective campaigns
- Professional disability advocates often develop these skills through in-house customised training within disability advocacy organisations, or through a range of community-based short training programs.

Disability advocacy is not:

- Providing counselling
- Making decisions for another person
- Providing mediation
- Providing case management
- Advocates can speak out for themselves or for

others who are at risk of being disadvantaged or treated improperly as a result of a disability. This can include missing out on jobs or services, being pressured to make a decision or choice, or being abused or neglected.

Why we need disability advocacy

Throughout history, people with disability have been hidden away or subjected to abuse, ignorance and prejudice. The power of disability advocacy over the past century has radically shifted thinking to recognise the rights of all people with disability to live in the community, with choices equal to others.

Disability advocacy came from the disability rights movement. In the 1970s and 1980s, significant battles were fought for the rights of people with disability, including the right to have access to a range of in-home, residential and other community support services necessary to support living an independent, unsegregated life.

Disability activists joined forces, like those working for civil, women's and Indigenous rights, to demand equal treatment, equal access and equal opportunity for people with disability. They challenged stereotypes, rallied for political and institutional change, and lobbied for self-determination – on the streets, in the courts, across the media, within services and in the halls of power.

"The good things in life are universal and include being treated with dignity, respect, acceptance; a sense of belonging; an education; developing and exercising one's capacities; a voice in the affairs of your community and society; opportunities to participate; a decent material standard of living; a normative place to live; and opportunities for work and self-support"
~ Wolfensberger et al 1996

Shifting models of thinking

Over decades, disability advocates have fundamentally shifted traditional models of thinking about disability to a new understanding where society as a whole takes responsibility for enabling inclusion.

The Medical Model of disability focuses on the person's impairment or physical or mental medical condition and regards the person as the 'problem' and unable to do certain things. This thinking has been fundamental in approaches like sending children to 'special' schools or employing people with disability only in sheltered workshops.

The Charity Model of disability sees people with disability as in need of 'help', unable to do things for themselves. While many charities offer vital support, much traditional fundraising emphasised the helplessness of people with disability and risked undermining their autonomy, independence and rights. It is a model often adopted by mainstream media.

The Social Model of disability is preferred because it makes a distinction between impairment and disability and looks to remove barriers that restrict life choices for people with disability. It holds that 'disability' does not come from having to use a wheelchair, for example, but from being unable to use stairs to get to work or board a train.

"**How this makes the difference:**

A wheelchair user wants to get into a building with a step at the entrance. Under a social model solution, a ramp would be added to the entrance so that the wheelchair user is free to go into the building immediately.

A teenager with a learning disability wants to live independently in their own home but is unsure how to pay the rent. Under the social model, the person would be supported so that they can pay rent and live in their own home.

A child with a visual impairment wants to read the latest best-selling book that his or her sighted friends are enjoying. Under the social model, full-text audio recordings are made available when the book is first published."

~ Scope, UK

There is always Good Reason To Smile

By: Dayo Gbadebo

My little brother is not like any other brother, my little brother is special.

Olaoluwa was born with cerebral palsy and since his birth has never been able to walk, talk or even feed himself; that has been his life and he hasn't known any different.

Back when I was younger (and even now), taking Laolu out was a mammoth task that would involve a lot of planning and logistics to pull off. Things like what he would eat, how to transport his wheelchair, where he could lay down and rest, where he would change his diapers, e.t.c had to be considered. Going out was a task, but going out to public places was in itself another hurdle; the stares, the looks of pity, and the questions at times could be overwhelming.

Luckily for My older brother and I, our parents had explained to us early on that our little brother was special and didn't need to be pitied, which really helped us later on when trying to explain our family situation to friends and those who asked.

I remember when Laolu came out of an eighteen-hour long scoliosis surgery, the first thing he did when he woke up was to smile, I'm guessing that was his way of telling us all he was ok.

