

Self Help Kit

Forming and Maintaining a Parent Self Help Group:

A discussion guide for parents /
caregivers of persons with
intellectual disabilities



Supported by:



Landsforeningen LEV was founded in 1952 by parents from all over Denmark. The mission for LEV was and still is to advocate for all people with intellectual disabilities and their families and inclusion for all in the society

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Foreword

Persons with Intellectual Disability (ID) in Ghana are the forgotten and voiceless people of our country. The cultural stigma and challenges faced by parents/caregivers of persons with ID in Ghana is so strong that many parents/caregivers hide their children or are reluctant to take a stand against the discrimination and abuses experienced by their children and family. Inclusion Ghana believes that this situation will change by giving support to parents/caregivers to come out of the shadows and demand equality and rights for their children. With this rationale, Inclusion Ghana supports the formation of Parent Self Help Groups (PSHGs), which are the key building blocks to creating grass roots change in Ghana, and gives groups ongoing support and training.

The benefits of PSHGS are clear: members often form close connections and in doing so, create a place of acceptance and provide one another with support. PSHGs are also places of learning, advocacy and awareness raising. Passionate and unified parents/caregivers have great power when they work together to create change.

This Self Help Kit (Kit) is first and foremost designed for parents/caregivers of persons with ID. We hope this Kit will inspire parents/caregivers to form PSHGs and also motivate those who have formed groups to continue to meet, discuss challenges they face in the community and come up with ways of solving them as well as work towards improving the lives of persons with ID in Ghana.

We wish to thank a variety of people who contributed to the development of this Kit. We are grateful to our board, staff, volunteers and member organisations, who contributed their expertise. We also thank the parents/caregivers themselves, who generously shared their experiences, feelings and hopes for what PSHGs can achieve. Special appreciation goes to Landsforeningen LEV and the Danish Disability Fund for their kind financial support.

Sincerely



Auberon Jeleel Odoom
National Co-ordinator
Inclusion Ghana

Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.

- Margaret Mead

Inclusion Ghana Profile

Inclusion Ghana (IG), a member of Inclusion International and Down Syndrome International, is a network organization working to reduce stigmatization and ensure full inclusion of all persons with intellectual disabilities (ID) and their families by advocating for their rights and needs. IG envisions equal opportunities and inclusion for all persons with ID in Ghana and has four main intervention areas:

Training

- ✎ Strengthening the capacity and existing institutional structures of member organizations to support their quality service delivery to persons with ID and their families

Research

- ✎ Performing research to advocate for the improvement of the lives of persons with ID and their families

Education

- ✎ Maintaining an authoritative body of information and knowledge about ID
- ✎ Supporting proactive community outreach by education of member organizations
- ✎ Providing accessible information that supports stakeholder ability to make informed choices

Advocacy

- ✎ Advocating for inclusion, and participation in all aspects of life for persons with ID and their families
- ✎ Proactively informing, influencing and developing public policy at the community, regional and national levels in collaboration with the greater disability community
- ✎ Supporting court action or other initiatives by persons with ID and their parents/caregivers to demand their children's rights

Purpose of the Kit

Hi, my name is Gifty Nyamekye. I will be the storyteller for this Kit. I will tell you more about my family and myself in a little while. First, I'll tell you about what you have in your hands and how to use it.

This book is a Parent Self Help Kit developed by Inclusion Ghana for parents/caregivers of persons with intellectual disabilities and also organizations wanting to form parent self help groups (PSHGs). It gives input on how parents/caregivers of persons with ID can come together, help and support each other by forming PSHGs. In this Kit, you will follow 5 different families. These families have different lives in many ways but they all have something in common; a child with ID. It is not about which child is the most or least disabled. It is about parents/caregivers talking about their experiences and thoughts and working to improve the lives of their children as a group.

All the material in this Kit is fictional but you may recognise something from your own life in the family situations and stories. You may recognise the life conditions, opportunities and challenges they have or some of the feelings the parents/caregivers express about having a child with ID. You may also read about some familiar situations like going to the market, mosque or to church.

This Kit will guide you through how to set up a PSHG and the benefits that joining a PSHG might bring parents/caregivers and also their children. You can also use it as a tool to work through issues that those in your group face and help you to guide discussion. This Kit cannot stand alone but is a guide towards how to cope and take action in various situations and how parents/caregivers can help and support each other.



