‘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’

Sarah Snow, Medical Assistance Sierra Leone, and Mary Penn-Timity, Sierra Leone Autistic Society

Children and adults with autism, epilepsy and other disabilities in the Sierra Leone context are at extreme risk of witchcraft accusations and subsequent harmful treatment.

Mary Penn-Timity of the Sierra Leone Autistic Society and Sarah Snow of Medical Assistance Sierra Leone will share experiences from their involvement in autism and epilepsy-related initiatives in Sierra Leone.

Sierra Leone: Key Health Statistics

- **Sierra Leone remains one of the poorest countries in the world and life expectancy in 2016 was the worst in the world at 50.8 years for women and 49.3 years for men.**

- **Maternal mortality figures are the highest in the world.**

- **Almost one in five children don’t reach their fifth birthday.**

Epilepsy in Sierra Leone

Epilepsy rates are high, due to

- **birth trauma**
- **meningitis**
- **malaria**

Local studies suggest rates of between 1-2%, equating to around 100,000 people

Epilepsy Clinical Provision

In 2009 Medical Assistance Sierra Leone, Consultant Neurologist Dr Lisk and the Epilepsy Association of Sierra Leone worked together to set up the first clinical epilepsy service.

Demand was huge. In one year the pilot clinic in Freetown attracted over 1,000 patients.

- **10,000+ patients now on medication;**
- **23 clinics established nationally;**
- **Over 3,000 heath workers trained in epilepsy diagnosis;**
- **Teams of Epilepsy Support Workers are based in 3 Hubs across the country;**
- **2 EEGs purchased and available for patients**

Key Facts Re Treatment

- up to 70% of patients will have their seizures completely managed by treatment, subject to them remaining on medication;
- around 25% will see a substantial reduction in seizures;
- around 5% will not respond to medication alone.

We are however reaching only approx. 5-10% of those who require treatment.

Stigma is one of the greatest barriers to accessing treatment.

Detailed data collection at the pilot epilepsy clinics in Freetown in 2011 (Jalloh, Lisk et al, 2011) shows the need for effective awareness-raising.

- ☐ **The average person waited 6.5 years from their first epileptic seizure before seeking medical attention.**

- ☐ **Amongst patients attending clinic, 74% have experienced alternative/traditional treatment within the community for their condition.**

This will range from inappropriate treatment (eg, the wearing of amulets) to harmful and dangerous (such as drinking kerosene, and sexual assault).

Over half of clinic attendees in that study (54%) believed that epilepsy was caused by demons or bad spirits.

We have not met anyone with epilepsy who has not been accused of witchcraft, either directly or indirectly through comments made to a parent/carer or other family member. This is a universal experience for those affected in Sierra Leone.

Epilepsy & Witchcraft Accusations: Understanding the Problem

A 2018 qualitative study led by Ibrahim Bangura for MASL involved 25 individuals accused of witchcraft and parents accused of witchcraft because of the epilepsy of their child. The study indicated that:

- the main source of confirmation for witchcraft accusations are traditional healers, spiritual healers, religious leaders and other traditional leaders in the community.
- Family members were frequent initiators of witchcraft accusations.

"Originally, it was the traditional healers who alluded that I was a witch and my parents accepted the information without question". (Abu, Waterloo)

Family feud can also be exploited to levy witchcraft accusations. Musu, a young girl with epilepsy, told us that:

> *"My older sister of the same father but not the same mother was the first person to accuse me of witchcraft. She told the school that my mother was also a witch and that she has passed on the witchcraft to me so that I can harm my sister"*

Responding to Accusations

From our research and the experiences of running the clinics, very often the witchcraft accusation is made as a benign suggestion to help to find a solution to the presenting epileptic seizures. Balu, a woman with epilepsy, stated:

> *"None of our neighbors accused me of witchcraft. It was my father who had the feeling that my condition may be related to family rivalry and witchcraft as he believed that such things were not uncommon with his own family and relatives”.*
>
> *"As a result of my father's perception that some family hands were involved in my condition, I was willing to cooperate with him. So I followed him to some traditional healers who told him that my aunt - his sister - was responsible for my condition: that she was the one entering and possessing me whenever I have the seizure”.*

The data collected reveals that the majority of the respondents acquiesced to the demands to perform the requested actions following the accusation of witchcraft. The following statements are examples of this.