My little brother is a remarkable reminder that even in the most uncomfortable of situations, a complete constraint of mobility and independence, there is still always a good reason to smile. Olaolu loves life, loves who he is and never wastes a moment wishing he was someone else.

For most people, we seek a life bigger and more extravagant than who we are. This exhausting cycle of seeking an unobtainable perfection only ever leads to disappointment. I encourage everyone to use my brother as not just an inspiration but a reminder that no matter your situation, in the darkest of times, there is always good reason to smile.

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MCC CONTACT DETAILS:
Address: 24C Adewunmi Adebimpe Drive, Maruwa Roundabout,
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Mobile: 07045706893, 09034977897
e-mail: info@mannacentre.com
www.mannacentre.com

Advocatng for Cerebral Palsy- The Benola Way

- Bunmi Afolabi and Dianabasi Akpainyang

"To provide high potential professionals with a general management education which stresses professional ethics and service to the community through the practice of management"

Air Vice Marshal (AVM) Femi Gbadebo (Rtd). an alumnus of the Lagos Business School's Owner Manager Programme (OMP) 15 has a career background in training and development; having spent most of his time in the Military training pilots for the Nigerian Air Force. As one of Nigeria's most experienced instructor pilots, he played a major role in the training of virtually every pilot that the Nigerian Air Force produced between 1982 and 1991. He went on to serve as Directing Staff at the Command and Staff College, Jaji and later at the National Defence College, Abuja.

After retiring from the Air Force, he felt a natural inclination to go back to teaching but at a post graduate level and he saw Lagos Business School as the ideal place to fulfil that desire. However, in order to be able to teach business people, he needed to understand how business people think, having never really been a business person during his career. He therefore decided to undertake a programme at LBS, which he anticipated would give him the required knowledge to add to his wealth of experience and subsequently pass on that knowledge. The Owner Manager Programme was the most relevant to him and thus, he enrolled.

A lukewarm approach to his various attempts to join a number of training and management consultancy outfits on completion of the programme and the lessons learned from the experience opened his eyes to the need to become more marketable. Hence, he took the decision to go into advocacy for disability issues. He no doubt had excellent credentials there, being a parent of a child living with cerebral palsy; a neuro-developmental disability which results
in lack of coordination, poor motor movement and in most cases severe deformation.

WHY CEREBRAL PALSY?

AVM Gbadebo and his wife, Alabi, have dedicated the last 19 years of their lives to the care of their son, Olaoluwa, who was born with cerebral palsy. While AVM Gbadebo worked away from home serving in various military units around the country for the first 12 years of Olaoluwa's life, Alaba virtually cared for him alone. For that reason, Gbadebo always felt more needed to be done to help people with Cerebral Palsy.

Unfortunately, most of the special schools around attempt to provide care for all physically challenged persons together in one institution and this makes it difficult to give those with cerebral palsy the much needed specific attention.

Added to that is the fact that special schools in Lagos are most located in Surulere, with limited school bus facilities.
This makes it difficult for parents who have children with special needs and live far away, to access their services.
Additionally, Gbadebo recognised that while there is a dearth of schools, the real challenge was not just that of availability. The severe deficiency in general knowledge of Nigerians about disability, particularly neuro-developmental delays like cerebral palsy was a source of major concern.

Counselling services for parents of such children were also lacking, leaving them at the whims and caprices of fiendish citizens who make a fortune ripping them off with bogus claims of a cure. In other words, there was a vacuum to be filled by anyone willing to take up the enormous task of advocating for the rights of the disabled, particularly where it involved taking the message to those who make government policy or are in a position to influence policies.

There was also a need to take the message to the private sector in order to sensitise them on the need to intervene and help create the needed services, support existing special schools/homes as well as help fund new schools. This is the vacuum that Gbadebo then sought to fill, as much as he could.

