Transforming Severe Developmental Disabilities: Using an Integrated Delivery System

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Blazing Trails is an outcome based community rehabilitation program and service provider, specializing in training and education. Our clients are encouraged to set goals and to focus on attainable destinations.

We are dedicated to assisting individuals living with disabilities navigate some of the challenges along life’s pathway.
What is an Integrated Delivery System?

- An integrated delivery system (IDS) also referred to as an integrated health care delivery system is a generic term referring to at least a joint effort of physician and hospital integration for a variety of purposes such as to access the market on a broad basis, optimize clinical outcomes, accept and manage a full range of arrangements to provide a set of defined benefits to a defined population, align financial incentives of participants (including physicians), and operate under a cohesive structure.
Government Must Be Willing to Protect and promote the health and well-being of children and youth.

The Health Policies and Legislation in Health Care Must:

● 1. Promote Health
● 2. Promote Safety
● 3. Promote Disease Prevention
BUILDING BLOCKS TO Integration

Level 1: Physician leadership

Level 2: Teleservices

Level 3: Empowered consumers
WHO IS SEATED AT THE DEVELOPMENTAL DISABILITY TABLE

- ADHD
- Autism Spectrum Disorder
- Cerebral Palsy
- Hearing Loss
- Intellectual Disabilities
- Learning Disability
- Vision Impairment
- Fragile X
- Down Syndrome
- Fetal Alcohol Spectrum Disorders
- Physician leadership - physician decisions drive 80% of all healthcare expenditures, *Primary care network, Information systems*.

- Electronic data networks TO transmit healthcare information throughout the community and to accelerate the process are necessary
Why Psychiatry?

- 1. Selected Psychiatry based on their vast understanding of mental health disorders.
- 2. Ability to help afflicted individuals and support the caregivers.
- 3. Psychiatrists are medical doctors.
- 4. The Psychiatrist are available to provide different modalities of diverse or individualized care to patients.
Variety of Professionals for Disabilities

Developmental disabilities require an integrated care system to manage care. Sometimes, individuals need all of these professionals. Sometimes, they need a few of them. Other times, these professionals are needed for just a specific reason to solve one small problem.

- SPEECH THERAPY
- OCCUPATIONAL THERAPY
- BOARD CERTIFIED BEHAVIOR ANALYST
- EDUCATIONALIST
- SOCIAL THERAPIST
A Speech Language Pathologist – also referred to as a “Speech Therapist” - provides evaluations and remediation of a variety of disorders and/or delays. Some include:

- Articulation disorders
- Cognitive impairments or delays
- Social language use
- Dysphagia (Swallowing)
- Pragmatic disorders
- Expressive and receptive language impairments or delays
- Fluency/stuttering
- Voice disorders
- Auditory processing disorder
- Oral motor and oral feeding issues
Occupational therapy is a client-centered health profession concerned with promoting health and well being through occupation.

The primary goal of occupational therapy is to enable people to participate in the activities of everyday life.

- Helping children achieve their developmental milestones such as fine motor skills and hand-eye coordination.
- Educating and involving parents, careers and others to facilitate the normal development and learning of children.
BCBA: Board Certified Behavior Analyst

- ABA is a systematic approach for influencing socially important behavior through the identification of reliably related environmental variables and the production of behavior change techniques that make use of those findings.
- Behavior Analysis is the scientific study of principles of learning and behavior.
- Two primary areas of study include the experimental analysis of behavior and applied behavior analysis.

The research points to body of research literature on how behavior is learned and changes over time.

The experimental analysis of behavior is the scientific foundation of applied behavior analysis (ABA).
The social therapist can work in a variety of formats with small groups, children, teens or young adults who have difficulty in social situations because of a variety of challenges learn appropriate social behaviors.

When a social therapist is needed

Perhaps a child, teen or young adult is having trouble at school, seems unhappy or bored, exhibits problematic behavior or has a hard time developing and maintaining relationships? Perhaps he/she is lagging in social skills development or has difficulty with non-verbal cuing?
Electronic health record (EHR), also called Electronic Data Networks or electronic medical record (EMR)

Necessary because data is stored digitally, the information can be shared easily among a patient's various health care providers within a facility, and can be sent quickly from one facility to another if a patient finds a new health provider.