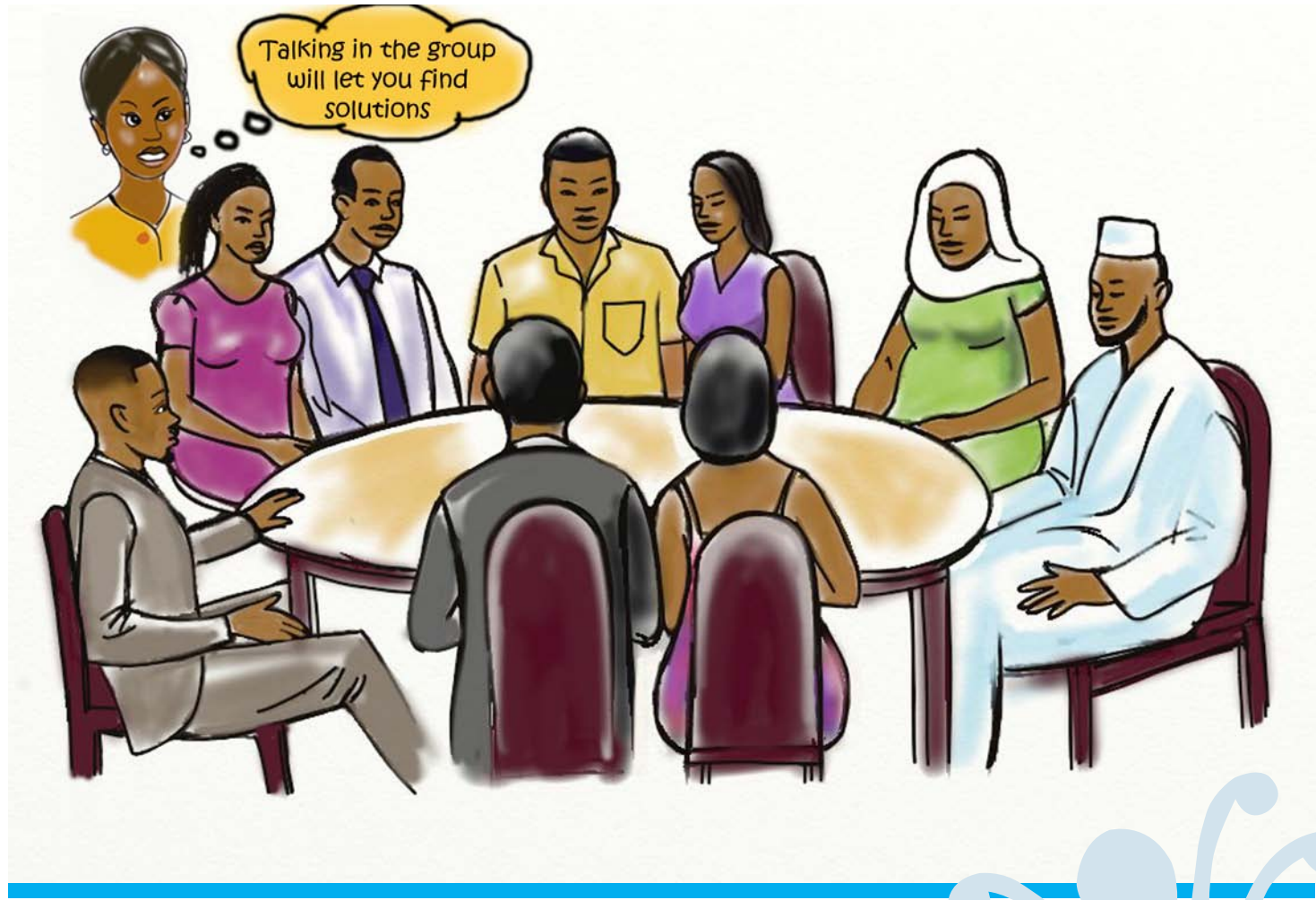
What is a parent self help group?

Through this Kit you will learn more about how to form and run your own PSHG. As a starting point though, I would like to give you an overview of what a PSHG is and how you can form one.

A PSHG is a group of between 5 and 10 parents/caregivers of persons with ID. The group is formed:

- ☺ to give parents/caregivers a chance to meet others with the same difficulties;
- ☺ to help and support each other;
- ☺ to talk about their problems together and find solutions as a group;
- ☺ to learn from one another on how to raise a child with ID;
- ☺ to learn about services that are available to help their children; and
- ☺ to work together to improve their lives and the lives of persons with ID.

Can you think of any other reasons why a group is formed?



Overview of forming a parent self help group

The background

It can take some effort to set up a PSHG. This is because parents/caregivers of persons with ID may not see the point in meeting with other parents/caregivers. However, new groups are started each month by ordinary people with a little bit of courage, a fair sense of commitment, and a good amount of caring. As this Kit will explain, the benefits to parents/caregivers and their families from joining a PSHG can be significant.

Remember that in the PSHG, people will sometimes share emotional experiences. Therefore, to encourage sharing and a common history, the group should all be parents/caregivers of children with some type of ID. This will make it easier for members to share their experiences and challenges, as well as their solutions and successes. Parents/caregivers belonging to a group will also be empowered to break certain myths, views, and perceptions of society towards persons with ID.



Bring your experience
and challenges to the
parents/self help group
meeting

Do

The illustration shows two women in conversation. The woman on the left, wearing a purple top and a light blue headscarf, has a distressed expression with her hand to her face. The woman on the right, wearing a yellow patterned top, is speaking to her. A yellow speech bubble above them contains the text 'Bring your experience and challenges to the parents/self help group meeting'. Three small circles between them suggest sound or emphasis.

Identifying parents/caregivers for a parent self help group

Ok, now that I have given you all the important information about PSHGs, I will explain to you how my group was formed.