> *"**I always did what they ask me to do** because if I don't, it will appear that I have pre-knowledge of my condition and that I am being stubborn. I am afraid that I may be beaten or treated worse if I don't do as I was told"* (Abu)

> *"I was asked to pay Le 2,000,000 by a Muslim healer to cure the child of the witchcraft. I bargained and end up paying Le 300,000. The child's mother, when she learnt about the child's condition and the accusation became frustrated and accused me of being responsible for giving her child to witchcraft. **I would do anything. I wanted the child to be better so that I can clear my name"*** (Mariama)

> *"**I did everything I was asked to do.** I did them because I notice that the herbalist and my parents were having secret meetings. Since I was not sure what they were discussing and I felt it was for my own good, I did whatever I was asked to do".* (Balu)

Parent/carer in her 30s, Bo District, Sierra Leone

"The village elders forced me to confess that I was a witch and that I was responsible for my child's condition. I was asked to do many things that I am ashamed to talk about"

"I did these things because I could not do anything else as they were all convinced that I was a witch. My life is bitter. No one believes anything I say. I am in the community but I am not part of them" .

Those accused of witchcraft in our study recognise very well that they are in a no-win situation, hence the high rates of compliance (84%) – hoping to placate family and community members by following instructions and participate in activities that are frequently harmful and abusive.

Refusing to be Treated for Spiritual Possession

Only a few respondents claim that they refused to do what they were asked to do. Below are two examples of those who refused to engage in actions that they were told to do.

> *"I told my father that I will rather die than marry and have sex with the herbalist. I was a child and he was a very old man“* (Sallay, a girl with epilepsy)
>
> *"I was asked to buy a white sheep and told that I should always have the sheep with me wherever I go - even when I go to buy palm wine as that was the business that I was doing.*
>
> *They also told me that that they will have to cover both me and the sheep together under the blanket and cloth, with a big pot of hot medicine to inhale the steam….I refuse to walk about with the sheep. I have never seen any adult person walking with a white sheep wherever they go and I will not do it. This will make people mock me more than the epilepsy“*
>
> (Brima, young man with epilepsy living in Lungi)

What can be done?

The issues outlined above are wide-ranging and complex and involve multiple human rights abuses, affecting access to health, to education, the right to live in safety.

Epilepsy can be treated for most people, so getting access to medical services as soon as possible reduces:

- the window of opportunity for witchcraft accusations;
- the likelihood of individuals participating in alternative treatments;
- the danger from further harm as a result of uncontrolled seizures, eg burns/drowning

Promoting Accurate Health Information Through Awareness-Raising

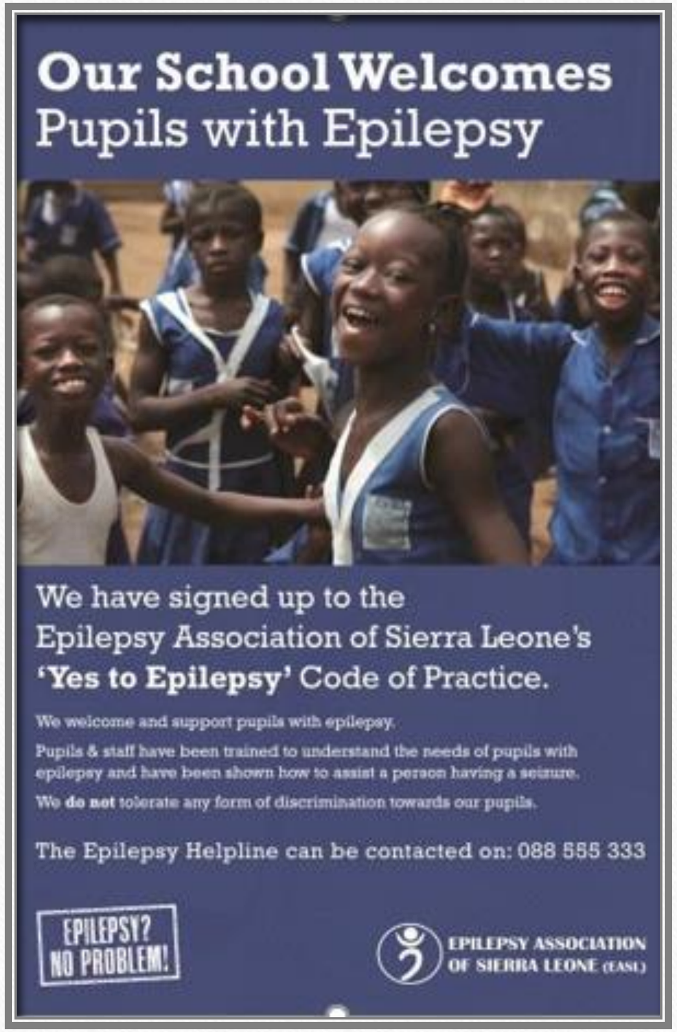
The epilepsy campaign has been developed and implemented with the key aim of promoting epilepsy as a medical condition requiring medical intervention, to challenge harmful misperceptions relating to witchcraft and to encourage people to come forward for treatment. This involves:

- The development of radio adverts/jingles;
- TV and Radio talk show appearances on stations nationally and in the provinces with self-advocates, parents/carers and traditional healers known to EASL who have refused to treat epilepsy patients as they know that their own treatment does not work;
- Community banners to promote local epilepsy clinics, and to provide the Helpline number;
- Mass marketing leaflets giving all clinic venues, with basic information about epilepsy, to go home in school bags, to be distributed at churches, places of worship, colleges and community gatherings;
- Community-based awareness sessions involving chiefs and local leaders, led by ESWs.

Our International Epilepsy Awareness Day and Week in February is very successful in bringing people with epilepsy forward – sometimes as many as 800 new patients have come forward in the weeks after this high-profile date in the calendar.

Schools awareness-raising programme

- ❑ Over 500 schools have participated;
- ❑ Epilepsy first aid training is delivered;
- ❑ Accurate information provided re epilepsy and local clinics and support available;
- ❑ Schools given a laminated poster to put in reception.



Our School Welcomes
Pupils with Epilepsy

We have signed up to the
Epilepsy Association of Sierra Leone's
'Yes to Epilepsy' Code of Practice.

We welcome and support pupils with epilepsy.

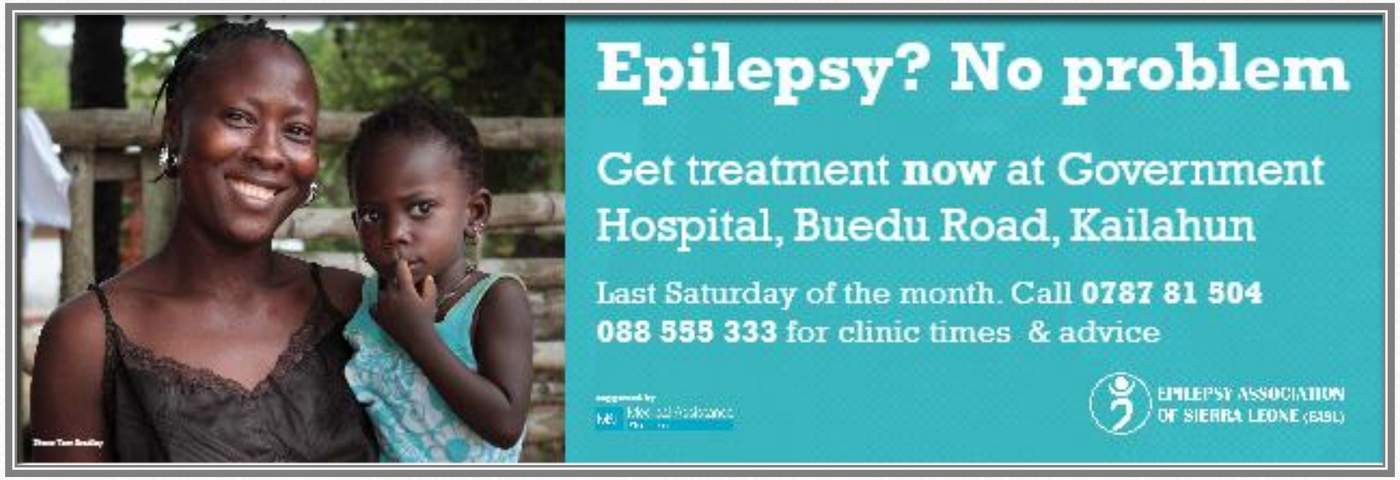
Pupils & staff have been trained to understand the needs of pupils with epilepsy and have been shown how to assist a person having a seizure.

