Pan-African Experiences of Autism: Transforming Rights into Reality

Report of Conference held at:

The British Council, Freetown, Sierra Leone, December 2017

Organised by Stepping Forward and Disability Africa with The British Council, Freetown, Sierra Leone
Marking The UN International Day Of Persons With Disabilities 2017

Pan-African Experiences of Autism: Transforming Rights into Reality

4 & 5 December 2017
The British Council, Freetown, Sierra Leone

Organised by Stepping Forward, The British Council Sierra Leone and Disability Africa

Conference Partners

Stepping Forward works to facilitate and accelerate access to essential services, information, resources and life opportunities so that all people affected by disability can live a full life.

The British Council builds trust and understanding between people worldwide by enabling them to share ideas and knowledge. The office in Freetown has been in operation for 75 years. The British Council/DFID co-funded Connecting Classrooms programme focuses on inclusion as a major area of policy interest.

Disability Africa exists to improve outcomes for disabled children by providing community-based services and building more inclusive communities.
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1 Executive Summary

The Pan-African Experiences of Autism: Transforming Rights into Reality Conference was convened by Stepping Forward UK, The British Council Sierra Leone and Disability Africa to mark the United Nation’s International Day of Persons with Disabilities 2017. The theme for IDPWD was ‘Transformation towards a sustainable and resilient society for all’ and the event aimed to act on previous calls by the UN Secretary-General to focus on autism globally, ‘to address stigma, lack of awareness and inadequate support structures’.

Globally many autistic children and adults are living difficult lives, denied education, support and acceptance, and often prevented from participating in family and community life. In resource-poor settings in particular, the lack of opportunities for support and education, accompanied by the profound and isolating stigma that can accompany disability, can put individuals and families in intolerable and often dangerous situations. This practical conference was aimed at developing working partnerships to transform rights into reality. The conference brought together a selection of best practice and perspectives from African countries, with the aim of providing opportunities for individuals, organisations and others to share experiences, information and to plan genuine strategies for transformative action.

The event was expertly chaired by Martyna Foday of Freetown Teachers College. Martyna’s professional role as Distance Education Manager, supporting rural teachers in isolated villages, offers her a unique insight into the hidden lives of children with disabilities in Sierra Leone. Simon Ingram-Hill, Director of The British Council Sierra Leone, which hosted the event, outlined the organisation’s commitment to equality and diversity and in particular its work around education and inclusion. Disabled people are often marginalised and excluded from quality education and inclusive education, in particular, is not always available to those who need it: children may not start school at all and are more likely to leave school early. An inclusive education can provide the mechanisms for educational development across the school system and so raise standards and attainment for all pupils, whilst also reducing the economic costs of exclusion and marginalisation.

Guy Warrington, the British High Commissioner Sierra Leone, reported that whilst Sierra Leone has taken important steps towards advancing human rights for persons with disabilities - including ratifying the UN Convention on the Rights of Persons with Disabilities in 2010, enacting the Persons with Disabilities Act and setting up a National Commission on Persons with Disabilities in 2011 - little attention has been given to implementing the provisions of the Persons with Disabilities Act. This must change. UK Aid is working in Sierra Leone to address disability issues – including collecting data on the access that persons with disabilities have to critical services including health, education and social protection. This data will be used to build accountability of service providers to the disabled people.

Policy can play a key role in driving forward and enabling social change and Mr Alli-Korosa, Head of Special Needs, Ministry of Education, Science & Technology,
highlighted that the Ministry has not yet developed a policy aimed directly at special education. Policy can lead to the allocation of resources and he stressed that the training of teachers and the supply of teaching and learning materials are crucial in the establishment of inclusive education. Dr Abs Dumbuya, Chief Executive Officer of The Dorothy Springer Trust and Chairman of Freetown Cheshire Home shared some of his experiences as a disabled person in Sierra Leone and in the UK in relation to affecting policy, legislation and implementation. As well as the national policies, Abs underlined the importance of the Sustainable Development Goals and the commitment within the SDGs to reach people with disabilities which we can all use to push for greater change in our societies.

The need for awareness-raising particularly among rural communities was raised by Rugiatu Koroma, human rights advocate & former Deputy Minister of Social Welfare, Gender & Children’s Affairs. Rugiatu shared stories of families and villages taking decisions to stop feeding disabled children, of phone calls to the Ministry to say ‘we have a child here who can turn into a snake’ – who is later found to have epilepsy – and the tendency to turn to alternative treatment when faced with disability or illness. Families who are bringing up children with disabilities need a range of support – social, financial and access to services. Rugiatu stressed the need to continue with the development of appropriate services and strong advocacy to ensure that the rights of people with disabilities can be genuinely met in Sierra Leone.

The conference was punctuated throughout by stories from parents and carers. We heard from Dr Virginia George who shared her experiences of bringing up her autistic daughter: we heard of the stigma, the hostility and accusations ‘that you are not religious enough, that your child’s condition is atonement for sins you may have committed; that the child herself is demonic.’ Working with qualified and experienced health specialists enabled Dr George to understand her daughter’s condition better and learn how to support her. Exploitation and violence are too often the daily realities for many autistic people. Osman Mansaray spoke about the carer’s role that he took on after the death of his parents, and the challenges of keeping his autistic brother safe from harm and exploitation. His brother Dauda has not received payment for his labouring job for many years but still wants to go to work. When he walks around in the community he is taunted by people and often physically attacked. Awareness-raising plays a central role in in creating safer communities for people with autism and learning disabilities.

The lack of knowledge and awareness about autism interacts with many other factors in late identification and diagnosis of the condition. Chief Consultant Psychiatrist Dr. Muideen O. Bakare of the Federal Neuropsychiatric Hospital, Enugu, Nigeria provided an accessible overview of the current situation of autism in Africa. Continuous education to increase knowledge and awareness about autism is required in African communities to enhance early recognition and interventions for affected children. Research findings suggest that etiology of autism is still being explained by supernatural causes (Bakare et al, 2009b). In Africa, witchcraft, demonic afflictions, evil spirits possession are common acceptable mode of explaining etiology of autism and other childhood neurodevelopmental disorders.
Autistic children, teenagers and young people need additional help and support with education. Some will need highly-specialised education, others will follow a more mainstream path. Andy Nowak of Queensmill School, an autism specialist school in London, shared some of the educational approaches and systems of communication in use at the school. None of these approaches would have an impact, Andy stressed, if we did not approach all of our work with acceptance and love for the child. In all settings, an individual will not thrive and develop without these two key integral components being in place. As we discuss services, resources and educational approaches that are not yet available in Sierra Leone and other countries, it is important to remember that we can start today to help autistic children to learn by first of all accepting and showing love to them. The case for inclusion was outlined by Dr Tsitsi Chataika of the University of Zimbabwe with the sharing of multiple practical strategies - recognising that learners with autism need a variety of interventions to thrive in the inclusive classroom. Like all successful strategies, inclusion requires investment: resources, high quality training, cooperation with home and regular evaluation are all essential for inclusion to be genuinely effective. These sentiments were echoed by Angela Hennelly, Director of the British Council Tanzania, who found that only one school would accept Lola, her autistic daughter, when she moved to Tanzania. That school had a commitment not to exclude any child, as a result of special needs training undertaken by the Headteacher; with the help of a teaching assistant she was included in the school. 

Local autism organisations are starting to develop in Sierra Leone: John Koroma spoke about the Sierra Leone Autism Council, which was founded in 2016. The Council works with a network of partners to promote autism awareness and advocacy. The Sierra Leone Autistic Society (SLAS) is working on multiple fronts to support access to education and to health care, to raise autism awareness nationally and to provide direct support to families. In 2017 SLAS opened the first autism school in Sierra Leone; the Browne-Penn Special School uses multiple approaches - sensory play, motor skills development, art therapy, physical education alongside community visits – and has been overwhelmed by families wishing to register their children. Dr. Dawn Cooper-Barnes of The Autism Society of Liberia talked of her experiences accessing quality support for her son whilst living in the USA and of working with other parents to provide support in Liberia. The training to improve Liberia’s mental health services provided by the Carter Center has been a key achievement in the development of services for children and adolescents living with autism. Mental health workers are being trained to provide community-based help for families dealing with the difficult issues surrounding developmental conditions and issues of abnormal behavior associated with autism. Low cost methods, built on existing health service infrastructures, can play a key role in providing access to health care.

Mary Penn-Timity’s powerful speech began with a list of some of the names that she has been called since she had a child with autism: ‘I am a witch; I am the mother of a devil child; I did not take blessing from my husband’. Seeking support and advice in Sierra Leone had been challenging; staff in government departments had not heard of autism and it was not easy to find a doctor who knew about the condition. These experiences and her background in education are enabling Mary to advocate for the
rights of autistic children and adults in Sierra Leone and to work with a number of organisations on the development of services.

Umu Bentil, mother of a young autistic woman with intellectual disabilities, offered words of support to parents and carers: ‘Hold your child close and don’t let anyone tell you that your child should not be cared for’.

This was a practical conference aimed at developing working partnerships to transform rights into reality and priorities for action were discussed in detail. The value of play was highlighted by Disability Africa as an immediate intervention of value: it can end isolation, play centres can be set up with few skills and minimal expenditure and the benefits of the stimulation, socialisation and integration that comes through play are backed up by extensive research.

The role of civil society, of NGOS and other agencies, was highlighted, with experience shared by the Autism Society of Liberia and the Epilepsy Association of Sierra Leone. A successful strategy should focus on capacity-building at all levels of society to address abandonment and deliver fast and appropriate responses to those at risk; awareness-raising to counteract stigma and advocacy involving the full participation of autistic people.

The workshop on education highlighted the need for a national autism training programme for teachers, a strategy of support for parents, and the need to address the very poor teacher/pupil ratio experienced by many African countries. An interdisciplinary collaboration of professionals and parents, involving speech therapists, education psychologists, teachers, physiotherapists, should be available to support the child each step of the way.

Support for parents and carers is urgently required – in terms of respite through day centres, appropriate high-quality schooling and training for parents to understand autism in order to able to offer the best support to their children. Regular parent/carer support groups reduce social isolation, provide tools for supporting autistic children and essential peer support for carers. Free medical support at the point of need for children with autism would ensure that the right to health care is met.

Research on autism in Africa is very limited. Understanding the detailed context and the challenges faced by diverse communities across Africa will enable the development and the targeting of services and increase the impact of interventions. A range of methodologies will be required, with work taking place across multiple sectors – in education, health, social care and at the community level. Detailed needs analyses enable organisations and governments to make the case for funding, support and technical assistance and should form part of any autism strategy that is developed.

There is no doubt that the task ahead is huge. All partners are committed to taking forward outcomes from this conference and welcome further engagement with organisations and individuals to ensure that the commitment to action to raise awareness of autism and to develop appropriate autism services can go from strength to strength.
Introduction, Sarah Snow of Stepping Forward UK

The Pan-African Experiences of Autism: Transforming Rights into Reality two-day event was held to mark the International Day of Persons with Disabilities. We are grateful to the British Council for coming on board so entirely with this event and for ensuring the involvement of Dr Bakare from Nigeria and Dr Chataika from Zimbabwe.

We were delighted to have a mixture of skills and experience at the event. Some of us were new to autism, some of us had lived experience of autism – and of the stigma which often accompanies this - others had practical & professional experience of supporting autistic people in the community. We are grateful to Martyna Foday of Freetown Teachers College for chairing the Conference and supporting our presenters, many of whom had not shared their stories before this event.

I was particularly delighted to see so many parents and carers at the Conference, particularly from the Hosetta Abdullah Special Needs School and the newly opened autism school, the Browne Penn Special Education School. As a parent of an autistic son who is not functionally verbal and not able to communicate to us how he sees the world, it can be a struggle to know if the support and encouragement that we offer is appropriate and helpful. There is a young Japanese man, Naoki Higashida, who is autistic and unable to speak but who communicates effectively through a keyboard-like system. His writings can help us to understand what his world might be like. For me his words serve as an important reminder not to make assumptions about how my son sees and understands the world. One of the messages that Naoki says in a number of ways in his first book, written when he was 13, is ‘Don’t give up on us, even though we know it is hard for you. It is even harder for us’. In his latest book, published this year, he writes as a young man of 23 and his words have relevance to the core themes of this conference.

“The public need to know that the failure of people with autism to communicate doesn’t stem from inner self-imprisonment; it stems from a failure of others to see that we are open and receptive. To venture out into the world requires help from other people. Please lend us that support as we strive to live in society. “

I hope that we will quickly move forward to build on the findings of this Conference, continuing to plan together how we can work with autistic people and support them to live lives free of stigma and violence and in which the right to a family, a community and to education are secured.
3 Conference Background & Context

There are very few studies on autism in the African context but it is clear that specialist autism support services are limited across the continent - and in some areas are non-existent. Just 53 publications were identified in a recent review of research into autism in Africa (Franz et al, March 2017), but findings suggest a substantial need for large-scale clinical, training, research and awareness-raising programmes to improve the lives of people who live with autism in Sub-Saharan Africa. The UN Secretary-General has urged the international community to focus on autism globally, ‘to address stigma, lack of awareness and inadequate support structures’.

Globally many autistic children and adults are living difficult lives, denied education, support and acceptance, and often prevented from participating in family and community life. In resource-poor settings in particular, the lack of opportunities for support and education, accompanied by the profound and isolating stigma that can accompany disability, can put individuals and families in intolerable and often dangerous situations.

Generating Support & Action for Change

To genuinely improve the everyday lives of people living with autism there is an urgent need for increased support for awareness-raising programmes – and for sharing the latest developments in good practice, including in education, in research and in social care. As elsewhere, this complex process of social change necessarily involves multiple agencies - within the education sector, at NGO level, from within the community and at government policy level.