Many people in my community know my family and I, because I am often quite outspoken about my son, who has an ID. I have also been involved with an organization that helps families and persons with ID, called Inclusion Ghana. One day a woman from Inclusion Ghana, Alice, approached me and explained that parents/caregivers of children with ID can form PSHGs, as a way of giving each other support and learning about how to give better care to the children. Alice said that if I know any parents/caregivers that have children with ID I could bring them to the local school for a meeting next week where we can learn more about joining a PSHG.

After Alice left, I immediately thought of Esi Maame who lives a short walk from my place and who also has a child with ID. That day I spoke to Esi about coming to the meeting and gathering other people that she knew who might be interested. Esi was shy and said she was afraid bring her child out with ID. I told Esi that I understood this feeling but that this was a chance for us to do something for ourselves and for our children. After all, didn't we want a better life for our children? It is time to take a stand and trust that we can change our futures. Finally, Esi agreed. Together we went and met four other families in the community that we knew of with children with ID. Each agreed to attend the meeting.

Do you know anyone in your community who is a parent/caregiver to a person with ID that you think might benefit from joining a group?

What are good ways to find new parents/caregivers to join a PSHG?



Family Situation 1

I would now like to introduce my family and then each of the other families to you.

My husband and I are separated and I raise our three children by myself, without any support from my husband. My husband left our family after finding out that our third born son, Nii, had an ID. Nii had asphyxia at birth, which is a lack of oxygen. The doctor tried to help him but after a few days of observation the doctor confirmed that my child had experienced effects from the lack of oxygen and he has been diagnosed with cerebral palsy. As a result my child has both a physical and an intellectual disability.

Nii took his first steps at the age of three and by that age he still could not talk. Since that time my son's development has been very slow. For a long time his speech was still not clear and to other people it seemed like he spoke unintelligibly. With much patience I could understand what he expressed. At age 6, my son child learned to walk confidently and I sent him to a nearby inclusive school. His speech has improved a lot and now, at age 12 he can recite a poem even though with some difficulty. He can't write well but he can write some letters. He is sociable and enjoys being around people that love him. I am very proud of the progress my son has made, although it has been a difficult journey.

Do you know this situation?



Family Situation 2

I will also introduce Esi Maame's family. Esi's family lives on a small plot of land on the outskirts of the community. They have two rooms in their house and the pit washroom is in a shed next door. In their backyard the family has a small farm where they grow yam and mangoes. She has two daughters and her second was born with an ID. At first she developed the same as her sister but then at age three she stopped talking and walking. It was like she forgot what she had learned. Around this time Esi was forced to stop working, so that she could care for her fulltime. Esi's husband continues to work as farmer but most of the money that the family has is spent on medication and medical treatments for their second daughter. Her daughter was not toilet trained for many years and friends would say to her "why are you wasting your time with that child, it should be killed". Some people in the family also thought her daughter was a curse and advised her to dump the child in the river. Esi tries to protect her daughter from these mean comments by keeping her inside. It was very painful for Esi.

Esi's daughter can only communicate through sounds, which only Esi can understand. Her daughter is unable to work on the farm and generally sits in their house all day.

Can you recognise something like that from your own family?



