



FACILITATOR MATERIALS

November 2019

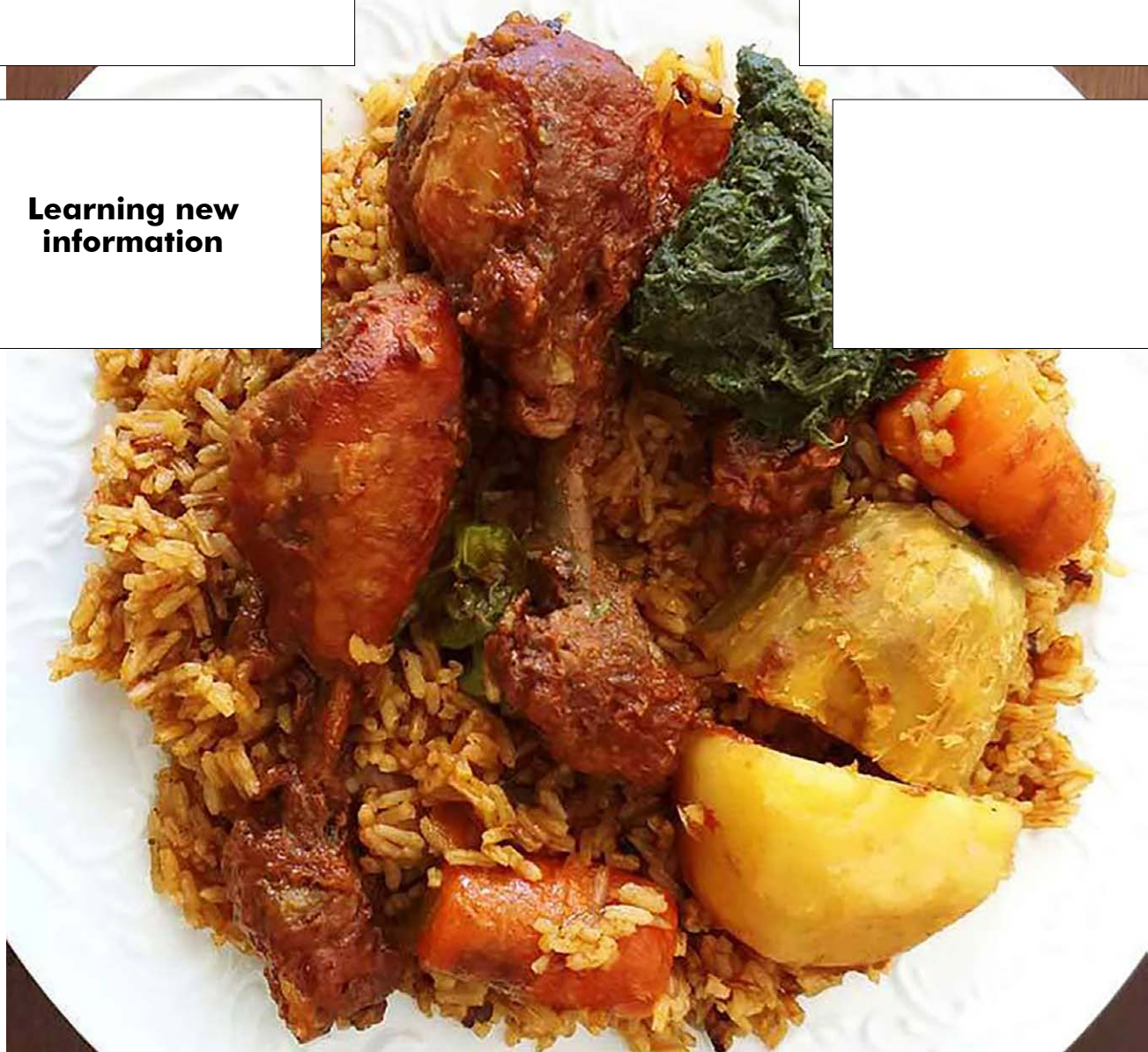
Facilitator material 0.1

**Making contact
with other families
with children with
disabilities**

**Being more
visible in my
community**

**Learning new
information**

**Understanding
that myself
and my child
have rights**



Facilitator material 1.1: James the investor

James goes to school with his best friend, Abdul.

James's mother says that when she leaves James at home, and there is someone who passes by the house, that he will describe the person and his characteristics when she returns. He knows the difference between right and wrong and this makes her happy.