This practical conference was aimed at developing working partnerships to transform rights into reality. The conference brought together a selection of best practice and perspectives from African countries, with the aim of providing opportunities for individuals, organisations and others to share experiences, information and to plan genuine strategies for transformative action.

The event explored how we can strengthen, support and widen best practice and what research needs should be prioritised. Attendees began to identify resources and to form partnerships to build capacity in education, training, social care, awareness-raising, as well as to form autism-specific networking forums in Sierra Leone.

We look forward to continuing this urgent process of transforming rights into reality with autistic people and their families in Sierra Leone.

Sarah Snow, Stepping Forward UK
4 Conference Papers

4.1 Opening Comments: Simon Ingram-Hill, Director British Council Sierra Leone

We are meeting the day after the United Nation’s International Day of Persons with Disabilities which has been celebrated every year for the last 25 years. This year’s theme is ‘Transformation towards a sustainable and resilient society for all’: each country celebrates the theme in different ways, and this year the British Council in Sierra Leone has chosen to mark it through this conference on autism with our partners. It is a privilege to engage with an area that I have no professional expertise in and little personal experience of but which is an area that goes to the heart of the diversity and inclusion work of the British Council.

The UK – through government, private sector civil society and community initiatives - has done a lot in recent years to tackle disability in its many manifestations through policies and action. The success of the 2012 Paralympics in London, was one example of how disability by no stretch equals inability. Last Thursday the new Secretary of State for International Development Penny Mordaunt in her first speech, announced the first ever Global Disability Summit in London to be held in July 2018. In her speech she said, and I quote “For too long many people living with disabilities in the world’s poorest countries have not been able to fulfil their potential due to stigma or a lack of practical support. They are, for example, missing out on school and the chance to work. Discrimination is unacceptable in today’s society. I want us all to act now and break down the barriers people with all disabilities face in their everyday lives, so they are not short-changed on opportunities to use their entrepreneurial spirit to help their countries prosper. That’s why I am bringing technology companies, governments and charities together at the UK Government’s first-ever Global Disability Summit in London in July 2018, to show our commitment to transform the lives of people living with disabilities”

Last year’s theme for United Nation’s International Day of Persons with Disabilities. Day were the 17 SDGs; four of them the British Council believes are particularly relevant to our work. Goals 4, 8, 10 and 11.
SDG 4: Ensure inclusive and equality education for all and promote lifelong learning
SDG 8: Decent work and Economic Growth
SDG10: Reduced Inequalities
SDG 11: Sustainable cities and Communities

I won’t focus on 8,10 and 11 here but would like to underline Goal 4 ‘Ensure inclusive and equality education for all and promote lifelong learning’ as this is of particular significance to the work of the British Council in Sub-Saharan Africa.

Every country in the world needs a high-quality, inclusive and equitable school system that supports young people to develop the knowledge, skills and values to live and work in a globalized economy and to contribute responsibly both locally and
globally. At the British Council, we believe that if economies are to be successful and our young people employable – they need to be able to generate and implement new ideas, use digital tools and apply their knowledge to solve real-world problems.

Disabled people are often marginalised and excluded from quality education and inclusive education in particular is not always available to those who need it – they may not start school at all and are more likely to leave school early. An inclusive education can provide the mechanisms for educational development across the school system and so raise standards and attainment for all pupils whilst also reducing the economic costs of exclusion and marginalisation. The British Council promotes the social model of disability, which focuses on identifying and trying to dismantle the barriers to participation that people with different impairments face.

In Sub-Saharan Africa, through our work with schools and the Connecting Classrooms project, we focus particularly on Inclusion in Education. We have already been on quite a journey in the last two years with this work, and Dr Tsitsi Chataika, at the University of Zimbabwe has worked with us a lot in the formulation of our strategy on inclusion. Recently we have carried out some research – and briefly the findings were these:

• In most of the countries the social model of disability is not well understood
• In most of the countries there are some policies and legislation around IE or they are in process of development and knowledge of its importance is not such a barrier but implementation is a challenge.
• Differentiated curriculum and assessments/examinations seem to be a significant barrier to IE in most countries
• It appears that attitude from teachers and parents is a significant barrier to IE in most countries
• Training of teachers and school staff is a significant barrier to IE
• Inability of mainstream schools and teachers to identify various SEN categories is a barrier

I am delighted that the British Council is able to contribute strongly in this conference. In conclusion, the British Council is fully committed to the objectives of this conference. I look forward to the outcomes as it will help us on our own journey in Sierra Leone, in other countries in SSA such as Tanzania and Nigeria and beyond this continent.

4.2 Opening Comments: Guy Warrington, British High Commissioner Sierra Leone

I must first commend the British Council for drawing attention to the important issue of autism and on the occasion of the International Day of Persons with Disabilities I wanted to say a few words on the wider theme.
Sierra Leone has taken important steps towards advancing human rights for persons with disabilities, including ratifying the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2010, enacting the Persons with Disabilities Act and setting up a National Commission on Persons with Disabilities in 2011. Unfortunately little attention has been given to implementing the provisions of the Persons with Disabilities Act. This must change.

Disability is an important agenda for the UK government: the Secretary of State for International Development announced last week that the UK will co-host the Global Disability Summit in 2018 with the International Disability Alliance (IDA). The Summit will bring together the international community to generate commitments to ensure people with disabilities can access a quality education, jobs, healthcare and infrastructure. We will encourage the Government of Sierra Leone to participate in this Summit and to work with us on their commitments to this agenda.

Disability will also be a major theme at April’s Commonwealth Heads of Government meeting in London. The new Minister for DFID is great advocate for your cause as she was previously Minister for Disability.

Here in Sierra Leone, UKAID is working to ensure that all UK aid-funded water, sanitation and hygiene interventions are disability inclusive - including making sure water access points are placed at appropriate height and/or openings (for examples taps) are easy to use, access gates are wide enough for wheelchairs and specific disabled toilets include entrance ramps and support bars for PWD. We are collecting data on the access that persons with disabilities have to critical services including health, education and social protection. We will use this data to build accountability of service providers to these people. We are also pushing hard to make sure that disabled people and other vulnerable groups are fully involved in the forthcoming elections both in terms of access and representation.

We will continue to encourage the Government of Sierra Leone and the entire development community here to step up their work on this agenda, to ensure that persons with disabilities can play a full role in society and contribute to the future prosperity of this country.

4.3 Presentation by Mr Alli-Korosa, Head of Special Needs, Ministry of Education, Science & Technology

By the time we leave here we will have a new knowledge and understanding that will help us to understand autism and relevant support strategies.

When we talk about special needs we often talk about people with different abilities. Special education is providing education for people who are differently abled. We have special schools in Sierra Leone, all of them primary schools, eg for the visually impaired, for the mentally challenged, the deaf and hard of hearing.

The Ministry of Education, up until the point that I am speaking to you, has not developed any policy whatsoever that is aimed directly at special education. I want to
repeat that – we have not had any legislation or policy whatsoever that will address inclusive education. The training of teachers and the supply of teaching and learning materials are crucial in the establishment of inclusive education.

I was attending one school and there was a boy at the back who had visual problems. He would get out of his seat and come down to read the board. The teacher would shout at him – I intervened and asked the boy what was the problem? He said that he could not see the blackboard clearly. I recommended making classroom adjustments which we did and all was OK.

In another class I visited there was a girl who was seated at the back and had a hearing impairment. She turned her head in a particular way to hear better. The teacher was not happy about it. I intervened and suggest that the child is given a seat on the left hand side of the classroom so that the affected ear can be facing the teacher. The situation was thus resolved and we recommended that she was referred to hospitals as appropriate.

We must train teachers, not blame them, so that they are able to incorporate inclusive education. We are carrying out collaboration with MEST and Handicap International on teacher training and we need a policy and a strategy. When funds are available we train and provide learning materials. The Ministry has to have funds to modify the learning infrastructure - toilets, ramps, learning materials etc – all crucial to an inclusive education.

4.4 Presentation by Rugiatu Koroma, Human Rights advocate & former Deputy Minister of Social Welfare, Gender & Children’s Affairs

Yesterday was the International Day of Persons With Disabilities. Sierra Leone did not officially observe this. That tells you how much we need to do on awareness-raising.

In my former role with the Ministry of Social Welfare I was asked to visit a village where there was a young child with a tumour on his face. Whilst we were in the process of exploring what help there was in Sierra Leone or elsewhere for his treatment, the decision was taken in the village to stop feeding him. We used what small money we had collected for the child by that time to carry out awareness-raising in the village and the surrounding areas so that communities better understand disability and can accept and support all children.

Last year I was visiting a village and I saw one very small girl covered in cuts and I asked her grandma, with whom she lived, what was the matter. Her grandma said ‘she has epilepsy. We are waiting for her to go’. Meaning that she is waiting for her to die. I asked if I could take Effah, the little girl, with me, to the nursery and school that we run.

After much deliberation the grandma finally agreed to come with us and help Effah settle in to the school.
Still we have people that cannot accept disability and who contact us saying ‘we have a disabled child here who can turn into a snake’. Then we go to the child and we find out that they have epilepsy.

We need to carry out awareness-raising amongst duty-bearers. We have a responsibility towards people with disabilities. We have an Act of Parliament which outlines our commitment - but that is not enough. This needs to be implemented. How many people with disabilities can access schools and ministerial buildings? We need to enable disabled children and the able-bodied to attend school and other activities together so that they have a sense of belonging and are genuinely part of our society.

In the villages we know that they perform traditional ceremonies to return the children who are not wanted. Do they tell you that by performing the ceremony the children will die? No. They must have something that they do to kill them. They say that they want to perform a ceremony and they go to the cotton tree, they have a white curtain and they have white bread flour that they mix. And this is what they use to make you believe that they will send the children back to where they came from. We need to understand what is happening and stop harmful traditions.

Effah’s grandmother had said that she planned to do a ceremony to say goodbye to Effah. We know what that means. Effah is now thriving at our school, has lots of friends and her learning and development is coming on well.

Families who are bringing up children with disabilities need a range of support – social, financial and access to services. We need trained social workers with practical experience. We need to continue with the development of appropriate services and strong advocacy to ensure that the rights of people with disabilities can be genuinely met in Sierra Leone.

From today, after this day, go back and help to change the perspective and understanding of people. Change their mindset. Let them learn to accommodate people with disabilities so that they have a sense of belonging.

4.5 Parent/Carers Perspective I: Dr. Virginia George, Sierra Leone

Autism Spectrum Disorder (Autism) is a serious brain-based developmental disorder that impairs the ability to communicate and interact. Symptoms vary. Signs of autism may become apparent as early as 2-3 yrs. old or later in adolescence and are not connected to the quality of life of parents or poor parenting. These children may start walking later than other toddlers. ASD is characterised by pervasive developmental disorders and intellectual disability (mental retardation). It reduces the child’s capacity to learn new skills. A child with autism may avoid eye contact, use facial expressions that do not match what he or she is saying. They make few gestures, and react unusually to sights, smell, textures and sound. These children can appear withdrawn, may communicate poorly, may prefer to be alone and exhibit repetitive behaviour. They may lack concentration and may be restless.
Autism is characterised by abnormalities in brain structure or function, therefore these children have a higher co-morbidity burden than the general paediatric population. This simply means that three quarters of children with autism may also have another medical or psychiatric condition such as chronic seizures (epilepsy), they may also be hyperactive as in ADHD.

There is no known single cause of this condition. Causes of ASD could be genetic, birth trauma (lack of oxygen), nutrition disorders, and illnesses such as meningitis, cerebral malaria, and external factors, such as wars, exposure during pregnancy to heavy metals or even stress during pregnancy.

The author of the book “The Reason I Jump”, Naoki Higashida has autism. He describes the individual as one whose faculty of speech is taken away. Explaining that you are hungry, or tired, or in pain, is beyond your powers. The mind may be compared to a room where twenty radios all tuned to different stations are blaring out voices and music. The radios have no off switches or volume controls, the room you’re in has no door or window and relief will come only when you’re too exhausted to stay awake. To make matters worse, there is no editor (ie one’s senses). You are no longer able to comprehend languages – even your mother tongue. Even your sense of time may be gone, rendering you unable to distinguish between a minute and an hour. Autism is a lifelong condition.

Ladies and gentlemen, this is the situation I found myself in 10 years ago when I realised my daughter was not developing as a normal child, a situation of restless, hopelessness and feeling sorry for myself. We sought as a family, from all spheres, mainly religious and traditional. Many would say ‘norto hospital sick’. I recall the nightmare of the Psychiatrist handing down the diagnosis of sub-intelligence etc etc. They did not register in my mind.

The issue of stigma was one of our biggest challenges. Social support (apart from family members) did not exist. Some people would out rightly blame you for not acting early to come to your child’s aid. That you are not religious enough, that your child’s condition is atonement for sins you may have committed; that the child herself is demonic.

Caring for an autistic child has not been easy, it’s not for the fainthearted. The whole period of 10 years has been learning to care for her. She had to be withdrawn from school for normal children. The lack of communication made it difficult to know what could be going through her mind especially when restless. We would blindly, as it were, try to diagnose the problem, risk administering one medication or another and sometimes end up getting it all wrong! You restart the diagnostic process in a state of utter confusion and spend long harrowing hours seeking relief which could be so evasive.