Esi stops work and takes care of her ID child fulltime



Esi's husband spends most of his money on medical treatments

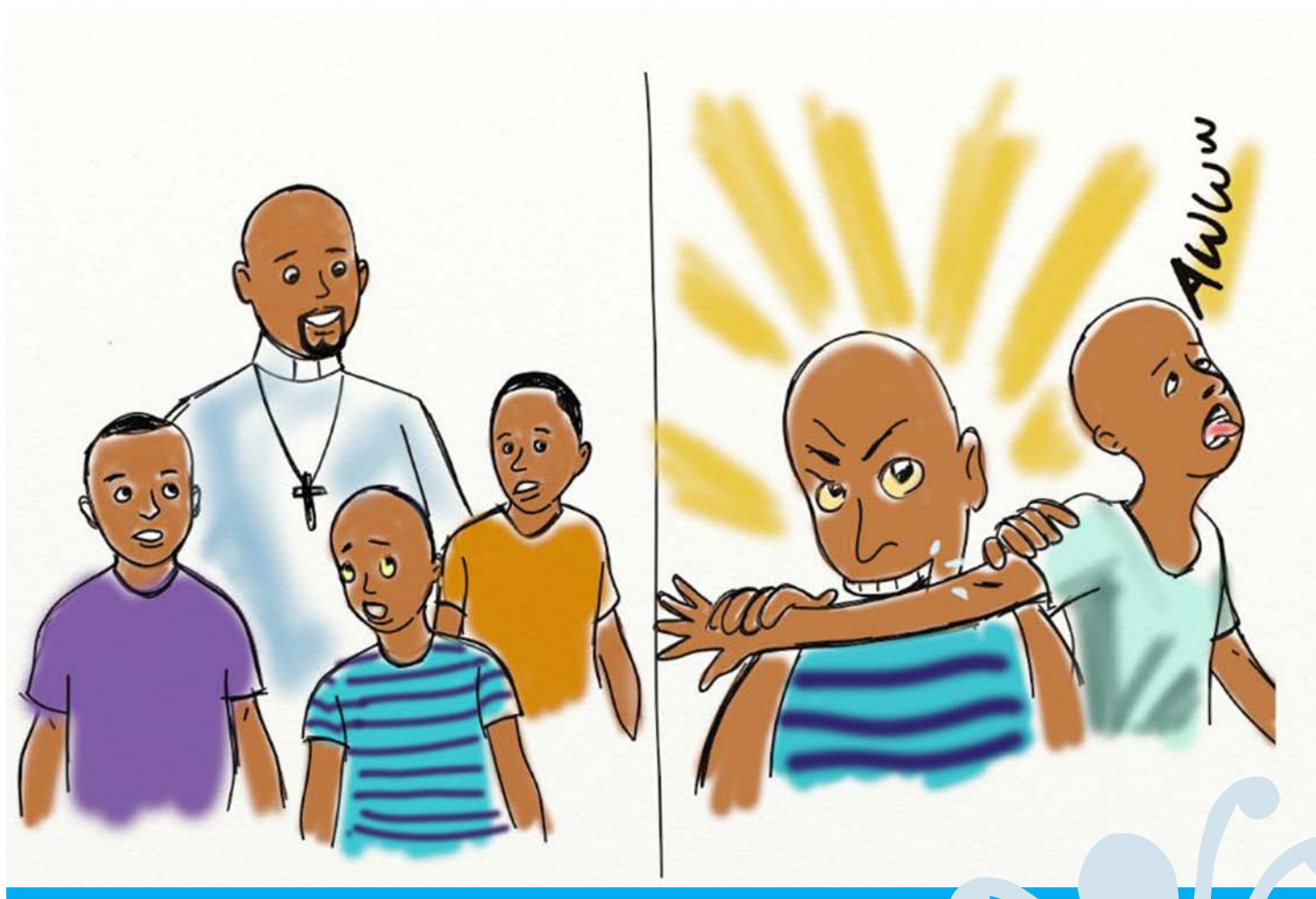


Family Situation 3

Another person that has agreed to come to the meeting is Kwasi Boateng. He is a priest in our area and has a son with an ID, Kofi, as well as two other sons. They live in a small house near the church. Kwasi cares for his three sons by himself. Kwasi's son Kofi has challenging behaviour sometimes. He can become agitated and rock uncontrollably. He also tries to bite himself and others and this can worry people around him. It is hard to calm him down.

Kwasi is often called to work at all different hours of the day and he finds it hard to ensure his son gets the care he needs when he is away. Some members of his church that have spent a lot of time with Kwasi have learned about his son and how to respond to his needs. These community members help a lot.

Is this family similar to yours?