We **do not** tolerate any form of discrimination towards our pupils.

The Epilepsy Helpline can be contacted on: 088 555 333

EPILEPSY?
NO PROBLEM!

EPILEPSY ASSOCIATION
OF SIERRA LEONE (EASL)



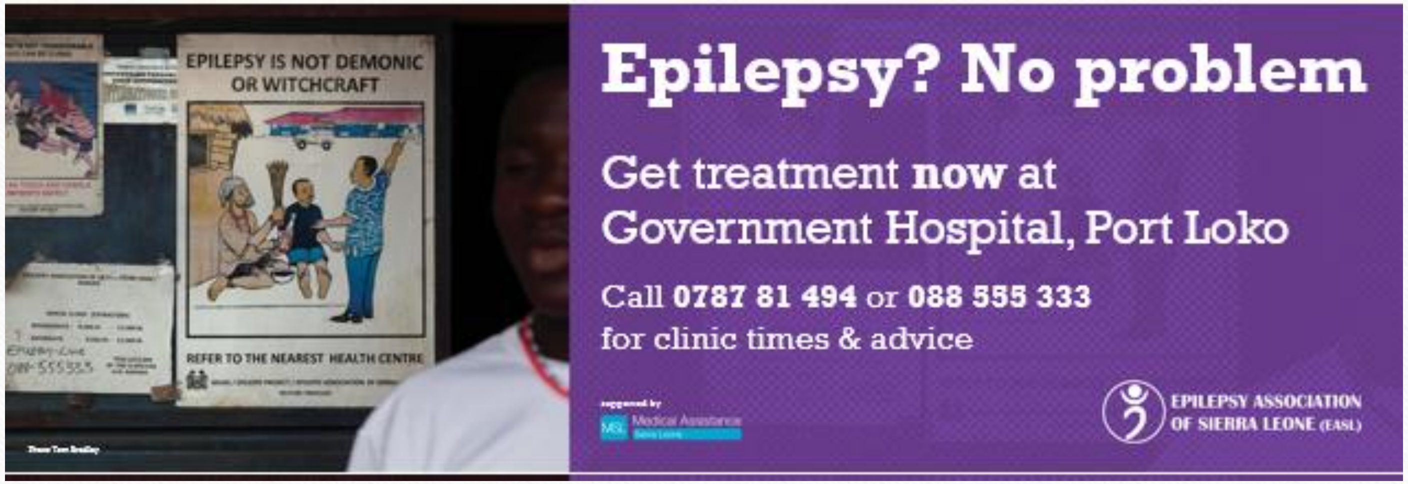
Epilepsy? No problem

Get treatment **now** at Government Hospital, Buedu Road, Kailahun

Last Saturday of the month. Call **0787 81 504 088 555 333** for clinic times & advice

supported by Medical Assistance

EPILEPSY ASSOCIATION OF SIERRA LEONE (EASL)