The experience is not one of perpetual doom. The patient can manifest love and care. She can observe that you are tired or sweating and feel morally bound to assist. Due to the attendant stigma and misconceptions, others – neighbours and other acquaintances - tend to dissociate with the problem and keep ‘a discreet distance’. In some cases, they demonstrate a hostile response.
As a parent, my plight has been cushioned by the fact that I have been trained and involved in providing health care to patients with epilepsy. My interaction with organisations like EASL, ILAE -St, Medical Assistance Sierra Leone and Stepping Forward – a UK based NGO has also helped greatly. These organisations in the past 5-7 years have been engaging in awareness raising, through sustained mass media and other education (formal and informal), about mental health, with a view to reducing stigma and hostility from the public generally.

Our country has a special needs school but unfortunately, we did not benefit from the services of this institution as the school had a lot of constraints and was hardly functioning.

I was fortunate to benefit from training for medical officers, selected from all districts in Sierra Leone, since our government has integrated CAMH care into Primary Health Care. This training helped me to understand my daughter’s condition and to better manage it.

May I take this opportunity to use this forum to appeal to our government to improve on existing policies and put in place effective implementation mechanisms to actualise a more tangible and practical manifestation of social support for patients with autism.

In conclusion, we must bear in mind that some autistic children can develop into outstanding assets to their societies and to their country.

4.6 Current Situation of Autism Spectrum Disorders (ASD) in Africa, Dr. Muideen O. Bakare, M.B.B.S, FMCPsych, MNIM

Historical Evidence & Prevalence of ASD among African Children living in Africa
First Report of ASD globally was by Kanner in 1943 (Kanner, 1943). Three decades later in 1970s, Lone (1976) and Lotter (1978) reported ASD among African Children in African continent, covering countries like Ghana, Nigeria, Kenya, Zimbabwe, Zambia & South Africa. In 1970s, the rough prevalence of ASD in Africa was about 0.7% among children with Intellectual Disability (ID) (Lotter, 1978).

Prevalence of ASD among African Children Living in Africa: Recent Pockets of Studies
Seif Elden et al (2008), though an Arab Study involves two Northern African Countries (Tunisia & Egypt). Prevalence of ASD were 11.5% and 33.6% among children with developmental disabilities in Tunisia and Egypt respectively (Seif Elden et al, 2008). A Hospital Based population study in Nigeria found prevalence of ASD
to be 0.08% (Bakare et al, 2011) - most likely influenced by low help seeking behavior for Childhood Neurodevelopmental Disorders (NDD). Prevalence among School Children with Intellectual Disabilities in Nigeria was 11.4% (Bakare et al, 2012).

**Prevalence of ASD among African Children Living Outside Africa**

Notable Studies are from African Immigrants living in Sweden:

- The prevalence rates of ASD among children of African immigrants living in Sweden were consistently higher when compared with prevalence of ASD among indigenous Swedish population.

- For instance, Gilberg et al (1995) reported a rate of 15% (200 times greater than that of the Indigenous Swedish Population) of ASD among children of African mothers residing in Sweden but who were born in Uganda.

The reasons for the higher prevalence of ASD among African immigrants outside the African continent are not clear yet, but such findings may be related to the Vitamin D etiological hypothesis of ASD among other reasons (Grant & Soles, 2009; Bakare et al, 2011b).

**Characteristic Features of African Children with ASD**

**Age of Onset:**
Period of onset of ASD symptoms among African children coincide with the period of less than five years that is characterized by vulnerabilities of African children to physical illness and infectious diseases associated with neurological complications such as cerebral malaria, meningitis among others. Mankoski et al (2006) reported that onset of ASD followed recovery from infection/physical illness in about 50% of the studied population of Tanzanian children. Symptoms of Stereotypic repetitive repertoire of interest / behavior may be less common among African children with ASD (Lotter, 1978, 1980, Bello-Mojeed et al, 2017).

There are excess of non-verbal cases over verbal cases in clinical population of African children with ASD presenting to orthodox medical practice (Bakare & Munir, 2011a; Bello-Mojeed et al, 2011) - indicating that the most severe spectrum of ASD is diagnosed mostly in Africa.

**Intellectual Disability and ASD among African Children**

Studies originating from Africa among African children with ASD suggest that intellectual disability is the commonest co-occurring diagnosed condition among the children (Lotter, 1980; Mankoski, 2006; Belhadj et al, 2006; Bakare & Munir, 2011b). Diagnoses of ASD in Africa is therefore rarely made exclusively of Intellectual Disability (Bakare & Munir, 2011b).

**Other Co-morbid Conditions among African Children with ASD**

Other documented co-morbid conditions among African children with ASD include seizure disorder (Lotter, 1978; Belhadj et al, 2006; Bello-Mojeed et al, 2011), oculocutaneous albinism (Bakare & Ikegwuonu, 2008) among others.
Identification and Diagnosis of ASD among African children

Late diagnosis had been found to characterized ASD and other Neurodevelopmental Disorders (NDD) among African children despite early parental concerns about development (Bakare & Munir, 2011a). Possible factors identified as being responsible for late diagnosis of ASD include:

- Poor knowledge/awareness about ASD (Bakare et al, 2009a; Igwe et al, 2011).
- Negative cultural beliefs and practices (Bakare et al, 2009a)
- Tortuous pathway to care/help-seeking behavior (Bakare & Munir, 2011a).
- Inadequate number of trained healthcare personnel and intervention facilities in Africa (Bakare et al, 2009a)

Poor Knowledge and Awareness about ASD

Review of literature reveals low level of knowledge and awareness about ASD among African parents and healthcare workers (Bakare et al, 2008; Bakare et al, 2009a; Igwe et al, 2010; Igwe et al, 2011). Lack of knowledge and awareness about ASD interacts with many other factors in late identification and diagnosis of ASD.

Continuous education to increase knowledge and awareness about ASD is required in African communities - this would enhance early recognition and interventions for affected children.

Negative Cultural Beliefs and Practices

Research findings suggest that etiology of ASD is still being explained by supernatural causes (Bakare et al, 2009b). In Africa, witchcraft, demonic afflictions, evil spirits possession are common acceptable modes of explaining etiology of ASD and other childhood neurodevelopmental disorders (NDD). Individuals with ASD and their families are often faced with discrimination and rejection, negative and derogatory comments, further promoting stigma and social exclusion.

To avoid stigma, parents tend to hide away affected children from the society by locking them up in the house. This may lead to late presentation and diagnosis of ASD among African children.

Tortuous Pathway to Care & Help Seeking Behaviour

With a background of supernatural etiological explanations for ASD, families of children with ASD often go through a tortuous pathway in search of spiritual help through traditional and religious healers before seeking help from orthodox clinical practice in Africa (Bakare & Munir, 2011a) – Figure 2.
Inadequate Trained Healthcare Personnel in Africa
Primary health care workers in Africa do not routinely undergo training in identification of neurodevelopmental disorders (NDD) such as ASD. The relatively few physicians equipped with some knowledge about NDD are those with specialization in medical fields such as Psychiatry, Paediatrics and Neurology. Inadequate trained personnel contribute to late diagnosis and interventions for African children with ASD.

Inadequate Healthcare Facilities and Intervention Centres
Compared with most western societies with trained professionals, better access to child care facilities and available intervention services, African children are seriously underserved, and have limited access to the few available child health care facilities for ASD (Bakare et al, 2009a; Bakare & Munir, 2011a).

Documented benefits of early identification of ASD include early entry into appropriate treatment programs with the aim of improving developmental outcomes such as language, social, cognitive and motor skills.
Multidisciplinary & Inter-disciplinary Management

The objective is to ameliorate impairment in the three domains of social interaction, communication and stereotypic behavior.

- Behavioral modification: Applied Behavior Analysis (ABA), Positive reinforcement; Prompting; Shaping & breaking down complex task into steps.
- There are communicative functions of difficult behavior - Difficult Behavior may be meant to communicate needs & wants of a child in language deficit.
- Teaching and Special Education: Should be tailored to individual child. May be home based or school based.
- Communication skill programs in Language Deficit: Sign Language; Computer generated pictures; Photographs. All these are aimed at symbolizing desire or needs.
- Social Skill Training: Examples include, Picture script; Social skills group.
- Pharmacotherapy: As indicated in treating associated behavioral problems like; Aggression, Disruptive behavior, Mood disorders, Attention deficits hyperactivity symptoms & Self Injurious behavior.

Special Education Facilities in Sub-Saharan Africa for Children with ASD

Most special education facilities in Sub-Saharan Africa focus largely on physical disabilities like blindness, being deaf/dumb among others. Bello-Mojeeed et al (2016) in a recent clinic-based study noted that majority of referral of ASD cases to orthodox clinic are from normal mainstream schools and these children are usually referred within one year of schooling when they are unable to cope. Many of these children so referred to the clinic are usually out of school without educational intervention due
to lack of suitable schools to meet their educational needs (Bello-Mojeed et al, 2016). Lack of requisite skills among Sub-Saharan African teachers to manage the disabilities associated with ASD is also contributory, implying the need for further focused training among teachers (Bello-Mojeed et al, 2016). Studies have suggested that many of affected children do not have access to any form of education (Bakare & Munir, 2011c), while educational attainment for the rest are limited.

An interaction between severity of symptoms, associated intellectual impairment and ingrained stigma in Africa are contributory to the observation of a low level of educational attainment among children with ASD.

**Collective Vs Individual Approach to Learning**
Normal mainstream schools in Sub-Saharan African countries have a tailored curriculum focused on Collective Learning, rather than emphasizing and focusing on the strength of individual child. While Individual Approach to Learning is largely recommended for Children with ASD, there is need for policies across Africa to incorporate such into the Mainstream Schools to promote Community Inclusion.

**Low Educational and Vocational Attainment among Adults with ASD and Community Development**
It is a likely trend that children with ASD that had little or no education opportunity are not going to fit into specific vocational ventures as adults, negatively affecting their contribution to general community development. Community perception of stigma also reduces community inclusion and thus reduce opportunity for Adults with ASD to contribute positively to their society.

**Summary**
- Despite worldwide reports of increased prevalence of Autism Spectrum Disorder (ASD), there is no large-scale community based epidemiological data on ASD in Africa.
- Recent studies on ASD among African children with intellectual and developmental disabilities suggest an increase in prevalence of ASD in Africa. However, there is need for a population based epidemiological study of ASD in Africa to confirm this trend.
- Period of onset of ASD symptoms among African children coincide with the period of less than five years that is characterized by vulnerabilities of African children to physical illness and infectious diseases associated with neurological consequences.
- When compared with children in Europe and North America, it has been observed that stereotypic repetitive repertoire of interest/behavior may be uncommon among African children with ASD. Large scale community based epidemiological study is needed to confirm this observation.
- There is an over-representation of non-verbal cases of ASD among African children presenting to orthodox medical facilities. This lack of or limited expressive language ability could be related to late intervention,
resulting from late presentation/identification of ASD among African children.

- In Africa, it has been observed that ASD is rarely diagnosed exclusively of intellectual disabilities – An observation that suggest that the severe spectrum of ASD are often presenting to orthodox medical practice in Africa.
- There is a wide gap between age of onset of symptoms and diagnosis of ASD in Africa. So, diagnosis of ASD has been observed to be late among African children.
- Possible factors identified from the literature that are associated with late identification of ASD in Africa include: Poor knowledge and awareness about ASD, negative cultural beliefs and practices, tortuous pathway to care and help-seeking behavior, inadequate number of trained personnel, inadequate healthcare facilities.
- There is scarcity of intervention programs for children with ASD in Africa. The few available services are very expensive with huge unaffordable cost to most of the parents of affected children.

Research funding for childhood neurodevelopmental disorders (NDD) needs to get some more priority in Africa as more African children survive beyond the age of 5 years.

Ways Forward
Future direction should focus on:

- Defining the magnitude of the problem of ASD and intellectual disability and needs assessment for affected individuals in Africa through a well implemented epidemiological study.
- Genetic and environmental studies as it influences ASD and intellectual disabilities in Africa are of importance in understanding the risk factors.
- Capacity building in terms of training for healthcare personnel, promoting human resource development in interventions for ASD and intellectual disability in Africa.
- Full implementation of existing legislations and passage of pending Bills that would promote education and employment opportunities for people with intellectual disability and ASD in Africa.
- Social policy formulation should address financial aspect of healthcare and special education provision for individuals with ASD and intellectual disability since this is not presently covered by any social policy in majority of African countries.
- Lastly research and social policy direction should focus on massive public health education to positively influence help seeking behavior for children with ASD and intellectual disability, which often leads to late diagnosis and interventions.
Conclusions

- Late identification of ASD is a common observation among African children.
- Late identification of ASD among African children suggests the need to intensify effort at addressing associated factors to improve overall prognosis.
- It is important to improve assessment and diagnostic services for ASD and increase the level of knowledge and awareness of parents and health care professionals about ASD in Africa through continuous massive education.
- There is need to provide enabling environment for training of different professionals that will be involved in multidisciplinary approach of managing African children with ASD.

4.7 Parent/Carer Perspective II: Osman Mansaray

My younger brother Dauda was born in 1989 and has autism and learning disabilities. He is now 28. Our parents died, and my brother lives with me. I take care of him. People constantly provoke and beat my brother when he is out in public.

During the Ebola time he was given some practical tasks to help at a local health centre, but despite him working for many months he was only paid for one month. After the Ebola crisis he was invited to stay on at the health centre where he is to this day. After several years of going there each day they have not once paid Dauda. When I intervened and said that they need to stop abusing him and pay him some money, my brother was very upset with me that he cannot go there anymore to help. So, we had to let him go back as he was unhappy.

I am frustrated that people take advantage of my brother and don’t help him to get a job where he can get paid and he can be accepted. Proper help is needed in this area. I am responsible for all his food, clothing and other necessities.