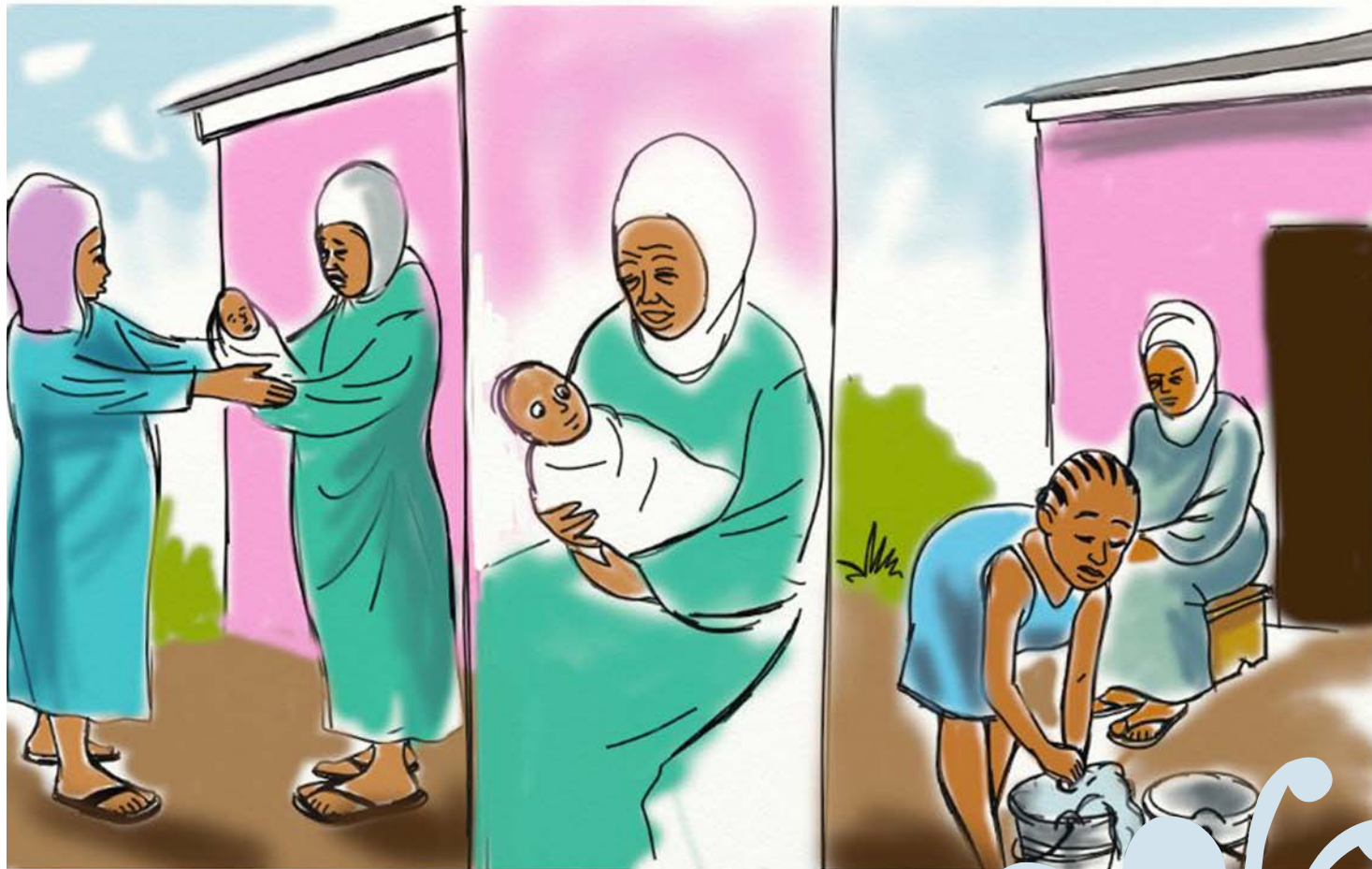


Family Situation 4

The fourth family is that of Ayishetu Ali. Ayishetu is the grandparent and guardian to Ama, who has an ID. Ayishetu's daughter Naa, and her husband had five other children when their last was born with an ID. She started having convulsions after being just a few months old and her development was slow. Naa was afraid that her husband would leave her due to the fact their sixth born had an ID, so when Ama was one year old, Naa decided the girl was too much of a burden on her and she left her with Ayishetu to be cared for. Now Naa and her husband rarely visit Ayishetu and Ama, as they prefer to pretend they never had a sixth child. Their marriage was on the rocks for a while but since Naa left the child with Ayishetu their relationship seems to have gone back to normal.

Ayishetu says that every child is a gift and she has been very dedicated to caring for Ama. Ayishetu has made sure everyone in the community knows Ama and she takes her with her everywhere she goes. Through Ayishetu's encouragement and attention I have witnessed Ama develop greatly over the years. In fact, she now is able to wash her own clothes and she even supports her mother to sell petty items in the market!

How is this family similar to yours?



Family Situation 5

Another family in our community is the Botsio family and the father, Toufic, has agreed to come to the meeting. There are eight people in the Botsio family; Toufic, his wife, Abena, and their six children. Their third born son was born with an ID. Toufic and Abena didn't realize their child had an ID until he was older. Toufic is a well known professional photographer and Abena is a nurse. The family is well respected and the rest of the children in their family are doing very well at school. In fact, the first born is studying law. Many people in our community do not even know about the family's third born child as he has been kept inside for many years and very few people have met him. I only found out because one day Abena gave medical treatment to my son with an ID. Whilst treating him, Abena asked me many questions about his development. Eventually she confessed that her child had similar difficulties. I was surprised and I think that maybe seeing my son being able to communicate inspired Abena to learn more about her own son and his potential.

Does this situation seem familiar to you?



First Gathering

Getting to know each other

Today is the day for our first meeting at the local school. The woman from Inclusion Ghana, Alice, has joined us and we have set up some chairs in a circle. I was feeling a bit nervous about how the meeting will go. I arrived first, then Esi, Ayishetu, Toufic, and Kwasi Boateng with his son. Alice has suggested that it is actually a good idea if we bring our children along with us to the meetings for more interaction and so that when they are older they can participate in the group.

To break the ice Alice suggests that we introduce ourselves. Alice has told me that it can sometimes be difficult to share personal stories, so I decide to start by introducing myself first and talking about my family and child with an ID. It was hard to get started but once I did the words seemed to come easily. As I talked I could see the other parents/caregivers relax and they also started sharing their situations briefly. Ayishetu mentions that her grandchild took a very long time to learn to walk. Toufic mentions that his child does not talk so well.

After that, Alice started by telling us about the main reasons for our gathering. She talked to us about Inclusion Ghana and what they do. She also told us about PSHGs and the need for parents/caregivers of persons with ID to meet, form groups and support each other. After Alice has finished talking, all of us were happy and interested.

How can a good meeting run with sharing personal experiences?

How can you get to know those in your group?



First Gathering

Deciding meeting topics

After Alice explained the PSHG concept to us, she asked us to think about the topics we might like to discuss in the future. We agree that having a child with an ID can be hard and that it is important that we talk about family life.