- An electronic health record (EHR), also called electronic medical record (EMR), is a computerized collection of a patient's health details. But it's more than just that — it's a way of storing and organizing patient information.

- Information stored within an EHR can include a patient's medical history (including immunization status, test results, and growth and development records), and other health-related data.
Technology to Consider:

- **Prevent medical errors.** Many medical errors are preventable by using EHRs. For example, some systems help doctors prescribe drugs by performing the correct calculations needed for drug dosages. They also monitor for and alert doctors of potentially harmful drug interactions, allergies, or possible allergic reactions. And patients can avoid getting extra X-rays or lab tests.

The ability to share or recall information quickly is one of the benefits of using the electronic health records.
LEVEL 2

TELESERVICES
TELE THERAPY
TELE-HEALTH
TELESERVICES: Saves time and efforts

- Teleservices - to reduce inappropriate demand for services by identifying problems in healthcare delivery by regularly monitoring patient satisfaction, by providing information and advice concerning the efficient and appropriate use of healthcare resources through telecommunications based triage system and enhancing access to providers throughout the integrated delivery system, improve health status by reminding patients to keep their appointments with providers, reinforcing compliance with prescribed healthcare regimens and encouraging participation in health promotion and disease prevention programs; Outcomes management (defining clinical practice patterns that improve patient outcomes and reduce the variation in clinical management of patients), Regional alliances (consolidation of providers into regional networks such as between urban medical centers and suburban and rural hospitals to reduce excess capacity and duplicate services and technology, improve access to specialty services, and achieve economies of scale in acquiring supplies and sharing equipment.)
TELEThERAPY: treatment in which the source of therapy is some distance from the body, as certain radiation therapies, health consultations, etc.

- Technology can provide specialists where none exist.
- Patients can book appointments and be seen in the privacy of their homes or in a private space.
- Helps patients take control of their treatments.

Teletherapy is cheaper than visiting the specialist in person!
Level 3: Empowered consumers

- The empowered consumer will keep to minimum the number of times they will be re-treated because of failing to comply with prescribed regimens or must be treated in high-cost acute settings because they did not address a disease in its early stage, adopt the concept of patient-centered care;
- *Prevention* - to understand how important preventive care efforts can be which includes wellness and fitness programs for employers, industrial injury medicine and rehabilitation services, workers’ compensation management and community health outreach, and people –
- *empowering the people involved* in the healthcare delivery system to be able to act in a positive, proactive manner to manage costs and quality under fixed, capitated reimbursement.
Managing Disability/Managing Autism

- How can we make sure families know the signs?
Helping Hands Philosophy

A process to encourage individuals with disabilities to develop their goals toward becoming independent. This is a self-guided model and is different for every client.

What may be independent for one person is different for another.

Persons with disabilities may reach different various stages of independence according to their abilities.

An individual that seeks employment through our program should be given an opportunity to try the world of work.

Review of literature shows that all people develop a better concept of themselves through work.
What Does This Mean To the Management of Disabilities?

1. There is a coordination of all entities involved in delivering health and social services to a patient with developmental disabilities;

2. Improvement of the quality of community care for patients;

3. The integrated delivery system supports all services for the patient.
Young adults with developmental disabilities face numerous challenges with regard to maintaining effective and continuous care, education and access as they mature into the various stages of adulthood.

Age-based eligibility requirements have historically contributed to widespread loss of services when youth reach adulthood, regards to disabilities.

**Vocational Assessment**
- **Vocational Adjustment Training (VAT)**
- **Personal Social Adjustment Training (PSAT)**
- **Supported Employment**
- **Job Placement**
- **Job Coaching**
- **College Admissions Assistance**
- **International Advocacy for Special Needs**

BLAZING TRAILS INTERNATIONAL... Specializes in developing opportunities for young adults with developmental disabilities
INTERNATIONAL ADVOCACY...To help provide a voice in the form of awareness that individuals with disabilities, Autism & related disabilities can lead a meaningful life.