4.8 Autism Understanding & Educational Support, Andy Nowak, Queensmill School, UK; Volunteer Adviser, Disability Africa

It is not possible to go into a huge amount of detail today, given the short time-scale available, but my aim is to highlight key characteristics of autism for those who may not have had much contact with autistic children or adults. I will then share with you some videos from the autism school where I teach and explore how staff there support autistic children in their learning and development. Let us start with looking at autism:
What is autism?
- A recognised condition
- Life-long – there is no cure
- A different way of experiencing the world
- Wonderful, amazing and full of potential

Autistic people find the following difficult:
- Communication (using and understanding language)
- Imagination
- Interaction (being sociable)
- Change and things that are new
- Understanding their senses

How can we support autism?
- Try to understand how autistic people experience the world
- Patience and calmness
- Empathy
- Change what we do to meet what autistic people need
- Like and love them for who they are
- Celebrate what they can do

Autism presents itself in multiple ways. At the school where I teach we have over 300 students, most of whom would be classed as having ‘severe’ autism. Their support needs are multiple and in the following videos I will share how our staff team work with the students to meet their needs, using diverse approaches which put the child or young person at the centre of all support.

Andy shared videos of autistic students at the school in various situations; the videos showed staff interacting with students with a range of needs. Some students were non-verbal; some were in distress; some needed support and direction to follow instructions. Staff modelled positive support and encouragement, responding to the needs of students and ensuring their safety and well-being at all times. Andy then led an insightful discussion on what can be learnt from the videos, showing how different each child is and how much they can tell us about themselves and their needs if we look closely.

We met Niyi
- He has different interests
- He likes to explore his environment using touch
○ His noises show he is happy and content
○ He finds movement enjoyable

**We met Mardon**

○ He can talk
○ He is well dressed and able to learn at school
○ He needs movement and flapping
○ He finds it hard to imagine and so flaps to stay calm

**We met Kyle**

○ He cannot talk and shows he is upset through noises
○ He doesn't like change
○ He is not motivated by structure or rewards
○ He calms down after kindness and patience

**We met Ella**

○ She does not make eye contact with adults
○ She needs lots of help to learn (gentle hand over hand)
○ She wears ear defenders as she does not like loud noises
○ Ella is experiencing a world different to ours

Whilst there are lots of educational methodologies and approaches and systems of communication that we use at the school, none of them would have an impact if we did not approach all of our work with acceptance and love for the child. In all settings, an individual will not thrive and develop without these two key integral components being in place. As we go forward in the next two days and are reminded of services, resources and educational approaches that are not yet available in Sierra Leone, it is important to remember that we can all start today to help autistic children to learn by accepting and showing love to them. This is the first step of all educational and development journeys and I hope that by reminding ourselves of this we can start today to improve the lives of autistic children - and not wait until such time as resources become available.
4.9 The Work of the Autism Council of Sierra Leone, John Koroma

Background
Sierra Leone Autism Council, founded in April 2016, is a programme of Stop It-Sierra Leone that works with a network of partners in autism awareness and advocacy and providing a variety of programmes and services that help to develop social and physical solutions. Our programmes are designed to share with participating organizations that work for autism. These organizations work to transition autism from the backyards to the door steps of communities onto the corridors of power. Our partners mostly learn and share about:

1. A history of autism in Sierra Leone from various sources,
2. Benefits of Partnership for autistic persons

Through collaborative relationship with local and international organizations and businesses, etc, we have placed ASD issues in the spotlight and this has helped to provide a renaissance about the condition in both the private and public sectors.

Those who are not ready for autism action are still being pursued and encouraged especially the Government of Sierra Leone, to place priority of ASD on the national development agenda and to address it on a national scale with local and international partners on board.

Organisational Network
We hold several meetings each week with various partners and organizations that work alongside autism affairs or have interest in autistic issues and discuss a variety of issues that help autistic people develop social and physical skills.

There are hundreds of local families in Sierra Leone going through similar experiences in raising an autistic child, with many more than you realize…right here in our community.

Working with partners such as Enable The Children, Browne-Penn School etc, who are providing family and sibling support and special needs education to children with autism respectively, has been a great experience and this is helping us to change the environment’s viewpoint about ASD towards three things: ACCEPTANCE, INCLUSION and ACCELERATION.

Acceptance
Today, more than any other time before, we need to inform all families to accept and support autistic persons in every community. Please support them by helping them to bond with friends, brothers, neighbours etc so they can feel accepted and stop discriminating them, or isolating them in corners, or tying them to sticks as if they are animals, etc.

Inclusion
When Evelyn Bockarie, a carer working with Enable The Children, came to us and spoke about her son being autistic and the struggles she goes through raising him with such a condition that is extremely misunderstood in this part of the world, we
wondered how we may help her. The best way for us was to give her a platform and include her in our campaign. Today, Bockarie and her son are showing great strength of sustaining the campaign. This tells us that inclusion and participation has far more reaching impact in the fight to make Autism work than when we dissociate from or discriminate people.

**Acceleration**
We need legislation that addresses the several critical challenges facing the autism community in Sierra Leone, including funding for scientific research, therapeutic treatment and services. Autism Sierra Leone Council and its partners will not relent to advocate for adoption of laws in the next parliament of the Republic of Sierra Leone to incorporate ASD in the health programmes of the country.

**Community Action**
We have been talking, but community action is very important here to sustain our campaign for autism and chiefs are implored to take the lead to provide support by issuing authority to stop first the discrimination against autistic persons now, and to bring all those families together in a supportive environment.

With community action, we can help siblings understand autism, further introduce techniques to encourage interaction and bonding with their siblings.

We also offer other programmes that may be of interest including:

**Autism Educational Assistance**
To facilitate the work of people dealing with autism, we have initiated Autism Educational Assistance through fundraising programmes to support children with special needs gain education at Browne-Penn, the first established Special Education School for autistic children in Sierra Leone.

These and many other programmes coming would support children affected by ASD to go to school.

To become a member, please visit our office at: Ground Floor, East Wing, 17 Off Kingharman Road, Brookfields, Freetown. Tel: +232-76-482792 / +232-30-717611 Email: stopitsierraleone@yahoo.com

4.10 The Sierra Leone Autistic Society & The Browne-Penn School, Freetown: Alice Browne and Mary Penn-Timity

**Sierra Leone Autistic Society**
The mission of the organization is to enhance the well-being of people living with ASD, their parents and care givers, through advocacy, empowerment, research, training and bio psychosocial (health, psychological and social), as well as educational support. The organisation was set up by two women with extensive experience of disability and social work. Alice Browne is a graduate social worker with a primary concentration of clinical and a secondary concentration of management and community organization.
with specialization in Families and Children. She is also a licensed mental health therapist with extensive years of experience working with families and children. Alice also has a degree in psychology with extensive trainings working with special needs children.

Mary Penn-Timity is a Biological Science (BSc Pharmacology with Immunology) graduate, with a post-graduate certificate in analytical chemistry. She has a Masters degree in social work with specialization in Mental Health and children and families. With regards to autism and special needs, Mary has over 16 years of personal experience (with a daughter who has severe autism) and many years of professional experience.

**Aims of Sierra Leone Autistic Society**

- Reduce Stigma and Increase awareness
- Empower individuals and families using person/family centred approach
- Development of programmes such as research, training, educational activities
- Collaboration

**Functions of SLAS/Staff**

- Research
- Assessment and diagnostics
- Educational support: Browne-Penn Special Education School (BPSS)
- Nationwide Sensitization
- Trainings
- Doctors
- Therapists
- Pharmacologist
- Special needs instructors
- Mental Health Nurses
- Social Workers
- Research Assistants
- Support workers

**Browne-Penn Special Education School: Every Child Matters**

Browne-Penn Special Education School (BPSS) is set up for children with developmental disabilities whose needs cannot be met within mainstream schools.

Sierra Leone has both national and international obligations in the form of:

- The Sierra Leone constitution which was amended in 2008 with regards to equal rights and adequate educational opportunities for all citizens at all levels
- The Sierra Leone Persons With Disability Act (2011)
- The UN Convention on the Rights of the Child (1989);

Which all work to ensure the human rights, well-being and educational rights of children with disabilities
We use multiple approaches: Sensory Play, Motor Skills, Art Therapy, eye and hand co-ordination, Self Help skills & independent living skills, Physical education, Community Visits.

The tools that we use include Individual Education Plans, personal goals/objectives, intensive interaction times, community visits and progress reports.

Speech And Language Support

BPSS ensures every child has a communication passport. We utilise The Picture Exchange Communication System (PECS) for basic speech and language support.

Education Is Key

- there are professionals and very successful individuals with autism in other parts of the world.
- if those professionals and very successful people did not have access to education who would have noticed and nurtured their talents/skills/knowledge?
- ask yourself this question: would we be able to have a professor with autism in Sierra Leone as we do in the USA/UK/etc, without access to effective education?

Please support SLAS to extend its objectives:

- There have been many requests for BPSS in the west end of Freetown, Waterloo and other locations.
- Many parents can’t afford the transportation costs of coming from afar.
- Training needs are enormous.
- Early intervention is paramount- so diagnostic services are needed.
- Research is important!
- Sensitization is key.
Our Son Zwannah

Zwannah, came into our lives on June 2, 1990 at Howard General Hospital in Columbia, Maryland, USA. It was an especially traumatic birth because intensive labor seemed to go on and on and on. I remember my husband, Nat, pleading with the doctor and nurses to do something. The doctors responded by looking at the monitors that I was hooked up to, shrugging their shoulders, and saying, “There is no fetal distress. The baby is fine. It will just be a little while.” I had a history of relatively long labors and therefore the prediction was that after 12-16 hours I would produce a normal, healthy baby in a routine vaginal delivery. Nat was persistent. He said to the doctors, “But the mother is distressed and I am distressed!” Finally, just as they were debating performing a Caesarean section, out popped Zwannah’s head swiftly followed by his rosy body. He was kicking robustly and wailing loudly as only a healthy nine pound baby would. The doctors were vindicated, and Nat and I immediately forgot everything other than the burst of joy that expectant parents experience when a much-anticipated child is finally born.

One day, my husband, Nat, asked me, “Have you noticed that Zwannah is behaving strangely?” At the time, Zwannah, our youngest son, was two years old. Before that auspicious day, he had been developing normally as far as we could tell. He could walk. He babbled what sounded like words. I especially remember that he said the word, “light.” He gave hugs and blew kisses and did all the most endearing things that baby boys the world over do. But Nat insisted that lately Zwannah had taken to staring into space blankly and not responding when you entered the room and called to him. He no longer said “light” when you turned on the light. I went through the denial until the moment of truth….then came the big diagnosis. It is a fallacy to believe that having a definition of autism somehow prepares you to deal with life with a child who is severely or even mildly affected by autism. Permit me to share with you my family’s journey with autism thus far.

- An uneventful pregnancy
- A traumatic birth that was soon forgotten
- Beautiful, good-natured, alert baby boy
- “Have you noticed that Zwannah is behaving strangely?”
- Initial denial

Zwannah’s development was decidedly abnormal. He could not speak. He was unable to interact socially appropriately. In a sense, we could not reach him. He was locked within himself. There was no cure and no known cause although there were many theories. The psychologists recommended massive speech, behaviour and occupational therapy. Zwannah was fortunate that we lived near Baltimore where the Kennedy Krieger Center – a major autism research center at Johns Hopkins Medical Center – is located.
Milestones

- Moment of truth: Pre-school Teacher
- Diagnosis: Pervasive Developmental Disorder
- Challenges on top of Challenges
- My Epiphany
- School IEPs – without deliverable services
- Pioneering studies at Kennedy Krieger – Johns Hopkins
- No words*self-mutilation*eloping*insomnia*mania
- Finally words – then perseverance
- What to do in public? Traveling?
- Lack of public awareness bring ugly stares
- Foray into various medications with side-effects (Ritalin, Adderall, Wellbutrin, Depakote, Risperidol)
- Moving to Abidjan and learning to read!
- Moving to Liberia and designing services based on IEP of an American Special Education Teacher
- Many lessons learned
- Graduating from High School & Finding placement into Adult Services
- Creating something out of nothing: Autism Society of Liberia
- Ongoing challenges but many joys

Zwannah & Joseph, a helper who spends a lot of time with him, doing age-related activities.
The Autism Society of Liberia

- wants to raise awareness so that families affected by autism will know that they are not alone
- Wants the medical community to integrate routine screening for ASDs
- Wants educators to pursue special training and provide accommodations to children affected by autism
- Wants community service providers to give support to families that are challenged by caring for family members with autism
- Wants community to provide social opportunities and jobs for adolescents and adults affected by autism

The Liberian Context

The Ministry of Education, Liberia has a Department of Special & Inclusive Education. The Director of Special & Inclusive Education, Mohamed Konneh, has established a Commission on Special & Inclusive Education. The Ministry of Education has drafted a policy on “Inclusive Education” as of September 2017

Ministry of Education: Inclusive Education (IE)

Inclusive Education is clearly defined as applying to all marginalized children and youth. The current IE Policy, recognizes the wide range of learning needs and categories of persons with disabilities, including, persons who are blind or have low vision; persons who are deaf or have hearing impairments; persons with intellectual impairments; persons with mobility challenges; persons with learning disabilities; persons with speech, language and communication impairments as well as persons with multiple disabilities. The Policy Objectives and Strategies are:

- To promote access to education for all children & youth
- To ensure participation and achievement for all children and youth
- To develop inclusion-oriented human resource
- To ensure the participatory development of sustainable inclusive education
- To promote Inclusive life-long learning
- To provide a safe protective learning environment

Within this strategy there are two specific goals:

- Transition existing “special education” institutions to serve as resource/assessment centers to assist the mainstream system to become more inclusive and special units/schools for those with severe disabilities.
- Using UNICEF & Washington Group statistics, strengthen the Education Management Information System (EMIS) to reflect students with disabilities
and other marginalized learners both in and out of school, providing disaggregated data that can inform the planning and provision of better services.