I mention that I would also like to discuss how to cope with being a single parent. Esi says she would like to talk about how to avoid the family break ups you hear about when people have a child with ID. Ayishetu would like to discuss how to handle the isolation from the extended family as her family has now stopped visiting her and her grandson. Esi says she has experienced the same thing.

Alice suggests writing a list of future topics so that we make sure to cover them all. She says that at each meeting we should pick the topic for the next meeting so that we can have an organized program.

Are the ideas the group talks about also relevant for you when you think about your family life?

Are there other things your group would like to talk about?

.... being a single parent



Family break ups



Isolation



First Gathering

Agreeing to form a group

As I look around the room at the new faces who have come together to meet for the first time, I start to feel a connection with these people. Although we have a lot of differences in our families and our lives, we all share something in common: we have a child with ID.

I tell the group that I have a lot to learn from them all. Kwasi agrees, saying that although his congregation gives great support, the challenges faced by parents/caregivers are unique and he is glad to have people to talk to who understand his situation. Everyone is nodding as he says this. We all agree that we want to continue to meet.

Alice says that to form a PSHG we need to pick a leadership, as well as a regular meeting time and place. The group votes me as the temporary leader and I offer to call everyone prior to the next meeting to remind them to come. We agree to hold the meetings at the local primary school every two weeks on a Monday evening as this is the best time for everyone. We also decide to hold a ballot election at the next meeting to decide our ongoing roles in the group.

Toufic says that there is so much to talk about when it comes to our family so we decide it will be the topic for the next meeting. We all leave the school that day feeling a little more positive about the outlook for our children.

What other places could you hold your meetings at?

How can you ensure parents/caregivers come to the next meeting?



First Formal Meeting of the PSHG

Choosing the leadership

Two weeks have passed and it is time for our first PSHG meeting. When I called each of the parents/caregivers to remind them of the meeting they each were enthusiastic about attending and I am glad to see them all again. More of the group have brought their children along and they are getting to know each other. Community members are noticing us as they pass by, with curious looks on their faces.

Alice is at the meeting again as support. She has prepared some pieces of paper for us to write on for our leadership ballot. We first write our nomination for leader and put this in a box. I receive the most votes and so am the leader. I am excited and proud the group would like me to lead them. Next we vote in Toufic as the secretary.

Alice also suggests that we make some rules for the group. Ayishetu says we should turn our phones off or to silent mode during meetings, Kwasi offers that we should all arrive on time. Esi says we should all respect the views of others.

What are others ways of deciding leadership and what other positions do you want for your group?

What are other rules for your group?

Hello, I am glad to see you all again



We first have to write our nomination for leader and put it in the box



I received the most votes and so I'm the leader. I am very excited and proud the group will like me to lead them. Next we vote Toufic as secretary



Let's make some rules for the group



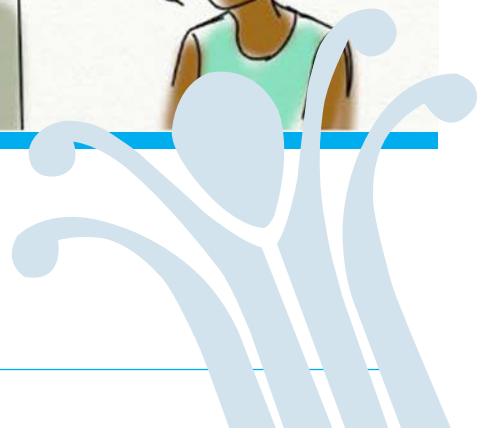
Why don't we turn mobile phones off or on silent during meetings