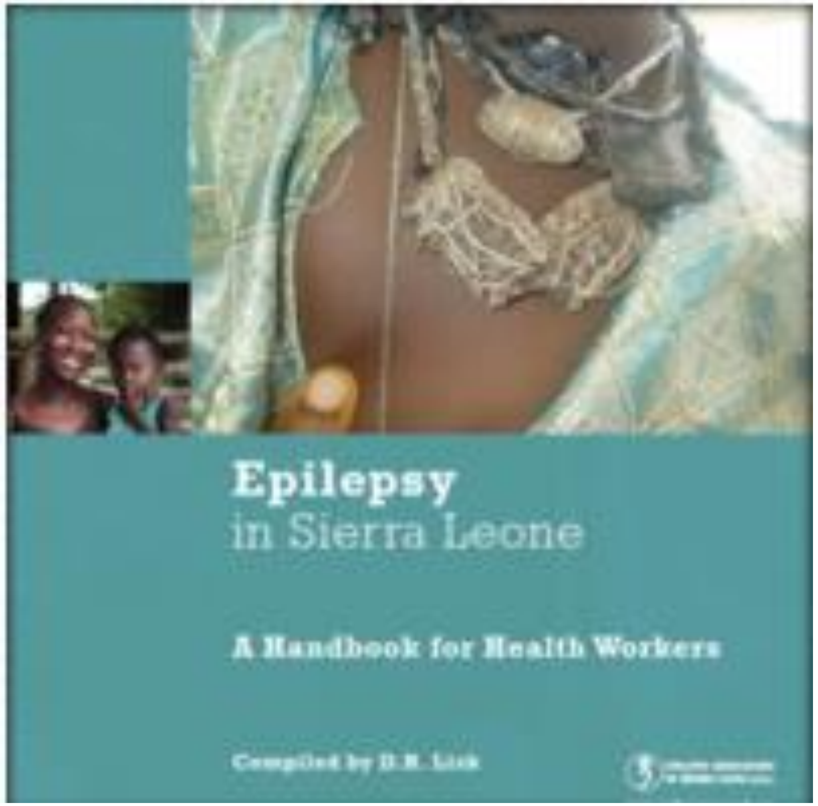
Epilepsy? No problem

Get treatment **now** at Government Hospital, Port Loko

Call **0787 81 494** or **088 555 333** for clinic times & advice

supported by Medical Assistance

EPILEPSY ASSOCIATION OF SIERRA LEONE (EASL)



Epilepsy
in Sierra Leone

A Handbook for Health Workers

Compiled by D.R. Lisk

Heath Worker Training

- Led by Consultant Neurologist Dr Lisk and the clinical team, working with the Epilepsy Assoc of Sierra Leone;
- Over 3500 health workers trained in ten years;
- Epilepsy is now on the curriculum at the Nursing Schools and at the Medical school using a module developed by Dr Lisk;
- One Doctor received a scholarship to study in South Africa, as a Paediatric Neurologist. Now qualified and returned to SL last year;

We have gathered recent data which shows 58% of people experienced alternative treatment before attending clinic – a reduction from the figure of 74% at the project start in 2011. This average figure ranges from 70% in Kabala in the North to 42% in Freetown.

We attribute this to the awareness-raising and the availability of the national network of epilepsy clinics. Many patients are coming within days and weeks of experiencing their first seizure - but this is offset by those coming forward after 30-40 years of living with untreated epilepsy.

A corresponding **reduction in reported witchcraft accusations** at clinic and **alternative treatments** is also recorded, as patients who develop epilepsy are treated promptly by medication.

But the situation is complex. Research carried out with long-term registered epilepsy patients showed that on average, 33.3 % of patients are still seeking alternative treatment after attending clinics and whilst on a successful medical treatment programme. This ranges from 45% of patients in the North of the country, to 23% of patients in Freetown.

Accelerating Change: What More Can be Done?

Removing witchcraft as a cause of epilepsy is a huge relief to individuals affected and it appears to have a snowball effect. People will know a community member used to fall down and have cuts and bruises from seizures – and now they don't after taking medication. Word is spreading that effective treatment is available at clinics and in many communities the traditional healers are not used for treating epilepsy. A number of project advocates are traditional healers with children with epilepsy.

Our awareness-raising model accompanied by the availability of services is supported by research which shows that only 25% of a social group is the tipping point that needs to be reached to affect social change. A study published in Science (2018) has quantified the number of people who need to take a stand before they can affect societal change on important topics like human rights. A rather modest 25% of people need to adopt a new social norm to create an inflection point where everyone in the group follows.

This research supports our own experiences of promoting a medical response to epilepsy and challenging the spiritual/demonic possession beliefs within concentrated communities in Sierra Leone. We have learnt that:

- Early stage research and baseline data is important for effectiveness and credibility;
- Each individual conversation, community dialogue, radio advert has a role to play. Every time someone shares accurate information or challenges a spiritual or demonic rationale for epilepsy, the impact spreads. This also creates **the 'community consensus'** that change experts say enables individuals to make changes that may go against the prevailing norms;
- Investing in quality training for health workers ensures best practice in health care but also impacts on the families and communities in which the health workers live. The 3500 health workers that the project has trained are conveying accurate messages at work and also within their communities, impacting on social change.

- Having a detailed understanding of people’s belief systems and decision-making processes is key for health and community workers so that patients can be asked the right questions and where relevant supported to make the right choices for their health.