State of Disability & Mental Health Services in Liberia

The Ministry of Health has established the Liberia Non-Communicable Diseases & Injuries (NCDI) Poverty Commission. Non-communicable diseases including mental illness is priority of this commission. This commission could have a positive impact on medical help for children, adolescents and adults living with autism especially those under the care of psychiatrists or psychologists. Currently only 4 psychiatrists are in Liberia with 3 of them provided by international NGO: Carter Center. Recommendations to include provisions for mental health treatment at primary care level in community health centers and hospitals with referral to major centers for ongoing care. Many drugs commonly used to stabilize children with behavior challenges are expensive or unavailable in Liberia and the commission made recommendations; the NCDI Commission proposes improved service in this area by subsidizing. Within the proposed national budget for Mental Health, there may be small incremental support for families living with autism.

Carter Center – Liberia Mental Health Initiative

The Carter Center’s Mental Health work in Liberia aims to build a sustainable mental health system through workforce development, policy, and anti-stigma programming in partnership with the Liberian government. The Carter Center and the Ministry of Health, Ministry of Gender, and Ministry of Education, and their local counterparts are further developing child and adolescent mental health services through funding from the UBS Optimus Foundation. The "Improving Child and Adolescent Mental Health in Liberia" project increases the number of school-based clinics, as well as the number of health and social welfare workers trained to assess, treat, and manage childhood social, emotional, and behavioral problems. It also trains teachers and school administrators to identify and refer children and adolescents with social, emotional, and behavioral problems; promote positive development; and support learning. Finally, The Carter Center works with Liberian institutions responsible for ongoing training, policy, and anti-stigma efforts. By the end of 2018, as a result of the Center’s work with its partners, particularly The Liberia Board of Nursing & Midwifery and the Liberia National Physician Assistants’ Association, mental health training will be fully integrated into Liberia's national curriculum for nursing schools, and the training of a specialized mental health workforce will be led by Liberia's Ministry of Health.

Carter Center Psychoeducation Module

Last year, I was privileged to serve as a facilitator along with the mental health experts in training nurses and midwives within the Family Psychoeducation Module on Child &Adolescent Mental Health. The Carter Center and its partners trained and graduated over 200 mental health clinicians, 42 of whom have a specialty in children and adolescents. The Center's partnership with Liberia’s Ministry of Health and the
Liberian Board of Nursing and Midwifery also produced an accreditation exam for graduating mental health clinicians. These accredited clinicians now work throughout the country in all sectors of health service delivery, and each of Liberia’s 15 counties has at least three mental health clinicians.

In Conclusion…

The training to improve Liberia’s mental health services provided by the Carter Center is a bright spot in the development of services for children and adolescents living with autism spectrum disorders. At least, mental health workers are being trained to provide community-based help for families dealing with the difficult issues surrounding developmental disorders and issues of abnormal behavior associated with autism.

But there is so much to be done! Even without the data to support the need, Liberia clearly currently lacks the basic services required to ensure that families (including children, adolescents and adults living with autism) have a chance to overcome the huge challenges they face.

*Our family’s journey with Zwannah has been a major challenge, but with the help of a caring community, WE HAVE MADE IT THUS FAR. We want to give back!*

### 4.12 Dr Abs Dumbuya, Chief Executive Officer, The Dorothy Springer Trust and Chairman, Freetown Cheshire Home

**About Me**

I contracted Polio at the age of 5 years, at the same time as losing my father and my mother remarrying. I was left to be brought up by my grandparents who later brought me to Freetown, after trying several traditional healers as my condition was considered to have been caused by witchcraft. This is the case with many of disabilities in Sierra Leone; especially epilepsy and autism.

In Freetown, I was admitted to the Freetown Cheshire Home, a residential home for children living with disabilities. A home which provides care and rehabilitation support. I worked hard in the home and in my education and was able to attend the best schools in Freetown, namely; Albert Academy first and later the Prince of Wales to enable me to move to the sciences. My life was turned around when I found myself in the UK and was supported anonymously by a British woman to pursue further education; gaining the best education with a string of qualifications. I only later found out my anonymous benefactor, after her death in 2003, had invested nearly £100,000 of her own personal money. I was overwhelmed by such generosity. After a brief visit to Sierra Leone in 2005, I realised what this generosity had meant to me, because had it not been for this financial sponsorship, I would have ended up in the streets begging like my colleagues we all grew up in the home together. I went back after my visit and was inspired to set up the Dorothy Springer Trust (DST), named after the woman who had changed my life and also as a way of giving something back to my country.
Since returning home permanently in 2011, I now manage the Dorothy Springer Trust as well as the Freetown Cheshire Home, where I serve as its Chairman. I also chair and work on various aspects of disability work in Sierra Leone.

**Brief insight into disability issues in Sierra Leone**

In terms of disability in Sierra Leone, there are diverse groups of Disabled People Organisations (DPOs), Institutions (e.g. Sierra Leone Union on Disability Issues, National Commission for Person with Disability, Freetown Cheshire Home, Milton Margai School for the Blind, National School for the Deaf) and Associations (e.g. United Polio Brothers and Sisters Associations, House of Jesus, etc). These are disparate organisations and normally do not speak with one voice - there is a lot of infighting amongst these groups. There is also intense competition amongst these organisations especially when it comes to money. There is also lack of unity and as disabled advocates we need to seek to bring these organisations together to be united and fight the common cause of discrimination, marginalisation and general negative perceptions towards persons with disability. I have recently engaged various bodies to try to solve current problems/impasse existing between a splinter disabled group and the national institutions such as SLUDI and NCPD. We continue to call on all to be united; as per recent article titles "What God has joined together, let no politician put asunder".

**Underpinning disability issues within the legal framework/instruments**

Sierra Leone passed the Disability Act in 2011, before then it signed up and ratified the UN Convention on the Rights of Persons with Disability (UNCRPD). We are currently working on the Inclusive Education Policy for the Ministry of Education, Science and Technology, which we hope will become a Bill and later an Act. These legal instruments are powerful tools for advocacy to help eradicate discrimination towards persons with disability and thus provide an enabling environment for persons with disabilities to compete equally in society.

Another legal international instrument is the Sustainable Development Goals which Sierra Leone has signed up to. Although the Millennium Development Goals (MDGs) failed to address disability issues, the Sustainable Development Goals have redressed this wrong, when it comes to disability issues. In fact, SDGs addresses disability directly or indirectly in 6 goals...

- **Goal 1. End poverty in all its forms everywhere.** Implement nationally appropriate social protection systems and measures for all...and by 2030 achieve substantial coverage of the poor and the vulnerable. The 'all' here calls for also; all forms of disability. Unfortunately, Sierra Leone has focused too long on just the visible disability and now we need to start talking about such invisible disabilities such as Autism, Epilepsy...

- **Goal 4. Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all.** Ensure equal access to all levels of education and vocational skills for the vulnerable, including persons with disabilities, indigenous peoples and children in vulnerable situations. We captured this in the Inclusive Education Policy for MEST and sharing our experiences at the
FCH, where we have about 2 children with Autism and teachers do not sometimes know how to handle these children.

**Goal 8. Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all.** The goal states that "by 2030, achieve full and productive employment and decent work for all women and men, including for young people and persons with disabilities, and equal pay for work of equal value"

**Goal 10. Reduce inequality within and among countries.** The goal states that "by 2030, empower and promote the social, economic and political inclusion of all, irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status.

**Goal 11. Make cities and human settlements inclusive, safe, resilient and sustainable...this goal talks about public transport, building accessible for persons with disabilities.** I mentioned my experience in advocating for an accessible train station in Bracknell, UK engaging the media to publish articles and my interviews. This later led to the rebuilding of the station with lifts etc. So my advocacy work has not just started in Sierra Leone but dates back during my time in the UK. The important thing about universal accessibility is that it benefits society generally...as the station in Bracknell for example, is now being used by old people, pregnant women, parents with pushchairs, passengers carrying heavy luggage and so on.

**Goal 16. Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels.** The goal says "ensure responsive, inclusive, participatory and representative decision-making at all levels". This is so relevant that disabled people are given the opportunity to participate in politics and in all spheres of society and should therefore be given the platform to do so. As far as equal access to justice, until we have sign language interpreters for example, in our court systems, people with hearing impairment will continue to be disadvantaged. There is also limited expertise in disability law in this country and we need more legal clinics to provide assistance to disabled people as far as their rights and the law is concerned.

4.13 Parent/Carer Perspective III by Mary Penn-Timity

I am a mother of four children, one of whom has autism. Jes is now aged 17 and was born in the UK. I am originally from Sierra Leone and we recently returned to live here after my husband was offered a job.

I want to start by sharing a few things that people have said about me as the mother of Jes:
• I am a witch
• I am the mother of a devil child
• I did not take blessing from my husband
• I cheated on my husband
• I am useless
• I did something very bad, so God punished me by giving me Jestina (my child)
• I sacrificed my child to go abroad and make money
• I am not religious enough!

All because I have a child with autism

These are things that have been said about and to my autistic daughter:

• Jes is a witch
• Jes is a devil child
• Jes is bad luck and so deserves to die
• Jes should be left in the bush, to be returned back to the devil she came from
• Pregnant women should not be around Jes or they would have a devil child like her
• Other children should not play with Jes
• Jes is a mad person
• Jes should be feared, not loved

All because Jes has autism

Jes’s Story
Jes was born in London. She is the eldest of four children.

She was hit by a van at around two years old. This was the last time that she ever said Daddy or Mummy. She lost her speech. Jes was diagnosed with severe autism at around three years old. Due to the fact that autism is not always visibly present at birth we will never know whether it existed from birth or whether the accident just exacerbated it.

Jes received early intervention at home and progressed; so mainstream school was recommended. Jes attended mainstream school until age 8. Jestina deteriorated so
much within mainstream school; she could hardly do anything for/by herself. The educational psychologist and the family agreed that Jes needed to go into a special school where her needs could be better met.

Jestina went into special school in the UK with nearly all skills lost. Jestina was worked with intensively throughout her special schooling; and progress was achieved.

**Support provided for Jestina and the family as a whole – the UK experience**

- A child development centre where she was observed and diagnosed by multi-disciplinary team
- home visits to provide early intervention in-house support for progress in many areas
- intensive support within ‘specialist’ school
- special school education;
  (i) with lots of opportunities for learning new skills (e.g. swimming), self-help skills (e.g. to dress/feed herself), community visits, speech and language support, hearing, vision and dentistry check-ups
  (ii) individual education plan to target Jes’ needs; with adapted curriculum
  (iii) safe environment
- parent support groups/outings and respite for family
- school bus service to ease transportation worries – was very challenging to transport Jes
- psychiatry services – for medication etc.
- therapeutic services - e.g. arts/play therapy, sensory room activities (both at school, home and external centres)
- dietary support – tested for allergies/intolerances and nutrition advice provided
- general practitioner – who regularly monitored Jes’ medical needs; especially as she is non-verbal (so regular check-ups) and needed referral from time to time to different specialists.
- social worker who looked at Jestina’s holistic needs and also advocated for support/services that were key

**The Sierra Leone Experience**

- nowhere to turn to for help; we went to a Ministry to ask for sign posting to autism services, and were asked “what is autism?”
- no database of autism services/referral pathways
• several doctors told us they don’t know about autism and so couldn’t help our child

• a medical personnel told us that she could never progress/improve so we should just keep her at home with 24 hours nursing care

• a medical personnel prescribed a discontinued drug for Jes; thankfully her mum’s pharmacology background meant she was able to make a life saving decision

• we were told there was no school that could meet her needs.

• we were told by many many people both professionals and non-professionals to take her to ‘the medicine man’

• heard neighbours saying that we sacrificed our child to go abroad and make money

• when Jestina went into crisis; several times neighbours ran away stating that ‘debul don ol am’

• we were thrown out of several restaurants/taxis etc. when she went into crisis; fear that she was a ‘debul pikin’

• initially Jes could only interact with her siblings as other children feared her

• in a church we attended, we were told to take her for one month fasting and prayer; but that we should leave her there for that duration also.

• very expensive nappies in Sierra Leone

• stigma – plus plus!!!!

**What Has Worked In Sierra Leone?**

• lots of opportunities for one-to-one input; especially in Browne-Penn School (as it’s not as costly as it could be in the UK and other countries which has been very positive for Jes)

• the fight to get Jes out of nappies is gradually being won; she now mainly wears nappies for bedtime only; this is because of what we call ‘the pinning technique’.

• in Sierra Leone they ‘pin’ on children to do certain things; but be careful, because ‘pinning’ should be realistic and achievable without going into ‘abusive’ mode

• sensitisation

• lots of love from immediate and extended families

**Recommendations From A Parental Perspective**

• education (access to schools) – where we can spot and nurture talents

• child development centres for effective diagnosis
• parental support – eg. training to understand autism to better support our children
• research – evidence-based interventions/strategies
• legal obligations need to be implemented

Thank you for listening to Jestina’s story.

4.14 Parent/Carer Perspective IV: Angela Hennelly, British Council Tanzania

I am the parent of Lola who is 14 years old girl and on the autistic spectrum. What I have heard at the conference today and yesterday is very familiar to me - as the mother of Lola - but also from the experiences people who I have spoken to in Tanzania: the problems that parents and carers are experiencing in Sub-Saharan Africa and a lot of what you said this morning regarding name-calling and the misconceptions about autism.