Let's all arrive on time



Let's respect the views of others



First Formal Meeting of the PSHG

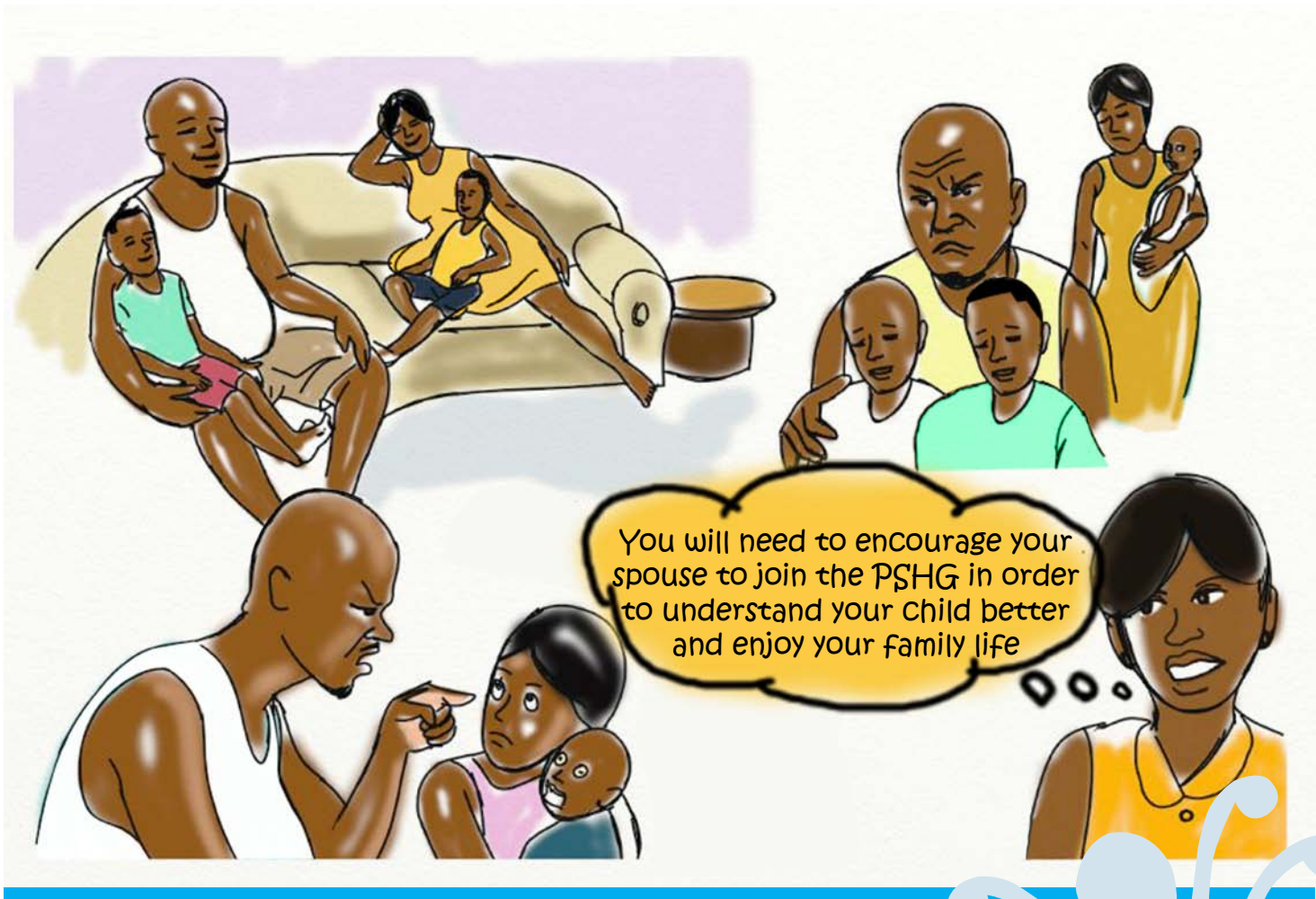
Family life

I remind everyone that today our topic is family life. Since the last meeting I have realized that I need to share my experiences so I decide to tell my story in more detail to the group.

I explained that before I had my child with an ID, my family of two children and husband were all living together and we were happy. After I had my third child, Nii, everything changed and I notice a difference in my husband's behaviour towards Nii and I. It became clear that Nii was not well accepted by him. For example, he refused to pay for Nii to attend physiotherapy and laughed when I said he would one day go to school. My husband became aggressive and argumentative with me whenever he was home. He even started seeing another woman. I couldn't absorb my husband's behaviour anymore and I decided to quit the marriage and give my child with the disability the same opportunities as his other siblings. Since I left my husband, none of his family members have come to us or help us in any way. This is because of the Ghanaian perception that when a woman gives birth to a child with a disability, the woman is in some way responsible.

Esi also quietly admits that her husband is also close to leaving her family and that he too blames her for causing their child to have an ID. He says that life is too hard since their daughter was born and he has had enough of it. I was surprised to hear this. I felt like I was the only one in my situation and I felt some relief that I was not alone. Toufic suggests inviting Esi's husband to join the group, to get support and to learn more about his child.

Can anyone in your group relate to this story?



First Formal Meeting of the PSHG

Family life

Ayishetu says she was always very close with her four children and their families. When her children started having their own families she would regularly stay with them to help care for the young babies. Once the grandchildren grew, Ayishetu would also care for them when their parents needed to work. Ayishetu's children each reacted differently once Naa's daughter with ID was born. The extended family stopped coming together as often and there was less sharing of the child challenges. Ayishetu was still involved in caring for Naa's children but the rest of her children started staying away. Now that Ayishetu is the caregiver to Ama, she rarely sees her children or other grandchildren.

Toufic shares that he and his wife were scared that this would happen to them, which is why they hid their child.

Can you relate to this situation?

How can you overcome situations like this?

We were all one happy family, when Naa's child with ID was born everybody started acting differently. The extended family stopped coming together



My wife and I were scared this would happen to us that's why we hid our child



Second PSHG Meeting

Community life

Today everyone seems more comfortable together. This week our PSHG discusses the challenges we have faced in the community. Esi explains to the group that when her daughter was first born they all continued attending church as a family, as they had done in the past. As her daughter grew up though the church members started to look at her family strangely and they made comments that she was a bad mother. After experiencing this for a few months Esi stopped attending church and now her family goes without her and her daughter. Esi says she can't stand being looked down upon. Ayishetu says that she experienced something similar when she started taking Ama to mosque each week. Ayishetu explains that she called a meeting where she introduced Ama to members of the mosque and explained her disability. Ayishetu said that this changed their perception and now the mosque has embraced Ama. She says the mosque is a place of support for Ayishetu. Kwasi says that his church was also reluctant at first but now they love his son, despite his challenging behaviour.