Things to do...

More presentations at International conferences

Push for governmental legislation and have it implemented.

Develop more vocational awareness programs for adolescent youth with Autism and developmental disabilities

Keep this model for success and branch out to other locations in Nigeria and then Africa!
AUTISM

- Autism is the most severe developmental disability. Appearing within the first three years of life, autism involves impairments in social interaction — such as being aware of other people’s feelings — and verbal and nonverbal communication.
- Some people with autism have limited interests, strange eating or sleeping behaviors or a tendency to do things to hurt themselves, such as banging their heads or biting their hands.
- Adapted from the Encyclopedia of Psychology
What are Neurodevelopmental Disorders?

- Neurodevelopmental disorders are disabilities associated primarily with the functioning of the neurological system and brain. Examples of neurodevelopmental disorders in children include intellectual disability (also known as mental retardation), attention-deficit/hyperactivity disorder (ADHD), autism, and learning disabilities.

- Children with neurodevelopmental disorders experience difficulties with language and speech, motor skills, behavior, memory, learning, or other neurological functions. While the symptoms and behaviors of neurodevelopmental disabilities often changes as a person ages, some individuals with neurodevelopmental disabilities in childhood do have permanent disabilities. Diagnosis and treatment of these disorders can be difficult; treatment often involves a combination of professional therapy, pharmaceuticals, and home- and school-based programs.

- (US) National Center for Health Statistics, a division of the Centers for Disease Control and Prevention
OUR MODEL

Issues of Development
(Some Issues Prevent the delivery of positive outcomes for individuals with disabilities.

- Awareness
- Screening
- Education
Top Issues In Development

10. Poverty

9. Drinking Water

8. No Electrical Supply

7. Agricultural for Survival
6. HIV & Infectious Diseases

**HIV PREVALENCE**

**FSW**: In 2009-10: HIV prevalence was 11 per cent. In 2011-12 preliminary data says it is 7 per cent.

**MTH**: (Men having sex with men, Transgenders, Hijras): HIV prevalence was 23 per cent. Now, it is 10 per cent.

**IDUs**: (Injecting Drug Users): HIV prevalence was seven per cent. Now it is three per cent.

**STDs**: (Sexually Transmitted Diseases): Incidence of STDs has come down from 18 per cent to two per cent.

State consumes close to **10.9 crore** condoms, which are supplied by NACO. The overall supply of condoms by NACO in the country is **44 crore**.

5. Preventable Health Care

75% of healthcare costs are spent on **PREVENTABLE DISEASES**

Source: cdc.gov
4. War

3. Pollution
2. Social Cultural Exclusion

What is it?

- Social exclusion is basically the state where people lose their self-confidence and bury themselves into deeper and deeper wretched poverty along with greater isolation. With no social and cultural framework, a country can go haywire due to complete loss of morals and ethics from the society. Free will, as great as a gift it is considered to be, will prove to be the worst nightmare for any third world country.
1. HUNGER- 870 million hungry people

- More than 870 million people of the entire developing world population have no food to eat or a very precarious food supply i.e. more than the population of the US and the European Union combined.

- Almost the undernourished population of the world lives in developing countries. 60 percent of these hungry are women, 50 percent of pregnant women in developing countries lack proper maternal care, resulting in over 300,000 maternal deaths annually from childbirth. A third of all childhood death in sub-Saharan Africa is caused by hunger related diseases, around 2.6 million deaths per year, one child every five seconds.
The Blazing Trails-GT Bank
Nigerian Autism Initiative

A MODEL FOR
AWARENESS

Local funding

International Advocacy

Health Professionals

College of Medicine

Psych Hospital

Public Participation
1.2 million Nigerians living with autism and their families are left to bear their cross alone. Despite the challenges posed by the condition, awareness is still very low in Nigeria. An awareness for this condition has been created by GT Bank to address the prevailing lack of societal awareness about Autism in Nigeria.
GT Bank Autism Programme 2014
Behavior Clinic at University of Lagos Teaching Hospital (LUTH) and Blazing Trails Int’l Center
GT Bank Autism Programme 2011-2016
Behavior Clinic at University of Lagos Teaching Hospital (LUTH) and Blazing Trails Int’l Center
IT HAS BEEN OUR PLEASURE TO SERVE AS TECHNICAL SUPPORT FOR AUTISM AND RELATED DISABILITIES ON NIGERIA!!!!!!
Organized SIX conferences with sponsorship and partnership from Guaranty Trust Bank. Additional partnership is from Lagos University Teaching Hospital and College of Medicine.