THE BIRTH OF BENOLA

Benola is "a non-profit organisation committed to change and progress for persons living with cerebral palsy, striving for their inclusion into every facet of society in order to ensure they live a life without limits." The general perception of Nigerians and indeed most Africans is that disability is all about being vision impaired, deaf /dumb or having, a physical disability as in missing/disfigured limbs etc. This wrong perception which even permeates government establishments has resulted in a situation where most disabilities are left out of consideration.

As a result, while the World Health Organisation estimates that there are as many as 25million people living with disabilities in Nigeria alone, government agencies still insist on working with a figure of less than 2million disabled persons. This is because they only see those with visible challenges and of course, destitute as being disabled.

However, when one considers that disabilty is defined as; "a restriction in the ability of a person to perform a normal activity of daily living with someone of the same age is able to perform"; and that an impairment or a handicap fall into the same category, with each representing varying levels of ability differing from the normal, the situation becomes clearer.

Benola is not a school, neither is it a home. Rather it is a non-profit organisation working to increase the level of awareness about cerebral palsy and better options for disability management well as helping to build capacity for existing schools, encouraging the development of new schools and empowering parents to better manage their children living with cerebral palsy through the use of information, capacity building and counselling services. Training and counselling are particularly important in Nigeria where people typically see either a spiritual reason or solution to problems, even where medical solutions exist.

The resort to spiritualising disability has pushed many parents to live in denial about the true state of their children, thereby denying them the much needed care at an early stage. Sadly. this remains the case even though research has shown that early intervention plays a key role in the management of all developmental disabilities and a child with cerebral palsy, or any neuro-developmental delay, if helped early, preferably before age two, can develop the necessary skills and flexibility needed to enable them live a much better quality of life.

Another cause for concern is the fact that most medical personnel, particularly those who are yet to undergo advanced training in neuro-developmental disabilities, have tittle or no knowledge about cerebral palsy and as such a good number of them, tend to advise parents to do away with their disabled children, often citing cost of care (both financial and otherwise), and lack of viable management options as their main reasons. Finally, as a respectable member of the international community and a leading voice on the African continent, Nigeria cannot continue to ignore her estimated 25 million citizens living with disabilities. For their sake and in order to ensure that Nigeria soon joins the league of nations where the disabled are given the opportunity to exploit and fully develop their potentials, Benola is working to ensure that every Nigerian and in due course, every African, has a better understanding of disability.

WHAT BENOLA DOES

At inception in February 2013, Benola's first priority was to build in-house capacity and in the process gain the confidence of the medical and special education communities as well as that of parents and care-givers. This they did by organising a number of workshops and conferences on the subject of cerebral palsy, management options and the peculiarities of living with the condition in Nigeria. In addition, also attended international cerebral palsy conferences in India, England and America. The result of all that effort was the presentation of a document, 'Benola's Roadmap for Cerebral Palsy in Nigeria', in February 2014.

The document, which is directed at mobilising and ensuring the integration of the efforts of all stakeholders towards giving increased responsiveness to, and provision for all those living with cerebral palsy was well received by the former Governor of Lagos State, His Excellency, Babatunde Fashola, Mr Fashola at a reception in his office, on 9th July, 2014, tasked Benola among other things to 'build a centre for cerebral palsy in Lagos and come up with a cost effective training programme on cerebral palsy and early intervention for relevant staff of Lagos State'.

A similar call was repeated by the former Chief of Air Staff, Air Marshal Shola Amosu, after the presentation at Headquarters of the Nigerian Airforce, Abuja on 18 July, 2014. Since then, Benola has worked tirelessly to complete the design of an ultra-modern Cerebral Palsy Centre to be sited in both Abuja and Lagos and, with the help of its dedicated volunteer consultants, is currently developing appropriate curricula for the training of healthcare personnel so as to ensure that, in no distant future, every healthcare professional in Nigeria graduates with a basic knowledge of developmental disabilities and early intervention.

Studies are also ongoing to determine the most appropriate way of compiling a credible database for

cerebral palsy and other disabilities in Nigeria
Benola does a lot of high level advocacy via the media while directly engaging key influencers and policy makers in order to ensure that;

- The mind-set of parents and medical personnel towards disability is changed from treatment to that of management.