I am going to share a short video which is symbolic of the journey that I have taken.

I have been in Tanzania for a year and a half. 20 months ago I visited Tanzania to find a school for my daughter, to find a doctor and to find out what support was available for her.

All the schools that I visited said ‘No’ to my daughter. The only one that said yes had a British headmaster who had experience of special needs. He said to me that we do not exclude – so we began at that school for a few hours a week with somebody acting as Lola’s helper, who had worked with a boy physically challenged children. However, we found that Lola had little support and was simply asked to sit in a corner with her helper and pretend to read books. Lola had also learnt how to exploit the introverted character of her helper and started to refuse to follow simple instructions which previously she had responded to.

At the same time, one school - who had previously refused to accept Lola - came back to us. There were two teachers interested in working with Lola, but the school would only give Lola a couple of sessions per week. This was quite a new direction for them.

By December 2017, 15 months since Lola had started at her second school, she enjoys 50% of a regular timetable which includes 1:1 with the arts teacher, 1:1 with a special needs teacher, a juggling class (she had also excelled in her Lego class!) and lunch near the serving desk where she pays for her meal and meets lots of people. Our current helper is wonderful, a very patient, kind person who has two children of her own. She has no experience of special needs but has endeavoured to get to know Lola and the world of autism. She practices what Lola learns at school at home. She helps Lola develop her social skills, gradually introducing her to the noise of the canteen. The school community now knows Lola better and, as the video shows, has been encouraged to pro-actively acknowledge Lola even though she
may not react immediately. All this has been achieved mainly through the children encouraged by a few special teachers teaching their colleagues and parents how to interact with Lola. The effect of Lola on the school community has been very positive. Even the headmaster, who was perturbed at the beginning by Lola’s refusal to say hello to him in the corridor, is another of her champions. Sometimes when we are in the supermarket, children will come up and greet Lola. She was invited to a big noisy birthday party, but her classmates took great care of her, always ensuring that I was in her line of vision. We stayed two hours and went home exhausted.

Lola’s behaviour has improved markedly. She is much more settled when she travels. She has begun to vary her wardrobe learning the appropriacy of certain clothes for going out (she lived in sarongs). She has learnt to borrow books from the library and return them (before she would pack them away and refuse to give them back). This has all been achieved in great part by ‘the kindness of strangers’, most of whom had never heard of ‘autism’ or, if they had, often equated this with a stereotype such as portrayed in ‘Rain Man’. We are truly grateful for their continued patience, kindness and understanding.

A video is shown of Lola with friends in her class, in which her peers are helping her to join in with activities and showing acceptance and fondness for Lola within an inclusive setting.

4.15 Disability and The Right to Education, Dr Tsitsi Chataika, University of Zimbabwe

Characteristics of Autism

Social withdrawal symptoms such as:

- Showing little interest in making friends
- Preferring to spend time alone
- Having difficulty showing empathy
- Showing little response to smiles or eye contact

Impairment in communication such as:

- Speech developing slowly or not at all
- Inability to initiate or sustain conversation
- Repeating words or phrases (echolalia)
- Inability to generalize. Speech is interpreted literally
- Having unusual intonation, rate and volume of speech
Possible signs of autism at any age:

- Avoids eye contact and prefers to be alone
- Struggles with understanding other people’s feelings
- Remains nonverbal or has delayed language development
- Repeats words or phrases over and over (echolalia)
- Gets upset by minor changes in routine or surroundings
- Has highly restricted interests
- Performs repetitive behaviours such as flapping, rocking or spinning
- Has unusual and often intense reactions to sounds, smells, tastes, textures, lights and/or colours

Medical & Mental-Health Issues Commonly Associated with ASD

- Epilepsy
- Feeding
- Sleep disturbances
- Attention-deficit/hyperactivity disorder
- Anxiety
- Depression
- Obsessive compulsive disorder

Inclusion & Autism

Learners with autism are increasingly being placed in mainstream education “inclusion” settings (Boutot & Bryant, 2005). Proponents of full inclusion suggest that the least restrictive environment always the mainstream classroom for all children and youth with disabilities, including those with autism spectrum disorders (ASD). Proponents for full inclusion suggest that students receive a better, or at least no worse, score on cognitive tests if they stay in the mainstream classroom (Stubbs, 2008; Vaughnn, Moody, & Schrumm, 1998).

Inclusive education for children with autism increases social integration. Having reciprocal relationships with peers is key to a child’s social emotional and even cognitive development (Scheuermann & Webber, 2002). Research suggests that learners with autism in inclusive settings are accepted, visible and members of peer groups (Boutot & Bryant, 2005). The presence of typically developing children was significantly associated with decreased autistic behaviour as compared with the presence of other children with autism (Levy, Kim & Olive, 2006).

Full inclusion as a policy, explicitly and implicitly discourages the development of impairment-specific approaches, while the unique characteristics of learners with autism make some level of individualisation essential. Transition is particularly difficult for learners with autism and must be proactively managed (Mesibov & Shea, 1996).
Autism is a largely heterogeneous health related disorder with regard to function (Dunlap & Burton-Pierce 1999). The characteristics of the individual learner would determine the level and intensity of the support s/he needs.

**Interventions in the Classroom**

Learners with autism need a variety of interventions to be successful in the inclusive classroom:

**Social Skills Interventions**

Social stories are relatively short, straightforward descriptions of social situations, specifically detailing what an individual might expect from the situation and what may be expected of him. However, there is substantial variation in their use, and research into their effectiveness has been limited [It is not known whether they are effective].

A recent review article found that the limited studies available showed generally positive results, and concluded that the approach is promising (Thresholds, 2008).

**Inclusion-Friendly Strategies to Facilitate Social Skills Achievement**

- Rehearse skills needed for appropriate social behaviour such as conversations.
- Focus should include maintaining eye contact during conversations, learning social greetings, and maintaining conversation.
- Practice newly learnt social skills with puppets or adults before encouraging learners to use them in unstructured environments such as break times.
- Provide explicit instruction about conversation etiquette.

**Communication Interventions**

For learners who are nonverbal or have little verbal ability:

**Augmentative and Alternative Communication** – This is a form of communication used in place of (to augment) speech—With individuals with autism, a picture board is often used. Many people with autism are visual thinkers. (Temple Grandin 2002).

The goal of AAC is to teach individuals to initiate speech using an alternative to vocal speech. The research for this intervention has not yet been proven to be valid since the scope of individuals used in the research is too narrow to be generalized (Randle 2005). In a mainstream classroom, a trained inclusive educator would need to facilitate its use.

**Other Strategies**

- Avoid long strings of verbal instructions. Give only 1-2 instructions at a time.
- If the learner is verbal and reads, the steps can be written down. Highlight each step. If s/he is nonverbal, use pictures.
People with autism have problems with remembering the sequence. If the child can read, write the instructions down on a piece of paper. "I am unable to remember sequences." (Grandin, 2002)

Model procedures, expectations, thinking strategies, or directions.

Pre-teach new concepts and content vocabulary to students. This step helps reduce the anxiety that students with autism feel when a transition must be made instruction.

If possible tell the learner before an unusual occurrence in the classroom. Children with autism do not like change. Many individuals are extremely sensitive auditorily. Sirens, bells, and assemblies may all cause stressful reactions in students with auditory sensitivities.

**Behaviour Interventions:**

*ABA—Applied Behaviour Analysis*

ABA is characterised by discrete presentation of stimuli with responses followed by immediate feedback, an intense schedule of reinforcement, data collection, and systematic trials of instruction (Schoen 2003).

*Functional Behaviour Analysis—FBA*

An observer assesses the student’s behaviour—noting frequency, triggers of the behaviour, and setting of the behaviour. This allows the teacher to be proactive in behaviour management. Remove or minimise environmental stressors that trigger behaviour problems.

**Inclusion-friendly strategies to facilitate learning and participation**

- Give the individual a ball to squeeze or a weighted blanket to wear. Pressure from the object calms the nervous system and relieves stress.
- Rehearse appropriate social interactions.
- Reward appropriate behaviours.
- Use overt positive feedback—Negative feedback does not work since the learner focuses on the negative consequences rather than on the behaviour that precipitated it.
- Have a visual schedule—written or pictorial. Learners often respond poorly to unpredictability and may engage inattention-getting behaviours.

**More Teaching Tips**

- Highlighting directions on worksheets, numbering steps for more complex tasks.
- Encourage one or two sentence knowledge summaries from a book chapter or unit. Don’t assume understanding.
Use strong interest areas as motivators to assist students in engaging with new and/or difficult material.

Provide examples of finished products and writing assignments.

**Interventions for Academic Concerns**

“Children with Autism are able to learn, function productively in society and show positive gains with appropriate education and treatment plans in place. Without appropriate support, the child may never realize his full potential.” (Igafo-Te’o 2006).

Use direct instruction skills - Instruction for students with autism must be highly structured, with teacher-led lessons. Instruction should include teacher feedback, reinforcement and practice (Hallahan, Lloyd, Kauffman, Weiss & Martinex, 2005).

**Use the Autism Spectrum Inclusion model**

If learners with autism are to learn, it will require a coordinated effort of mainstream education teacher using appropriate strategies, coordinated communication and decision making with trained support personnel, meaningful home participation, and consistent and frequent evaluation of practices. (Simpson, deBoer-On, & smith-Myles, 2003). Use concrete visual methods to teach number concepts.

- Many individuals with autism think in pictures.
- Letters can be taught by letting learners feel plastic letters. Touch is often their most reliable sense.

**Key Points**

- The greatest area of needed instruction are communication skills.
- Functional behaviour assessments and positive behavioural support are a needed element in the classroom.
- Direct instruction is needed for social instruction as well as academics.
- Involve the parents in educational decisions made for the learner. If possible introduce the parent/carer to new interventions used with their child.
- Hold high expectations for every child including the child with autism.

**4.16 Parent/Carer Perspective IV: Umu Bentil**

My name is Umu Bentil, the mother of Edna Bentil. When I gave birth to Edna I realize that her head was not like the head of a normal size baby. As years passed by I realized that my daughter is not doing well. So I keep her indoors for neighbours not to take notice of her disability. My mother was with me at that time as she was helping me with the baby. When she reached the age to go to school we try to locate a school that she will be able to fit in. We try the mainstream school at first but she was not able to cope until we heard about Hosetta Abdullah School in Thunder Hill.
She has been attending the school for the past 15 years now. But things are not alright with us, I have been going through difficulties in coping with her, I have to pay transportation, buy school materials, feeding and she is not the only child I have, we have to also help her brother and sisters. These are some of the challenges I’m faced with. I need help especially for food and accommodation facilities like the school home for the children. I cannot afford to pay transportation for her always. If my daughter is in the school home with other children it will be nice because this will reduce the case of sexual exploitation especially for the girls, child labour, provocation, discrimination etc. Some parents don’t have the time to protect their child from some of these problems.

I want my daughter to have some skills training work as she is a big girl now. These children need to learn skilled work like soap making, tailoring work, hair dressing etc for them to cope in the future. We also need help for transportation because most of us are living in long distance from the school and not all of us can afford to pay for transportation everyday. I love my daughter and I have always protected her. I say to you ‘Hold your child close and don’t let anyone tell you that your child should not be cared for’.

5 Improving Outcomes for Children with Autism – Practical Steps

5.1 Next Steps Workshop 1: Inclusion & Visibility - Securing Rights for Children with Disabilities

*Led by Disability Africa*

**The Big Issue**
We reflected on the devastating effects on children with impairments and very often women carers, that *stigma* and the ensuing *exclusion* have.

We noted that this effect of exclusion on the individual was typically much greater than the direct impact of any actual impairment a child may have.

**What Can we DO NOW?**
We considered the many calls throughout the conference for better health and education facilities especially more trained therapist, special ed teachers doctors and other specialist and reflected that while these are necessary we asked:

*Which African country can say they have, or are even close to having the infrastructures to realistically deliver these in any comprehensive way?*

We looked at the power of Inclusion to benefit people with impairments. Particularly how creating opportunities for disabled and non-disabled children to *play* together could have an immediate and significant impact.
Opportunities to Play will:
- Instantaneously end a child’s isolation
- Be an appropriately stimulating environment for a disabled child who may have suffered developmental delay through social isolation, perhaps for many years.
- Help disabled children develop vital social, coordination and communication skills.
- Help change negative attitudes of family members and the wider community
- Provide a context for assessment of other medical and educational needs
- Provide a platform for development of other community-based services - parental support groups, physiotherapy, etc.

A Programme We Can Start NOW:

Playschemes:
- Have high impact without the need for specialists or additional facilities - existing schoolrooms, meeting rooms or religious halls are appropriate.
- The skills required for playwork are inherently available in every community with the minimum of additional training required.
- They do not require input from medical or education specialists who are seldom readily available.
- They are achievable within locally existing skill sets.
- They require very little in terms of additional resources.
- By involving young non-disabled local volunteers as playmates and paraprofessional playworkers long-term attitudinal change can be affected.
- Are eminently sustainable and replicable by local communities because they can use existing facilities and skills at very little cost.

5.2 Next Steps Workshop 2: Strategies for Advocacy & Support: What is Required?

Led by Dawn Cooper-Barnes, Autism Society of Liberia and Max Bangura, Epilepsy Association of Sierra Leone

A successful autism support services strategy should involve autistic people and address these three areas:
- Capacity-building – take workers to university, embed training, train mental health workers, review laws
- Awareness – counteract stigma, address abandonment and have fast and appropriate response
- Advocacy – with autistic people (not for them), with WHO, addressing rights, regular national conferences
The strategy should:

1. Identify problems/draw on relevant research
2. Identify collaborative partners
3. Develop and implement relevant capacity-building and training activities
4. Develop and implement Awareness-Raising Activities
   a) media
   b) town hall/community sessions
   c) home visits
   d) community forum/faith-based meeting
5. Advocacy
   a) lobbying
   b) policy development
   c) Monitor implementation
6. Detail changes and record data for research purposes and to demonstrate impact/successful approaches.