Through this work an awareness for Autism and related disorders.

Each year a symposium and behavior clinic is designed to parents understand the things they can do to help their child lead a meaningful life.
Awareness of Disabilities Helps to End Violence within the Household

Among the Household violent manifestations are:
- Infanticide & mercy killings;
- Physical violence, sexual, emotional and/or verbal abuse of the disabled child in a violent household;
- Theory of child induced stress leading to violence;
- Neglect as a precursor to violence;
- Violence and abuse linked to social isolation
- Abuse by support staff within the home;
Socially Sanctioned Violence

- Lack of consequences for abusers
- Lack of knowledge about disability within the legal system
- Community based – disability specific risks
- Virgin rape and the AIDS epidemic
- Exorcism and related traditional practices
- Unnecessary or unproven surgical and medical treatments
Purpose of the Program

- Ensure Autism is diagnosed early in children
- Ensure children living with autism are not stigmatized and they receive the required support from parents, teachers, friends and the society.
- Encourage institutions and the Government to fund Autism research and its management
- Highlight societal fallacies concerning Autism Spectrum Disorders and change public perception
- Reawaken society’s consciousness and educate people about the management and requirements of children living with ASD.
- Make considerations for older youth with developmental disabilities.
- Protect the rights of people living with developmental disabilities.
Year One

- 2011 A call to Develop seminar to bring awareness of Autism to the Nigerian Community
- Developed a Team of 10 Professionals (Experts in their Field) willing to answer the call to go to Nigeria
- Team consisted of
  - Medical Professional
  - Educators
  - Behaviorist
  - Speech Pathologist
  - Sign Language ...
WHAT ARE CRP’s?

- Community Rehabilitation Providers (CRPs) are approved vendors who provide a variety of employment services to the individuals served by the Departments of Assistive and Rehabilitation Services.

- These services include a variety of assistance to support employment efforts for individuals with disabilities.
First Trip - 2011

This First Symposium Focused on
  - An Introduction of the Term Autism and was presented to approximately 200 participants
  - A minimal diagnostic of students at the Patrick Speech and Learning Center
  - Public Forum With whole group presentation by the professionals...
  - Data Collection
  - Small group workshop
    - on Language
    - Speech Pathologist
    - Mathematics
The Blazing Trail-GT Bank Nigerian Autism Initiative
A Model for Awareness

- Data found
- Parents felt that there is a cure for this disorder and they were shopping for cures and diagnosis
- Participants had concerns about the public perception of bringing individuals with Autism into the public
- Mothers complained that their husbands left them due to having a child with behavior issues
- Many parents were concerned that they might lose their status due to the child with Autism
Travel to Nigeria

- The 2011 Symposium Revealed that there was a need for
  - More Diagnostic testing
  - More workshops for therapist and caregivers
  - Participation from Nigerian Professionals

- The 2012-16 Symposium was more focused
  - Larger portion devoted to diagnoses
  - Autism Experts included among the presenters
  - Participation from Nigerian – Autism Professionals
  - Partnerships with LUTH / College of Medicine
  - Participation from Nigerian Government Officials
  - Radio Calling Show – to reach outlying areas
Trips – 2013-2015

- Symposium Attracted over 2000 participants
- Collaboration with the Lagos Teaching Hospital
  - Larger number of people evaluated
    - Diagnoses revealed a number of disorders lumped under Autism
- Data Collection
- Testimonials from Officials having children or family members with Autism
Who Cares About Disabilities in Developing Nations?

- This is the big question when considering the dilemma of individuals with disabilities?

- How do we build capacity to deal with Autism and other neurodevelopmental disabilities?
Which way do we go?