Facilitator material 1.2: James the investor

James tells his mum that if he was able to walk, he would have done work for her. Words like these give her hope. James' father says that he chooses to love James because the doctors explained his disability. He says that other parents fear this, but he chooses to be strong and to love James. He gives advice to all parents and says to take care of children with disabilities and to love them because they are special and have no problem. He says that of all his children, James is special, and he is able to look after his younger siblings.

James' mother explains that the counselling and training given to them at the hospital was important. They had a way of comforting them and this has given her patience.



Facilitator material 1.3: James the investor

James says that he is grateful that his mother did not abandon him. She loves him, and he loves her more than anything else in the world.

He says that other children like him deserve to go to school so that children can get used to people with disabilities as they abuse children like him, not out of hate but out of ignorance.



Facilitator material 1.4: James the investor

This is James' brother. As well as James's brother, Abdul is his best friend. They share secrets and they became like brothers.

They have started an organisation together.

James' mother wishes parents to take care of their children because children sustain us. James can help to wash. He always makes Abdul laugh.



Facilitator material 1.5: James the investor

James says that he can handle life's hurdles and turn out better than those who do not like him. His mother would like him to be a computer expert.



Facilitator material 1.6: James the investor

James ends "I would like to tell those who look down on us that we are not bad children and we ask of them that they love us like we love them too, so that it is easy for them to live with us".



Facilitator material 2.1

Group 1: Togetherness and belonging within the FAMILY

These stories should bring out the following issues for discussion:

1. Role of the father (positive and negative)
2. The importance of finding other 'allies' (these can be friends or people who have power in your community) to help you
3. The use of negative language which should be challenged

Story 1- Steven

My name is Steven and my wife sells fruit juice.

She cannot sell enough fruit juice and we went bankrupt. This happened because the wife of the person who rented us our house told our neighbours that our child's saliva was falling into the juice.

Her children also beat my son, and I think that she told them to do that.

I became angry and I made the decision to move us.

We changed homes.

In our new neighbourhood, I often place our child in his wheelchair to go greet some neighbours. Not everyone likes it. Nevertheless, I am doing what is right for my child. I sometimes take him to watch soccer on tv.



Facilitator material 2.2

Group 1: Togetherness and belonging at the COMMUNITY LEVEL

These stories should bring out the following issues for discussion:

1. Use of traditional doctors
2. Polygamous marriages
3. Value of community engagement
4. Disability in the workplace
5. The issue of disgust and drooling
6. Positive ideas of what can be done

Story 2 - Rose

My name is Rose.

I signed up to learn hair dressing and some of my classmates used to gossip about me because I used to go with my baby. They would say "that child is a 'mugongo', and the child scares us because her eyes always look up" ('mugongo' means stiff or unable to move and is used with a negative attitude)

I became angry and quarrelled with the women, and we even ended up in the administrator's office.

The administrator told my classmates off for gossiping about my child. The next day one came and apologised to me. She had gone home, and her child was burnt, and she thought that I wanted her child to be like mine.

The administrator told them to stop having wrong perceptions about my child. She also said how she loved my child. Now, even before everyone at the institute has their tea, my child is the first to be fed.

Facilitator material 2.3

Group 1: Togetherness and belonging the HEALTH AND EDUCATION SERVICES

These mini stories should bring about the following issues for discussion:

1. Examples of inclusion and exclusion
2. Negative traditional practices
3. Engagement of men

Story 3 - Bernadette

My name is Bernadette.

There was a time when I took my grandson to a health centre. The doctor asked me what happened to my child and said that children like mine do not grow. He would not attend to her, and left the room.

He did this because he thought that he was wasting energy on a child who was going to die. The doctor who normally attends to her came back, and gave her the medication.

I cried because I felt that my grandson was discriminated against.

Facilitator material 2.4

Group 2: Togetherness and belonging within the FAMILY

These stories should bring out the following issues for discussion:

1. Role of the father (positive and negative)
2. The importance of finding other 'allies' (these can be friends or people who have power in your community) to help you
3. The use of negative language which should be challenged

Story 4 - Mary

My name is Mary and I am 11 years old. This is my sister, called Blessing.

Some people in my family do not like to hold Blessing because she drools, and they say it disgusts them, especially when they are eating. This makes my mum upset.

My uncle loves Blessing, and he always send milk every day for her. He also pays for a motorist to take Blessing and my mother to the hospital for her check- ups.