Key areas, activities and themes to address:

Creation of support groups
Vocational skills training
Affordability, accessibility and monitoring
Identify allies
Maintain monitoring across the country, with clear feedback mechanisms
LOVE is needed
Identify who has autism, sensitise carers, public awareness through community town hall meetings, sensitise traditional healers, use local languages.
Bring together, and involve stakeholders, use testimony
Collaborate with others, community outreach, media platform, public awareness
Create awareness – debunk previous inaccurate ideas
Use faith-based organisations and mainstream schools
Train in the local language
Ensure training of both public and private mix of medical doctors
Laws – are more needed or current laws to be tested?
Challenge discrimination based on identity
Government ministries – explore budget allocation
5.3 Next Steps Workshop 3: The Right to Education - What Can We Do Now?

Led by Tsitsi Chataika, University of Zimbabwe

- Advocacy is required to raise awareness about autism in the community;
- Capacity development of teachers so that they can manage autism and other children with diverse needs;
- Teacher training colleges should review their curriculum for teachers to understand the curriculum differentiation;
- Capacitating parents of children with autism;
- Advocacy for an inclusive education policy;
- Teacher/pupil ratio to be addressed to promote inclusion;
- The reverse inclusion – mainstream go into special schools;
- Twin-track approach due to the current Sierra Leone context will benefit learners with autism;
- Inter-disciplinary collaboration of professionals and parents eg speech therapist, education psychologists, teachers, physiotherapists etc.

5.4 Next Steps Workshop 4: Support for Parents & Carers

Led by Virginia George, parent/carer

1. Special needs schools required, with support provided by government/NGOs
2. Awareness-raising and sensitisation at the community level
3. Ensure implementation of policies
4. Training for parents and carers to strengthen understanding of autism
5. Creation of day care centres
6. Free medical support for children with autism
7. Counselling for parents and carers
8. Formation of parent/carers support groups
9. Explore possibilities to finance low income for parents/carers
5.5 **Next Steps Workshop 5: What do we need to know? Research Priorities to Inform Strategies & Services**

Led by Dr Bakare and Mary Penn-Timity

Autistic people to be involved at all levels with all proposed research.

1 **Exploring prevalence:**
Sampling – age, size, type
A coordinated approach is required.

2 **Research to Understand General Perceptions of Autism in Sierra Leone**

3 **Identifying ways to target awareness-raising interventions with:**

- Community leaders
- Religious leaders
- Health/Education
- Workers/social workers
- Parents/carers
- Traditional healers
- Community members

4 **Exploring diagnostics:**
Health, clinical, referral pathways
Identifying appropriate screening tools.

5 **Research Methodology**
A range of methodologies will be required.
APPENDIX A: Selected Feedback from Attendees

‘I really want you to be having this kind of discussion every three months because everyday children in this nation are dying from this condition and get more medical personnel on board’.

‘Honestly, though I trained as a medical personnel, I never knew what autism is but after this conference children that I used to see as crazy, my view of them has totally changed. I’ve got a new idea that autism is not madness but just a state of being extraordinary’.

‘Autism is not widely known in Sierra Leone compared to the other types of disability and so different names are given to it. Therefore massive sensitisation and advocacy is needed.’

‘I say many thanks to all the organisers. The workshop was educative – we will take the message down to our communities’.

‘Very little or none is known about autism in Sierra Leone. I can now play a great role in my community helping people with autism after this conference’.

‘The video clips were very interesting. I learnt a lot about autism and how to treat individuals with autism’.

‘The main thing for me about the conference was that fact that parents willingly speak positive about their children with autism regardless of their challenges and nobody told us that their child is a burden.’

‘It is easy to learn and change perception of people when real live stories are shared. The other important tool is the video clips which were shared’.

‘Autism is really not new but people don’t know about it’

‘Children with autism should be treated with love. They are human beings like us’.
‘The government should fully support persons with autism’.

‘I really liked the balance of presentations – personal, professional, national and international’.

‘Sierra Leone is very much at the initial stage of awareness-raising so this was a very important event’.

‘These are people that we refer to as ‘Full-Full’ - that is they cannot cope with society. Traditionally we ask for them to be returned back by taking them to the sacred forest and make them disappear by burying them and make it secret.’

‘We need an awareness-raising campaign though social workers by empowering them in order to prevent the myth that us Sierra Leoneans have about autism. We need to pass laws or verdicts to local authorities in particular not to ever return or make an attempt to vanish an abnormal baby’.

‘In my country Sierra Leone I appeal for a hasty intervention on behalf of autistic persons so that we stop losing them or hiding them in rooms because of stigma to the parents’.

‘The life stories that were told at the conference were very useful and effective’.

‘The most useful bit for me was to see the care and love for autism from the presenters’.

‘I believe that autism in Sierra Leone is a great problem that needs to be addressed. There are thousands of children in Sierra Leone with autism that are being neglected. There needs to be more work done on informing the community so that they have a better understanding of those children. Special schools are needed to cater for these children, more experts are needed.’

‘This conference is timely and it opened our eyes to autism and disability’.
The presentation by both parents and carers were the most insightful – they are evidence-based life experiences that will inspire the community to realise their autistic children equally need love and care as other children.

‘I did not know what autism was until I came to this conference. When I go back to my community I will explain to them the meaning of autism and encourage people how to care for their children’.

‘My perception about autism was negative but after attending this conference on autism I can now confidently say my perception has changed.’

‘Before I was afraid of these kids – I thought they were demons from the sea or forest. I never had any idea. It is a pleasure for me to attend the event. I have learnt a lot about autism, epilepsy and disabled people now I have learned to love and care for them’.

‘The most useful and effective part of the conference for me for was hearing about the experiences of parents and carers’.
# Appendix B  Conference attendees

<table>
<thead>
<tr>
<th>Name</th>
<th>Organization</th>
<th>Notes: Role/interest</th>
<th>Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abbie Sessay</td>
<td>Parent/carer, Hojeta Abdullah Special Needs School</td>
<td></td>
<td>078 840 478</td>
</tr>
<tr>
<td>Abdulkarim Sessay</td>
<td></td>
<td></td>
<td>030 037 707</td>
</tr>
<tr>
<td>Abdul K Neatland</td>
<td>Youth Network</td>
<td></td>
<td>088 523 064</td>
</tr>
<tr>
<td>ABUP KARGBO</td>
<td>Epilepsy Association of Sierra Leone</td>
<td></td>
<td>076 712 439</td>
</tr>
<tr>
<td>Adama Conteh</td>
<td>Women Q'Hope (WqH)</td>
<td></td>
<td>078 858 811</td>
</tr>
<tr>
<td>Alex Sandoh</td>
<td>Epilepsy Association of Sierra Leone</td>
<td></td>
<td>077 534 845</td>
</tr>
<tr>
<td>Alfred Collie</td>
<td>Epilepsy Association of Sierra Leone</td>
<td></td>
<td>078 897 165</td>
</tr>
<tr>
<td>Alhaji Komba</td>
<td>Stop It Sierra Leone</td>
<td></td>
<td>078 288 881</td>
</tr>
<tr>
<td>S. Stephen Alh-Koroma</td>
<td>Head Special Needs, MEST</td>
<td></td>
<td>078 770 123/099 0080</td>
</tr>
<tr>
<td>Alhaji Y thanking</td>
<td>IDHA</td>
<td></td>
<td>078 440 637</td>
</tr>
<tr>
<td>Alice Brown</td>
<td>The Brown-Penn School</td>
<td>Co-Founder</td>
<td><a href="mailto:brovnapennscho@email.com">brovnapennscho@email.com</a></td>
</tr>
<tr>
<td>Alimata O. Keister</td>
<td>Stop It – Sierra Leone</td>
<td></td>
<td>076 608 479</td>
</tr>
<tr>
<td>Amelie Van Den Brink</td>
<td>Independent researcher</td>
<td></td>
<td>088 899 99 99</td>
</tr>
<tr>
<td>Amnechata Jalloh</td>
<td>Parent/carer, Hojeta Abdullah Special Needs School</td>
<td></td>
<td>088 849 250</td>
</tr>
<tr>
<td>Amnechata Karabo</td>
<td>Parent/carer, Hojeta Abdullah Special Needs School</td>
<td></td>
<td>088 174 705</td>
</tr>
<tr>
<td>Amnechata Bob - Lincoln</td>
<td>Stop It – Sierra Leone</td>
<td>Teacher</td>
<td>077 499 006</td>
</tr>
<tr>
<td>Amnechata Komea</td>
<td></td>
<td></td>
<td>077 448 729</td>
</tr>
<tr>
<td>Andy Nowak</td>
<td>Disability Africa/Queensmill School</td>
<td>Volunteer/ Deputy Head</td>
<td><a href="mailto:snovak@queenmill.lbf.sch.uk">snovak@queenmill.lbf.sch.uk</a></td>
</tr>
<tr>
<td>Anesta Hennessy</td>
<td>British Council Tanzania</td>
<td>Country Director</td>
<td>Anesta <a href="mailto:Henessy@britishcouncil.or.tz">Henessy@britishcouncil.or.tz</a></td>
</tr>
</tbody>
</table>