- Both government and the private sector are mobilised to get involved in providing an enabling environment and financial support for affected families.

- Medication which is quite expensive and often beyond the reach. of those in the lower income bracket is provided free or at the least, subsidised.

- More cost effective schools/homes for the disabled are built to help cater to the needs of those in the lower income bracket.

In the area of direct engagement with the public. Benola currently has four major programmes;

a) Benola Day on 14 June 2014, comprising of:
- Business lunch with health editors, held a week before, with the aim of soliciting their support in the awareness campaign about cerebral palsy and the Benola Vision.

- Advocacy visits to cerebral palsy homes/schcools.

b) National Cerebral Palsy Family Forum in August where experts deliver papers and provide free counselling services to CP parents.

c) World CP Day- Held every first Wednesday in October; it is a period when in collaboration with an Australian based advocacy group, Benola joins CP organisations in over 80 countries to raise awareness about cerebral palsy through a vast range of activities from charity/awareness walks to advocacy campaigns in schools.

d) Benola's Christmas Outreach - held in December, to give CP children in schools/homes and their families a touch of the Christmas spirit.

In addition, in October 2015, Benola started a school's outreach programme that has so far seen them conducting cerebral palsy awareness campaigns in places as diverse as Corona School, Ikoyi Edidot College, Ajah; Dowen College, Lekki and Grange School, Ikeja. In an attempt to start providing services to affected families, the maiden edition of Benola's Cerebral Palsy Family Network was held on 13 February 2016 with plans to make it a quarterly event.

Finally, to realise its vision of providing the much needed management services to families of children with cerebral palsy, Benola is currently encouraging upwardly mobile CP mothers/parent to consider opening Cerebral Palsy Centre within their area of residence.

It is the desire of Benola that all the above actions will help raise awareness about cerebral palsy and ultimately result in Nigeria becoming a fully inclusive society where people with disabilities are openly accepted and can move around freely. The team at Benola is also learning as they go along and they aim to never stop learning or disseminating knowledge.

ACHIEVEMENTS OF BENOLA

- Currently in the early stages of its 4th year of operations, it is noteworthy that Benola has already recorded a number of notable achievements, namely;
- The publication of a Roadmap for Cerebral Palsy in Nigeria
- The development of Referral and Coordinated Care Pathway for Cerebral Palsy in Nigeria
- A website currently rated as one of the most authoritative on the subject and the first point of reference when one searches for information on cerebral palsy in Africa.
- The completion of the design, drawings and BOQ of a state-of-the-art Centre for Cerebral Palsy and Assistive Technology
- Completion of curriculum for training of Healthcare practitioners in the area of neuro-developmental disabilities and early intervention
- A quarterly publication, 'The Cerebral Palsy Eye' that is in its 7th edition with a circulation of 2000.
- An impressive team of consultants and experts who as volunteers, are now helping to drive the Benola Vision

IMPACT OF LBS TRAINING ON BENOLA

AVM Gbadebo feels that the greatest impact his time at LBS had on him is the improvement of his knowledge of financial management, the importance of branding in the overall success of an organisation, a better understanding of HR and the impact it has on the success or otherwise of an organisation and the incredible networking opportunities in the LBS alumni network.

SUCCESSION PLAN

With a plan to establish a wide network of volunteers all over Nigeria in the next 24 months and extend its presence to other parts of Africa thereafter, Benola is on track for a massive manpower growth and with that will follow a clearer succession plan. But for now, it is one step at a time for an organisation whose time has definitely come!

Culled from Footprints Magazine, First Edition 2016.

6 Things a Teen With Cerebral Palsy Wants New Parents to Know

-By Chloe Tear

I cannot begin to imagine what it is like to hear the words "your child has cerebral palsy," because I have always been the one to have CP. It is all I have ever known, but does that have to be a bad thing?