For example, if someone is undergoing medical treatment for epilepsy at the same time as seeing a traditional healer this will affect the patient’s health and social welfare. The community-based Epilepsy Support Workers with language skills in the areas in which they are based have been key in supporting patients to access and remain on medical treatment, often against the initial wishes of their families.

- Traditional healers have been effective advocates, particularly when a family member has been affected by epilepsy and the healer passionately promotes the medical response to the condition. There are also unsuccessful examples when the traditional healer has decided that there are different types of epilepsies – some of which are treated by his methods and others which require medical intervention.

- Ongoing data collection/research to understand the evolving impact of activities.

AUTISM IN SIERRA LEONE

- There are no statistics to indicate the number of autistic people in Sierra Leone. However, there is no doubt that the disorder is prevalent.

- Epidemiological data estimates around 1%-2% of children across the globe are affected (Hahler, EM. & Elsabbagh, M. Curr Dev Disord Rep [2015]); taking this into account, it can be estimated that around 30,000-60,000 children in Sierra Leone are on the autistic spectrum.

AUTISM IN SIERRA LEONE

What is the problem?

- It is not uncommon to see people with autism in Sierra Leone; they are often referred to as " ehfulehfu" or "afflahun"

- They are accused of being witches, demonic and possessed.

- They are often subjected to harmful practices due to profound stigma

AUTISM IN SIERRA LEONE

Traditional Definition

- "Witch"
- "Debul"
- "Parents sacrificed the child for money"
- "Juju"
- "Mate Pikin"
- "Mother bathed at night"
- " Parents are cursed"

Scientific Definition

Autism is a complex neurobehavioural condition that includes impairments in social interaction and developmental language and communication skills, combined with rigid and repetitive behaviours.

MIATTA'S STORY

Miatta is a 9 year old girl with autism;

- due to limited to no diagnostic services her mum did not know what the issue was (ie. What condition Miatta had)
- Some traditional healers told mum that Miatta was a 'witch' and some said Miatta is a 'debul pikin' (devil's child)
- Miatta's mum was told to buy some items and that a ceremony will be performed to 'return' her daughter back to the 'debul' (in other words; infanticide)
- Mum said Miatta was on the verge of been 'returned' when she got in contact with Sierra Leone Autistic Society (SLAS) via SLAS' community sensitization team.
- Today Miatta is in SLAS' supported school (Browne-Penn Special School) and doing very well; and mum is a strong member of the parent support group.

FATMATA'S STORY

Fatmata is the mother of an eleven year old son with autism;

- Fatmata had been evicted many times from her rented properties due to neighbours pressuring landlords to evict her and her son Bundu.
- Bundu has severe autism and the nature of how it manifests causes him to scream loudly, and when this happens in the middle of the night (as Bundu struggled with sleep), neighbours assumed he was either a witch or possessed by the devil.
- Fatmata was suffering with depression and told Sierra Leone Autistic Society (SLAS) sensitization team she was thinking of "ending it all'; Bundu is now in school and mum received advice through support group which has helped with his sleep issues, etc.
- Sensitization was carried out within Fatmata's community and for the first time in a long while Fatmata and Bundu have a supportive community to live in

JES' STORY

- Jes is a 16 year old girl,
- Jes has severe autism
- In England where she was born 'fighting' for services was very challenging, BUT there was hope in knowing that services exist.
- When Jes and her family moved to SL (as dad wanted to go back to Sierra Leone): No school would admit Jes
- Her mum was called a 'witch', amongst other stigmatizing names and also told that Jes is a 'witch'
- as she went into crisis in front of the house one day, neighbours shouted "debul don ol am"; meaning she has been possessed by the devil.
- Jes' mum was told that she must have committed a bad sin and that's why God did that to her child.
- Jes is now in school and doing well; on the whole she is a very bubbly girl, except for when she has 'bad' days like any of us

JES IS MY DAUGHTER (THE ELDEST OF 4 SIBLINGS).

Jes is one of the few 'lucky ones'. Our family's awareness of what autism entails and the fact that we can provide for Jes' needs means that Jes has a fairly good life.

There are many families suffering in silence; accused of been witches, demon possessed, and instead of empathy they are treated with contempt; many families who are been strongly stigmatized.