<p>| Ann Reissner          | Education Consultant                                                        | teacher trainer                                            | <a href="mailto:drauemissier@gmail.com">drauemissier@gmail.com</a> |
| Anna Vines            | World Hope International/Enable The Children                               |                                                             | <a href="mailto:annavines@worldhope.org">annavines@worldhope.org</a> |
| Anthony Masaray       | Disability Africa                                                            |                                                             | <a href="mailto:massayar.anthony@gmail.com">massayar.anthony@gmail.com</a> |
| Aruna Allie           | Hojeta Abdullah Special Needs School                                         |                                                             | 077 635 357          |
| Augustine             | DHA                                                                          |                                                             | 088 064 990         |
| Ayububash Getachew    | Parent/carer                                                                 | Parent/carer                                               | <a href="mailto:ayububash@yahoo.com">ayububash@yahoo.com</a> |
| Avodele Brown         | Browne Penn School                                                          |                                                             | 010 433 493         |
| Cecilia Masaray       | Street Child - SL                                                            |                                                             | <a href="mailto:cecilmasaray@gmail.com">cecilmasaray@gmail.com</a> |
| Chalma Mamun - van Rae|                                                                              |                                                             | <a href="mailto:cmmamun@gmail.com">cmmamun@gmail.com</a>    |
| Charles Pessou        | Amnesty International                                                        | Clinical Psychologist                                       | <a href="mailto:pessou@amnestystva.org">pessou@amnestystva.org</a> |
| Cornelia Grubbhagen    | Epilepsy Association of Sierra Leone                                         |                                                             | <a href="mailto:grubbhagen@hotmail.com">grubbhagen@hotmail.com</a> 076 616 849/099 317 461 |
| Dawn Cooper-Banes     | Autism Society of Liberia                                                   | Co-Founder                                                 | 078 712 470         |
| Desmon Deno           | Epilepsy Association of Sierra Leone                                         |                                                             | 078 123 748         |
| Dr Abu Damboga        | The Dorothy Springer Trust                                                  | Founder                                                    | <a href="mailto:abu_damboga@yahoo.co.uk">abu_damboga@yahoo.co.uk</a> |
| Dr. Anthony Dusoo     | Surson, Connaught Hospital, Freetown                                         |                                                             | <a href="mailto:dussow1974@gmail.com">dussow1974@gmail.com</a> |
| Dr. Maideran O. Bakare| Federal Neuropsychiatric Hospital, Enugu, Nigeria                           | Consultant Psychiatrist &amp; Head Clinical Services &amp; Training Child &amp; Adolescent Unit | <a href="mailto:mbakare2000@yahoo.com">mbakare2000@yahoo.com</a> |
| Edward Marrs Lah      | Mental Health Coalition                                                      |                                                             | <a href="mailto:Edwardmarrs.mhms@gmail.com">Edwardmarrs.mhms@gmail.com</a> |
| Emmanuel Sessay       | Wellington Mobility &amp; Repair Centre                                          |                                                             | 077 272 754         |
| Ernest Caran           | Freetown Teachers College                                                    |                                                             | 077 961 431         |
| Eric Kamara           | Health for all Coalition                                                    |                                                             | 077 961 431         |
| Evelyn Beckarie       | World Hope International/Enable The Children                                |                                                             | 076 352 281         |</p>
<table>
<thead>
<tr>
<th>Name</th>
<th>Title/Latitude</th>
<th>Contact Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatimata Kamara</td>
<td>Parent/carer, Hasrita Abdullah Special Needs School</td>
<td>030 317 929</td>
</tr>
<tr>
<td>Felicia Addie Buckman</td>
<td>Browne Penn School</td>
<td>030 22 6008</td>
</tr>
<tr>
<td>Frances Beye Sesay</td>
<td>SLUDI</td>
<td>07 653 100</td>
</tr>
<tr>
<td>George Ferguson</td>
<td>BBC Media Action</td>
<td><a href="mailto:George.Ferguson@btinternet.com">George.Ferguson@btinternet.com</a></td>
</tr>
<tr>
<td>Ibrahima Kamara</td>
<td>Women of Hope (WoH)</td>
<td>068 646 157</td>
</tr>
<tr>
<td>Harvay Kamara</td>
<td>Parent/carer, Hasrita Abdullah Special Needs School</td>
<td>088 008 992</td>
</tr>
<tr>
<td>Hauw来到了 Malaysia</td>
<td>Jersey African Support Services</td>
<td>076 897 165</td>
</tr>
<tr>
<td>Helen Yoder</td>
<td>UBC Matin Hospital</td>
<td>Child Mental Health Specialist</td>
</tr>
<tr>
<td>Hon. Rosanna Tassy</td>
<td>Ministry of Social Welfare, Gender and Children’s Affairs</td>
<td>076 738 517</td>
</tr>
<tr>
<td>Ibrahim Sesay</td>
<td>Girl Child Network</td>
<td>099 69 61 29</td>
</tr>
<tr>
<td>Istanbul Sesay</td>
<td>Epilepsy Association of Sierra Leone</td>
<td>078745002</td>
</tr>
<tr>
<td>Ishmael Kamar</td>
<td>One Family People</td>
<td><a href="mailto:ishmael@onefamilypeople.org">ishmael@onefamilypeople.org</a></td>
</tr>
<tr>
<td>Istah Mahsoi</td>
<td>Health &amp; Development Professional</td>
<td>Evaluator for a project for people with epilepsy</td>
</tr>
<tr>
<td>Jennifer S. Duncan</td>
<td>Connaught Hospital</td>
<td>Mental Health Nurse</td>
</tr>
<tr>
<td>John Koroma</td>
<td>Executive Director, Stop It – Sierra Leone / Autism Council</td>
<td><a href="mailto:stopinsieraleone@yahoo.com">stopinsieraleone@yahoo.com</a></td>
</tr>
<tr>
<td>John Tucker</td>
<td>Epilepsy Association of Sierra Leone</td>
<td>078 781 456</td>
</tr>
<tr>
<td>Joseph Sesay</td>
<td>Wellington Mobility &amp; Repair Centre</td>
<td>078 739 091</td>
</tr>
<tr>
<td>Josephine Fatuma</td>
<td>Health for all Coalition</td>
<td>099 577 539 <a href="mailto:Fatumal88@gmail.com">Fatumal88@gmail.com</a></td>
</tr>
<tr>
<td>Josephine Kamara</td>
<td>Epilepsy Association of Sierra Leone</td>
<td><a href="mailto:Josephinekay95@gmail.com">Josephinekay95@gmail.com</a></td>
</tr>
<tr>
<td>Kadarih Giba</td>
<td>Parent/carer, Hasrita Abdullah Special Needs School</td>
<td>088 086 700</td>
</tr>
<tr>
<td>Kadarih Serev</td>
<td>Women Of Hope (WoH)</td>
<td>099 379 030</td>
</tr>
<tr>
<td>Laura Karronah</td>
<td>Freetown Cheshire Home</td>
<td>Headteacher</td>
</tr>
<tr>
<td>Mobility Aid Koroma</td>
<td>SL Psychiatric Hospital</td>
<td>Mental Health Nurse</td>
</tr>
<tr>
<td>Mayama Koroma</td>
<td>Townie SPN, MOHS</td>
<td>077 448 259</td>
</tr>
<tr>
<td>MARTIN SAVAY</td>
<td>Epilepsy Association of Sierra Leone</td>
<td>078212432</td>
</tr>
<tr>
<td>Martina Foyad</td>
<td>Freetown Teachers College</td>
<td><a href="mailto:martina.2002@yahoo.com">martina.2002@yahoo.com</a></td>
</tr>
<tr>
<td>Mary Penn-Tamby</td>
<td>The Brownes-Penn School</td>
<td>brow <a href="mailto:nepenpschool@gmail.com">nepenpschool@gmail.com</a></td>
</tr>
<tr>
<td>Mac Abu Basrie</td>
<td>Epilepsy Association of Sierra Leone</td>
<td>Founder &amp; Coordinator</td>
</tr>
<tr>
<td>Michael Walker</td>
<td>Stop It – Sierra Leone / Autism Council</td>
<td>079 94 31 36</td>
</tr>
<tr>
<td>Mipr Van Loomen</td>
<td>Mental Health Nurse</td>
<td><a href="mailto:enablingaccess.mipr@gmail.com">enablingaccess.mipr@gmail.com</a></td>
</tr>
<tr>
<td>Mike Carr</td>
<td>Disability Africa UK</td>
<td>Project Development Officer</td>
</tr>
<tr>
<td>Mohamed Fallay</td>
<td>Epilepsy Association of Sierra Leone</td>
<td>078 712 461</td>
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<td>Mohamed Issa Kamar</td>
<td>Epilepsy Association of Sierra Leone</td>
<td>078 712 465</td>
</tr>
<tr>
<td>Mohamed James Koroma</td>
<td>Department of Child and Adolescent Mental Health, Ola During Children Hospital</td>
<td>Child and Adolescent Mental Health Nurse Specialist</td>
</tr>
<tr>
<td>Mohamed Kanuah</td>
<td>National Coordinator, Sierra Leone Debatas Council</td>
<td>MedHubi</td>
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<tr>
<td>Mohamed Lamore</td>
<td>Parent/carer, Hasrita Abdullah Special Needs School</td>
<td>088 399 625</td>
</tr>
<tr>
<td>Mohamed Sesay</td>
<td>Observers Watch</td>
<td>091 7 17 85</td>
</tr>
<tr>
<td>Monique Sina Koratay</td>
<td>Jai Chinese Friendship Hospital</td>
<td>Mental Health Nurse</td>
</tr>
<tr>
<td>Mustafa Kamara</td>
<td>Jersey African Support Services</td>
<td>076 897 165</td>
</tr>
<tr>
<td>Oliver Sesay</td>
<td>Sierra Leone Autism Council</td>
<td><a href="mailto:gloro@yahoo.com">gloro@yahoo.com</a></td>
</tr>
<tr>
<td>Pastor Jonathan Williams</td>
<td>World Hope International / Enable The Children</td>
<td>Pastoral Support Worker</td>
</tr>
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<td>Princess Bina Kany</td>
<td>Stop It – Sierra Leone / Autism Council</td>
<td>Admin Secretary</td>
</tr>
<tr>
<td>Ros Law</td>
<td>Disability Africa</td>
<td>Director</td>
</tr>
<tr>
<td>Richard Fatuma</td>
<td>34 Military Hospital</td>
<td>Mental Health Nurse</td>
</tr>
<tr>
<td>Roland Penn-Tamby</td>
<td>Browne Penn School</td>
<td>076 586 853</td>
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<th>Contact Information</th>
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<tbody>
<tr>
<td>Rosetta Kargbo</td>
<td>Construction and Development Partnership</td>
<td><a href="mailto:rosettakargbo@gmail.com">rosettakargbo@gmail.com</a> 076945064</td>
</tr>
<tr>
<td>Ruth Ada Kamara</td>
<td>Women Of Hope (WOfH)</td>
<td><a href="mailto:ruthkamara@cohoient.org">ruthkamara@cohoient.org</a></td>
</tr>
<tr>
<td>Salematu Conteh</td>
<td>Parent/carer, Hosanna Abdulah Special Needs School</td>
<td>088 932 817</td>
</tr>
<tr>
<td>Sarah Snow</td>
<td>Stepping Forward UK</td>
<td><a href="mailto:info@stepping-forward.org.uk">info@stepping-forward.org.uk</a></td>
</tr>
<tr>
<td>Selma Sengeji</td>
<td>SRN, MOHS</td>
<td></td>
</tr>
<tr>
<td>Simeon Bangara</td>
<td>Ballatti Academy of Music</td>
<td><a href="mailto:simonbangara@gmail.com">simonbangara@gmail.com</a> 088 357 848</td>
</tr>
<tr>
<td>Simon Ingram-Hill</td>
<td>British Council Sierra Leone Country Director</td>
<td>simon <a href="mailto:Ingram-Hill@st.britishcouncil.org">Ingram-Hill@st.britishcouncil.org</a></td>
</tr>
<tr>
<td>Steven Faileh-Luake</td>
<td>Girl Child Network</td>
<td>078 049 406</td>
</tr>
<tr>
<td>Thomas Kariayo</td>
<td>Epilepsy Association of Sierra Leone</td>
<td>078 712 443</td>
</tr>
<tr>
<td>Tiana Alpha</td>
<td>Strong World Women’s Network</td>
<td>078 738 137</td>
</tr>
<tr>
<td>Tim Miller</td>
<td>Medical Assistance Sr.</td>
<td><a href="mailto:mail@samerialeone.org.uk">mail@samerialeone.org.uk</a></td>
</tr>
<tr>
<td>Tatsi Chatsaka</td>
<td>University of Zimbabwe</td>
<td><a href="mailto:Tatsi.chatsaka@gmail.com">Tatsi.chatsaka@gmail.com</a></td>
</tr>
<tr>
<td>Ulama Kamara</td>
<td>Epilepsy Association of Sierra Leone</td>
<td>077 774 449</td>
</tr>
<tr>
<td>Umu Beattil</td>
<td>Parent/carer, Hosanna Abdulah Special Needs School</td>
<td>076 718 889</td>
</tr>
<tr>
<td>Umar Nage Lind</td>
<td>King’s SL Partnership</td>
<td><a href="mailto:Umar.nage@kcl.ac.uk">Umar.nage@kcl.ac.uk</a></td>
</tr>
<tr>
<td>Victoria Aminta Koroma</td>
<td>During Children Hospital, Freetown</td>
<td><a href="mailto:koromavictoria@gmail.com">koromavictoria@gmail.com</a></td>
</tr>
<tr>
<td>Virginia George</td>
<td>Parent/carer</td>
<td>virgin@yahoocom</td>
</tr>
<tr>
<td>Winston Yamasani</td>
<td>Epilepsy Association of Sierra Leone</td>
<td>078 712 447</td>
</tr>
<tr>
<td>Zainab Kanara</td>
<td></td>
<td>088 181 354</td>
</tr>
<tr>
<td>Marie Kamara</td>
<td></td>
<td>099 76 07 11</td>
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<tr>
<td>Osman Musana</td>
<td></td>
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<tr>
<td>Prester Loping</td>
<td>Freetown Teachers College</td>
<td>078 236 064</td>
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<tr>
<td>Rose Marie M’boma</td>
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</tr>
<tr>
<td>Rev. S. Jenkins</td>
<td>Gateway Preparatory School</td>
<td></td>
</tr>
<tr>
<td>Abdulkafor Koroma</td>
<td>Jewels Preparatory School</td>
<td></td>
</tr>
<tr>
<td>Kezi King</td>
<td>Miracle Preparatory School</td>
<td></td>
</tr>
<tr>
<td>Theresa Sunday</td>
<td>Freetown Teachers’ College</td>
<td>076 639 225</td>
</tr>
<tr>
<td>Nalama Sesay</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Melelous Kamara</td>
<td></td>
<td>030 747 481</td>
</tr>
<tr>
<td>Fatoumata Fohre</td>
<td></td>
<td>078 490 819</td>
</tr>
<tr>
<td>Cesar Koroma</td>
<td>FDYP</td>
<td>078 491 456</td>
</tr>
<tr>
<td>Alice Koroma</td>
<td></td>
<td>077 73 53 82</td>
</tr>
<tr>
<td>Fleur Mafah Sesay</td>
<td>JCBAL Student</td>
<td>076 293 265</td>
</tr>
<tr>
<td>Assanah A Fohr</td>
<td></td>
<td>078 849 550</td>
</tr>
<tr>
<td>Ethel M Lasanaya</td>
<td></td>
<td>076 903 449</td>
</tr>
<tr>
<td>Sylvester Harding</td>
<td>JCBAL Volunteer</td>
<td>088 761 178</td>
</tr>
<tr>
<td>Ishmael Sayara</td>
<td></td>
<td>030 090 694</td>
</tr>
<tr>
<td>Rita M Harding</td>
<td>JCBAL</td>
<td>076 374 842 <a href="mailto:sbu_2007@yahoo.com">sbu_2007@yahoo.com</a></td>
</tr>
<tr>
<td>Mohamed Abide</td>
<td>AIM</td>
<td>088 88 7156</td>
</tr>
<tr>
<td>Latunji George</td>
<td></td>
<td>03024757</td>
</tr>
<tr>
<td>Margaret Reeg</td>
<td>Hosanna Abdulah Sch Secretary</td>
<td>079323164</td>
</tr>
<tr>
<td>Sadiye Bevoh</td>
<td>JCBAL</td>
<td>076681001</td>
</tr>
<tr>
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<tr>
<td>Amadu M Sesay</td>
<td>Women of Hope</td>
<td>088368523</td>
</tr>
<tr>
<td>Janata Johannus</td>
<td>ICBAI</td>
<td>079959568</td>
</tr>
<tr>
<td>Angela Jonny</td>
<td>ICBAI</td>
<td>078956670</td>
</tr>
<tr>
<td>Elizabeth Sheriff</td>
<td>RBCAI</td>
<td><a href="mailto:Elizabethsgetts@ymail.com">Elizabethsgetts@ymail.com</a> 078452174</td>
</tr>
<tr>
<td>Kamara Umar Mustari</td>
<td>DMT Mozambique</td>
<td>0777747349/079964233</td>
</tr>
<tr>
<td>Dr Ronald Cenaghain</td>
<td>Movement Against Poverty</td>
<td><a href="mailto:Mohammadsesey@gmail.com">Mohammadsesey@gmail.com</a> 0775292924</td>
</tr>
<tr>
<td>Andrew W Swayze</td>
<td>Director</td>
<td>0784300760</td>
</tr>
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We are grateful for the collaboration and support of the Epilepsy Association of Sierra Leone and Medical Assistance Sierra Leone with this event.