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<td>SHOULD THE BURDEN OF CARE COME FROM THE GOVERNMENT?</td>
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<td>SHOULD THE CAREGIVERS AND PARENTS ASK FOR HELP?</td>
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WHAT ABOUT NGO’S AND INTERNATIONAL PARTNERSHIP TO HELP DEVELOP AN AWARENESS FOR UNDERSTANDING DISABILITIES WITHIN THE LOCAL SOCIETY?
Innovations

1. We had some innovative sessions that included musical intervention with children who did not have functional speech ending up developing some speech.

2. Children with ADHD had psychomotor intervention and calmed down.

3. Parents used recommended techniques to successfully change negative behaviors.

A further look at the following issues are necessary to continue this project

This action research was limited because:

- 1) This program evolved to fit the unique needs of the program participants.
- 2) Each installment has been restricted to a two-week time frame.
- 3) Some patients are concurrently enrolled in a therapy plan. Others do not have a plan.
- 4) Study restricted to only subjects participating in the Orange Ribbon Initiative.
- 5) No government action as to how to develop statistics on developmental issues among the population.
- 6) No curriculum alignment or prescribed course of action for what to do if someone has a disability.
- 7) Study limited by geographic constraints. Patients come from all over the country to visit the behavior clinic.
International Meeting for Autism Research
QUESTIONS - COMMENTS
Early Theories on Causes for Autism were psychoanalytic in nature.

Reynolds and Dombeck (2006) point out that Bruno Bettelheim theorized that:

A. Autism occurred as a result of poor parenting, specifically as a result of neglectful parents who failed to stimulate their children;

B. Children with autism failed to develop normal empathy skills, because they were not given sufficient affection. Bettelheim coined the term "refrigerator mother" to describe the supposedly unaffectionate mothers who 'caused' autism in this manner.

C. Although these theories are mostly discredited today, Bettelheim was quite influential in our understanding of Autism today. It appears misogynistic (woman-hating) in the light of our contemporary understanding of autism, but it is of a piece with other early psychoanalytic theories, and should be regarded in that light.
Lars Jacobsson (2002) points out that stigma and discrimination of the mentally ill is a complex issue and an important task would be to try to identify which features in people with mental disorders evoke these negative emotions and reactions. It is obvious that a psychotic, badly dressed, bad smelling, aggressive and disturbing person evokes feelings of disgust and fear and runs the risk of discrimination and exclusion.
Less Desirable Traits

For stigmatization to occur, such differences must be linked to undesirable traits. For example, part of the stigma of mental illness and related disorders lies in the association of illness with stereotypes of potential violence, communication problems and unpredictability. These individuals are characterized as a ‘them’, quite different from ‘us’. Such stigmatized out-groups typically lack power, and their social status decreases due to a combination of overt and less obvious mechanisms.
Sartorius (2001) terms these the ‘vicious cycles’ of stigma and argues that they not only operate through individuals and their families, but also contaminate mental health services and psychiatric research. Sartorius describes, for example, how individuals are ‘marked’ with a stigmatizing trait. They are then discriminated against and disadvantaged.

The resultant reduction in self-esteem increases disability because they have less access to social and financial resources. As the cycle continues, the individual has diminished reserves to resist stigmatization, and so the cycle repeats, intensifying and entrenching stigma as it does so. Although stigma is discussed here (Sartorius) as a single concept, there may in fact be a range of diverse ‘stigmas’. It is likely, for example, that the sources and dynamic involved in the stigmatization of alcoholism are very different from those that relate to postnatal disorders. It is worth remembering that some stigmatization, such as that against criminal activity, serves useful social functions.
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<th>Condiment Cart Program</th>
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<td>- Placed individuals with disabilities as the face of customer service.</td>
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<td>- Trained group over the years for program to work in public.</td>
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The cart program has been very successful. The individuals receive the training and are actually employed to work as cart attendants. Many have been cart attendants since the beginning in June 2009.

Training for this position is done through Legends Hospitality Management and Blazing Trails International Center.