SIERRA LEONE AUTISTIC SOCIETY

What is currently been done to address the issues

- **In 2017: We established the first effective school for children with autism and other neurodevelopmental conditions.**
- **In 2017: we established a community and schools' sensitization programme, as well as parent support groups.**

- **In 2018: In collaboration with RCRC and our UK partner School (West London) we started a training programmes for education, social and healthcare workers as well as parents/carers, in relation to strategies and interventions to support children with autism, and also in relation to starting a diagnostic service for children with autism .**

- **In 2019: In partnership with Disability Africa, SLAS started an inclusive playscheme where children with autism and disability, and their non disabled peers come together to play. Other needs are addressed as they become apparent; for example, physiotherapy, educational support, etc.**

SIERRA LEONE AUTISTIC SOCIETY

BROWNE-PENN SPECIAL EDUCATION SCHOOL

TRAINING OF TEACHERS, SOCIAL WORKERS, DOCTORS, PARENTS, etc.

Click to add text

Establishment of services such as the school and play scheme

- The establishment of services means that carers have somewhere safe to leave their children so they can go out and:

(i) earn income,
(ii)study
(iii) learn a trade/career
(iv) Have some respite, etc.

This has helped to propel the Browne-Penn School andSLIP communities into becoming more inclusive communities as children and adults without autism and disability interact, within their communities, with those they once saw as witches and possessed.

- Through effective training for health, education and social care workers, as well as parents/carers: been able to diagnose means that other 'harmful labels' like witchcraft, possession, demonic, have less chance of getting the attention:

ADVOCACY & COLLABORATION:

SLAS does extensive advocacy: we work with relevant Government ministries (Social Welfare, Education and Health); and we have been able to achieve the following:

- Disability as a cluster of its own on the national strategic plan
- Incorporation of support for persons with autism in relation to social action support in Sierra Leone: such as cash transfers to carers of children with autism.
- Approval for Government assistance (financial and other resources) for Browne-Penn Special School; for sustainability
- Assistance from the Ministry of Social Welfare for children and young people with autism; for example, welfare grants.

SLAS works with other relevant organisations to add value:

- for example, we work with an NGO who provide physiotherapy for those children who need it, etc

SENSITIZATION & COMMUNITY SERVICES

- SLAS has teams of trained volunteers and other trained personnel who go into the communities (including schools, churches, mosques, etc) to spread awareness;
- For example, that autism is not related to witchcraft , demonic possession, and other harmful labels
- That you can have your belief, but your belief should not 'harm' anyone.
- Our sensitization programme has led to many seeking support from SLAS; and we are then able to further work with those who seek our support in ensuring that harmful practices are stopped, and children are protected. We also provide counseling for carers.

- Additionally, we see that communities become more inclusive as a result of our sensitization programme, and our community services. For example, (i) we have regular meetings with the Browne-Penn and SLIP communities whereby we update them, and ask for their feedbacks, (ii) we have community members/leaders within our Carers Teachers Association and School Management Committee. We involve and invite community members to some events; such as for our parents/carers outing.

What more needs to be done?

It is the combination of provision of key services, integrating children within their communities, support groups, key trainings, effective advocacy, collaboration with relevant others, and sensitization: that have led to more inclusive communities where we work, and many carers declaring that they will not 'return' their children with autism and other cognitive impairments . Cash transfers to carers as a result of our advocacy, have certainly added value. However, we are only reaching a very small number of children and their families, so the work needs to be scaled up.

- **We need to work more with traditional healers as they are linked to the harmful practices been directed at children with cognitive impairments and disabilities: that's not to say that there are no good elements to traditional healing.**
- **More effective working with the social welfare ministry, the police and the Family support unit, specifically in relation to child protection, needs to be focused on as there are many flaws in dealing with child protection issues.**

To conclude:

- Miatta, Bundu and Jes are not witches or devil possessed; they just need:

- People to have awareness of what they are going through; what it means to have autism and other health conditions that are linked to 'harmful labels'.

- They need services like any other children; a safe learning environment, health care, and to be integrated/be seen, and participate, in their communities.

- Whilst the political will exists, the resources are limited to none. Sierra Leone needs support to address the stigmatization and the lack of resources including expertise.

- SLAS was set up as a direct result of our family's frustration of been stigmatised and refused services for our child, and we realised that if something wasn't done to change the situation, many children like Jes, would continue to be subjected to stigmatization and other harmful practices.
- Whilst SLAS is doing very well, and working to complement government's efforts, support is needed to expand the services.