Facilitator material 2.5

Group 2: Togetherness and belonging at the COMMUNITY LEVEL

These stories should bring out the following issues for discussion:

1. Use of traditional doctors
2. Polygamous marriages
3. Value of community engagement
4. Disability in the workplace
5. The issue of disgust and drooling
6. Positive ideas of what can be done

Story 5 – John

My name is John, and I am a father of a 2-year-old daughter. We live in Uganda.

We need communities to be sensitised about cerebral palsy (and other childhood disabilities). They need to understand that it is an illness that is not spread, for example, when this child drools. The saliva does not infect you. Then people won't look at our children as disgusting things. What I think is that the government should sensitise people about cerebral palsy.

Then, even us as parents will not be discouraged to look after our children. We won't hide our children away, and husbands won't leave their wives. It can be sensitisation through posters, or in hospitals during immunisation day, and they will know it is not the mother who is to blame for the condition.



Facilitator material 2.6

Group 2: Togetherness and belonging in the HEALTH AND EDUCATION SERVICES

These mini stories should bring about the following issues for discussion:

1. Examples of inclusion and exclusion
2. Negative traditional practices
3. Engagement of men

Story 6 - Blessing

My name is Blessing.

I told the doctor that my child had a tongue tie (akanyata) and I wanted it to be cut so that my child could cry louder.

He asked me what happened to my child. I told him that she got tired during birth. He replied that it was not a tongue tie, and that even though it was cut, my child would not cry louder and her condition would not change.

I felt discouraged that he called my child "kano akaana" meaning a child so small. He should have called him "omwana" meaning a child.

I have never gone back.



Facilitator material 2.7

Group 3: Togetherness and belonging within the FAMILY

These stories should bring out the following issues for discussion:

1. Role of the father (positive and negative)
2. The importance of finding other 'allies' (these can be friends or people who have power in your community) to help you
3. The use of negative language which should be challenged

Story 7 - Carol

My name is Carol, and I live in Uganda.

My husband chased me away from the house because I had a child, Joyce, with cerebral palsy. He called the child 'ekikulekule' meaning 'something which is useless'. I had nowhere to go but went to the chairperson's place (head of the village). The chairman offered me a room.

I don't know what to do any more. I have heard that my mother-in-law is now looking for a second wife.

This is my only child. I will not have another child because my in-laws say that I give birth to snakes. I am afraid to have another child with cerebral palsy.

Facilitator material 2.8

Group 3: Togetherness and belonging at the COMMUNITY LEVEL

These stories should bring out the following issues for discussion:

1. Use of traditional doctors
2. Polygamous marriages
3. Value of community engagement
4. Disability in the workplace
5. The issue of disgust and drooling
6. Positive ideas of what can be done

Story 8 - Maria

My name is Maria, and I live in Uganda.

People say many bad words about my daughter, and they blame me because I am the 'co-wife' in the house. But I just have to be strong and look after my child.

Many people advised me to go to traditional doctors, but my husband has been supportive and has refused to take my child to the traditional doctor. He says my child is not bewitched.

I listen to people's words and I become sorrowful, but I can't do anything but listen to their words.

It is my responsibility to love my child, and do my best for her. Now I take her to the market with me, and I also find support with other families that have similar children.



Facilitator material 2.9

Group 3: Togetherness and belonging in the HEALTH AND EDUCATION SERVICES

These mini stories should bring about the following issues for discussion:

1. Examples of inclusion and exclusion
2. Negative traditional practices
3. Engagement of men

Story 9 - Betty

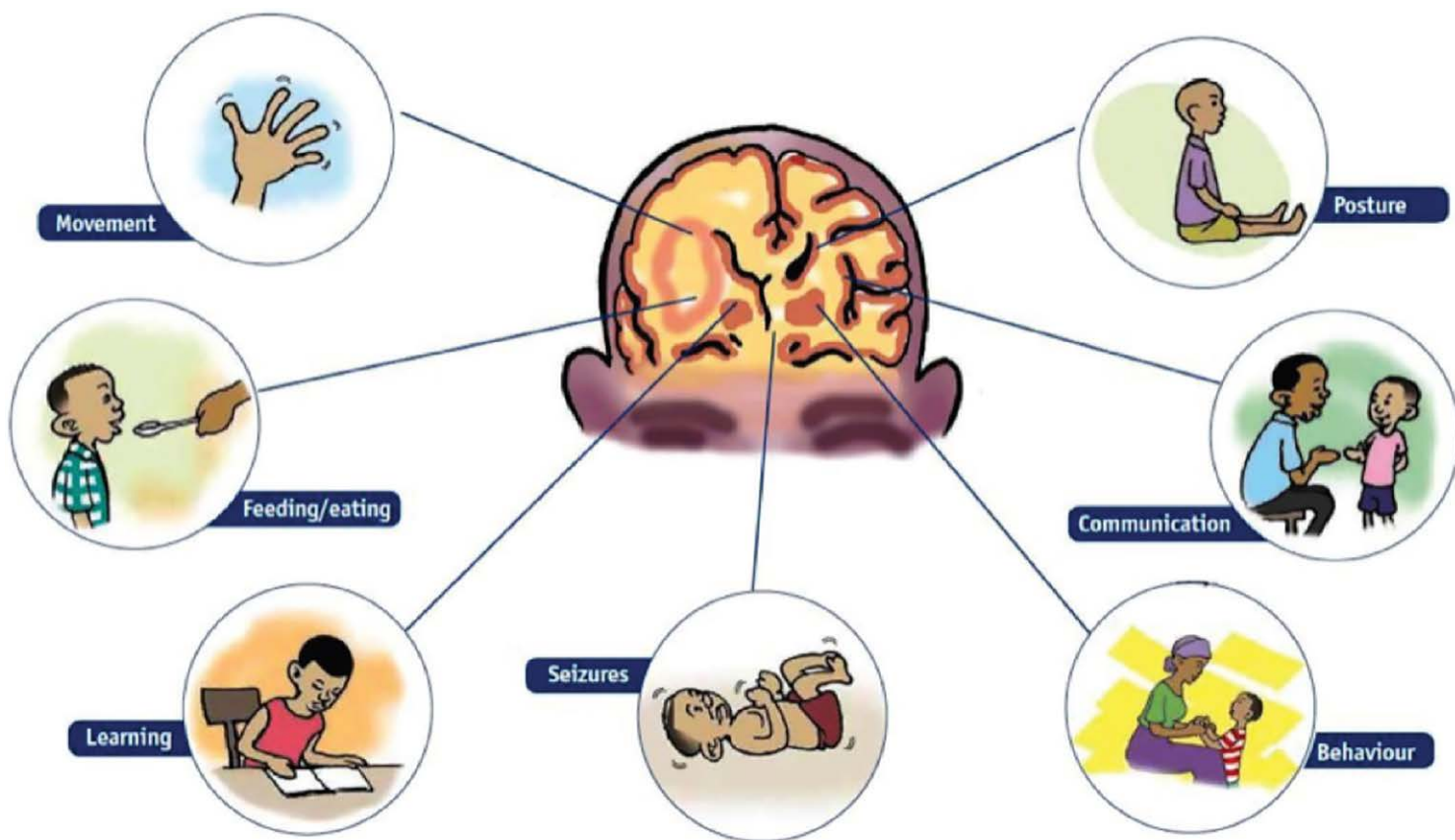
My name is Betty, and this is my son, James. I live in Malawi in a small village next to the main road. I am a trader in the market. I used to cry all day, and I did not take my daughter to the market because I thought that people would think that I have poor personal hygiene because of the way my child looks. Because she is drooling, people may lose their appetite to buy food. But my brother-in-law advised me to take my child to pre-school. They welcomed my daughter, and the other children also played with her and loved her. They understood that the drooling was part of her condition and was not infectious. My daughter also learnt to dry her own face with a small cloth, so that it did not soak her T-shirt.

Story 10 - Community Radio

A disability organisation in Uganda (The Spina Bifida Association) were offered to present on a radio slot. Normally it was always the mothers who presented; they often talked about how their partners had abandoned them. On one occasion a mother testified how supportive her husband was, and the radio station asked for more presentations from men who were still in the home with children with disabilities.

Three dads went and shared their experience; how they also wanted to run away at the beginning! After some time, they began to understand the condition, and to help more. But it was not always simple, as there was a lot of pressure from their families and peers. They called on their fellow men to stay and support the mothers and children with disability, and appealed to organisations to encourage men and let men come on board.

Facilitator material 3.1



Facilitator material 3.2



Facilitator material 3.3



Facilitator material 3.4



Facilitator material 3.5



Facilitator material 3.6





LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE



International
Centre for Evidence

in Disability