Those individuals that are capable of being trained for other positions are recommended for new placements.
Participant Status

- ASD
- CB PAULSY
- ANGELMAN
- TBI
- PDD-NOS
- ASPERGER
- DEAF
- BIPOLAR
- MENTAL HEALTH

Legend:
- LOW FUNCTION
- MODERATE
- HIGH FUNCTION
The chart in fig 2. shows that participants in the program are at varying degrees of functionality. The data also revealed that ASD, PDD-NOS, DEAF and ASPBERGER participants were likely to be functioning at all levels, with the majority functioning at the moderate level. Bipolar and TBI participants were less likely to be in the low function level. Participants diagnosed as Angelman functioned at the lowest level.

ASD participants, more than any other, were just as likely to be functioning at the low ability level as they were to be found moderate to high functioning ability.
JOKE KUJENYA reports:  *Autism is described as a complex disorder that is not caused by bad parenting or spiritual attacks. Of the one in every 88 children born with autism, 80 of them are said to be boys. The disorder, research says, grows from mild to severe given that every child is different and so, it warned that generalist should be viewed cautiously.*

*May 15, 2013*

[thenationonlineng.net](http://thenationonlineng.net)

Autism in Nigeria

- ASD presents a problem of detection in the child and its management is also demanding on the parents, teachers and society at large. Persons affected by this congenital disability are usually misunderstood and coping with routine social and environmental demands can be challenging. –

Lola Odedina, Deputy General Manager and Head, Communication & External Affairs group, GTBank said that the major challenge facing Nigeria’s management of Autism is the prevalent ignorance amongst the Nigerian populace and thus, this Bank is poised to support interventions geared at ensuring greater access to information and also, provision of an enabling environment for the efficient management of Autism in Nigeria. Furthermore, she said this was the rationale behind the Bank supporting the publication of the 1st ever Autism Information handbook for Nigeria.

See more at: http://www.vanguardngr.com/2010/03/gtb-drums-up-support-for-autistic-children/#sthash.Fx7FzxUM.dpuf
Mayo Clinic reports that a stigma is when someone judges you based on a personal trait. Unfortunately, this is a common experience for people who have a developmental or physical disability, and/or mental health condition. Stigmas may be obvious and direct, such as someone making a negative remark about mental illness or intellectual capacity. Or it may be subtle, such as someone assuming the individual could be unstable, violent or dangerous because they may have a mental health or developmental disability condition. Some of the harmful effects of stigma can include:
Some of the harmful effects of stigmas can include:

- Discrimination at work or school
- Difficulty finding housing
- Bullying, physical violence or harassment
- Lack of understanding by family, friends & community
- The belief that they will never be able to succeed at certain challenges or that they can't improve their situation

Mayoclinic.com
Historical Factors in Stigmas: African –African American Issues

- Similar to other ethnic groups
- Belief in supernatural factors as causation for abnormal behaviors
- Spiritual issues for birth defects:
  a. causes from bad actions
  b. cause inflicted from some one
  c. belief that cures to defect/behavior problems/mental health/intellectual disorders can be found in spiritual realm
- Family blames female for trouble related to birth defects
UN Secretary General’s Report on Violence against Children against Disabled Children

- Report found that while all children are at risk of being victims of violence, disabled children find themselves at significantly increased risk because of stigma, negative traditional beliefs and ignorance.
- These Violence are of two Sources:
  1. Violence within the household
  2. Sanctioned by society
Participants Queuing to attend Workshop
Lead Symposium Presenters
Presenters at Press Conference
What We have Found/Accomplished

- In the five years we found
  - More people open to bring their children into public places
  - Willingness to learn about Autism
  - A need to separate the different groups..
  - A Need for more governmental intervention

- A Bill past in Nigerian congress to focus on Children with special needs.
What We Would Like to Accomplish

- Health Mobile to go into the Rural Areas to
  - have children screened for Neuro-developmental disorder
  - Promote inclusion of children/people with neuro-developmental disorder into the mainstream society
  - identify and assess the different groups...ASD, Asperger, etc.
  - Reduce stigma associated with ASD and related disorders
- A Resource Center to
  - Offer information and screening tools
  - Workshops for parents and caregivers
- ASD focused research