When your child is diagnosed with cerebral palsy, I imagine you will have thousands upon thousands of questions about your child's expected progress, abilities / disabilities, meeting milestones and so much more. These questions can't be answered in any great detail right away — with the vast majority left to the "waiting game." You may research CP in the hope of finding these answers, or at least a bit of support in this new unknown world for you and your child. Everything I can tell you is purely based on experience over the last 18 years. Cerebral palsy is unique to everyone and part of quite a large spectrum, but I hope it can at least give you a possible glimpse into the future: highs, lows and everything in between.

1. They will surprise you.

Doctors have a way of erring on the side of caution and making predictions based on little information right from the start. However, people with cerebral palsy are often determined, even a little bit stubborn, to challenge these predictions. I may not have received my CP diagnosis until the age of 7, but being 8 weeks premature made even surviving a matter of fighting the odds. At that moment in time, it would have been impossible to know the next 18 years and all the challenges that have come my way, and also all the victories! It may have taken longer to walk, run, ride a bike, tell the time... but woe betide anyone who says I cannot do anything. Even if it may take your child longer, that can make it even more special when they get there. Your child will have their own unique milestones and their own victories, no matter how small.

2. There will be frustration.

I would be lying if I were to say it was all plain sailing — but isn't that the case with everyone? The hospital appointments, the physiotherapy, the urge to fit in with peers — at times, it can be incredibly difficult and I have shed many tears. When I was younger I was such a girly-girl; everything had to be pink and pretty. Trainers and a splint didn't really fit the look I was going for — all I wanted was nice pretty shoes. We spent hours in shoe shops, with a few shoes thrown in sheer anger as the "perfect" pair of shoes wouldn't fit over my newly cast AFO splint. People with CP are resilient, we have to be, but that doesn't mean it is all progress.

3. Family and friends can be a great support.

The support you can get from friends and family can be fundamental. At the end of the day, we all need a little helping hand — some people just need a little more. Also, I have found that having friendships with other young people who have CP can be incredibly valuable. When you are having a rough day, the opportunity to share similar experiences and know you are not alone in all of this can help. It can help to talk to adults with CP who've already been down the same road. For example, I am planning to attend university, and I have found speaking to other young people who are currently students to be really reassuring.

4. They will be amazing at adapting.

Who says you have to do everything just like everybody else? From personal experience, I know that sometimes it is actually easier to do things in your own way, in order to get the same result as everyone else. This could be mastering tasks with one hand such as tying shoe laces or eating a meal. Adapting is often part of every day, and at times it can be difficult to come up with solutions, but you do get there. For some people adapting can include the use of certain equipment in order to gain independence, and from experience I know this can sometimes result in a love-hate relationship. However, it can allow loads more freedom and the ability to achieve much more. It may just take time to adjust to these adaptions.

5. Humor will get you through.

Sometimes you have to laugh, even if it's just so you don't cry. Laugh at the fact that you have ended up on the floor... again! Laugh at the fact you did something and might have looked a bit silly. Yes, at times this can be hard, and laughing isn't always the answer — but it will certainly help. "When you find humor in a difficult situation, you win" — I believe this is so true, and certainly a quote to live by!

6. The diagnosis is a very small part of your child.

Your child is not the diagnosis they have been given. They are not solely the label put on them without permission. First and foremost, they are your child, who happens to have cerebral palsy, just like they happen to have blue eyes or brown hair! A diagnosis may seem like it is taking over at times, but really it is only one piece of the thousand-piece puzzle that makes up a child. Having cerebral palsy can open so many doors and opportunities; it can make your child unique in the best way possible. The diagnosis is what you make of it. Turn those obstacles into opportunities, don't look back and never ever put a limit on what you can achieve.

The Cerebral Palsy Eye is asking: What is one thing that people might not know about your experience with Cerebral Palsy and what would you say to teach them? If you'd like to participate, please send an email to info@benola.com. Please include a photo of yourself and a 1-2 sentence biography.

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