Kwasi offers to meet with Esi and her pastor to try to overcome this negative perception, as it is very important that Esi and her daughter can attend church.

Have people in your group experienced something similar?

What is another way that this challenge can be overcome?

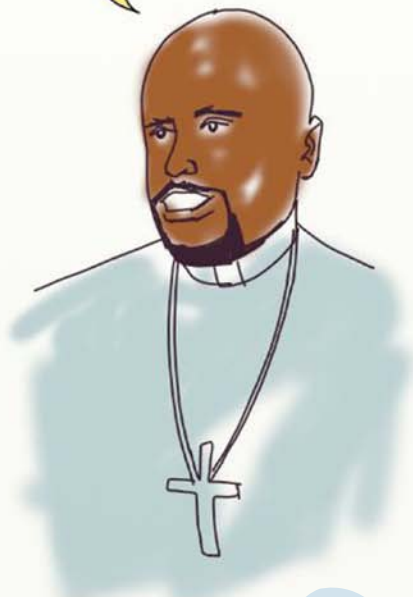
We were attending church as a family. Ever since my daughter grew up, people started to look at my daughter and I differently. So we stopped attending church



I also had a similar experience when I started sending Ama to the mosque



Esi, I will like to meet you and your pastor.



Second Formal PSHG Meeting

Community life

Kwasi Boateng tells the group that he has encouraged his son to do some chores for himself from time to time and that one day, he sent his son to a nearby market to buy some vegetables. His son has trouble speaking sometimes and took a while to order the items. The lady at the market refused to sell him anything, saying she wouldn't sell to a 'fool'. She said that if she sold to him then no one else would buy from her. Kwasi said his son came home empty handed and very agitated. After a while Kwasi worked out what had happened and went to the market to speak to the seller. Kwasi told the woman that all of God's children are created equally and that his son was no exception to this. He is not a fool or someone to be feared. Kwasi told the woman that his son's condition is not contagious either. The market lady was shocked and apologized. Now Kwasi's son goes to her regularly to buy his items and this interaction has really helped his socialization. I thank Kwasi for sharing this stories. I feel the strength Kwasi has shown gives me courage.

Is this situation familiar to yours?

Have you had other challenges in the community?



Third Formal PSHG Meeting

Feelings as a parent

Today I see Esi has a huge smile on her face as the children all come together before the meeting. The topic for this meeting is to discuss the feelings we sometimes have as parents/caregivers. I tell the group about a time I went to the market with my son and he made some very weird noises that made people look at us strangely. I could not understand what he wanted so he started screaming very loudly. The people at the market were looking at us, and this made me feel so ashamed of my son. We soon went home and I felt angry at my son for the embarrassment she had caused me.

Toufic also talks about the time they took their son with them to the store and he started picking up things and dropping them and they could not stop him. Toufic says she felt so ashamed of his son after this event and he has not taken his child with him anywhere again. Toufic starts to get upset, saying he does not know what to do with his son but he also feels ashamed that he keeps him inside. Esi, sitting next to Toufic, comforts him. The meeting continues and everybody talks about their child and some events where they felt ashamed or angry at their child as they seem different from others.

After this meeting, we realise that all of the parents/caregivers sitting here know that their child is not like other children. Most of us have felt ashamed and frustrated about our children even though we all love them children very much and want to help and support them.

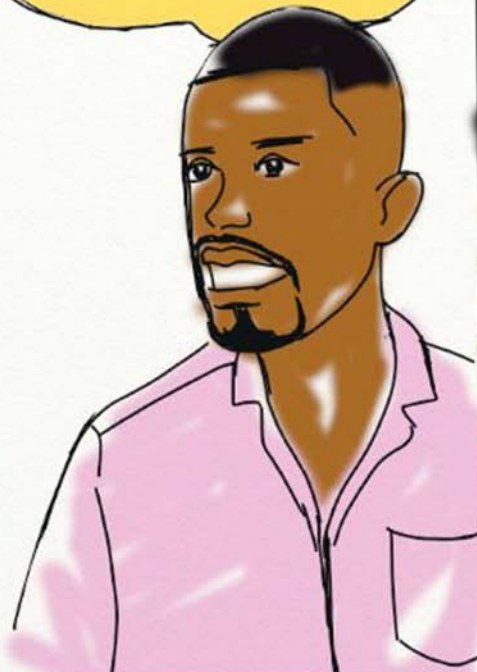
Can you recognise something similar from your life situation?

How can they help their children?

Today I can see Ama has a huge smile on her face. I remember when my son made very strange noise when we went to the market. I felt so ashamed.

I had a similar experience with my son when we went to the store to buy some items. He started picking items and dropping them and I couldn't stop him. I felt so ashamed.

Don't worry Toufic. With training things will get better

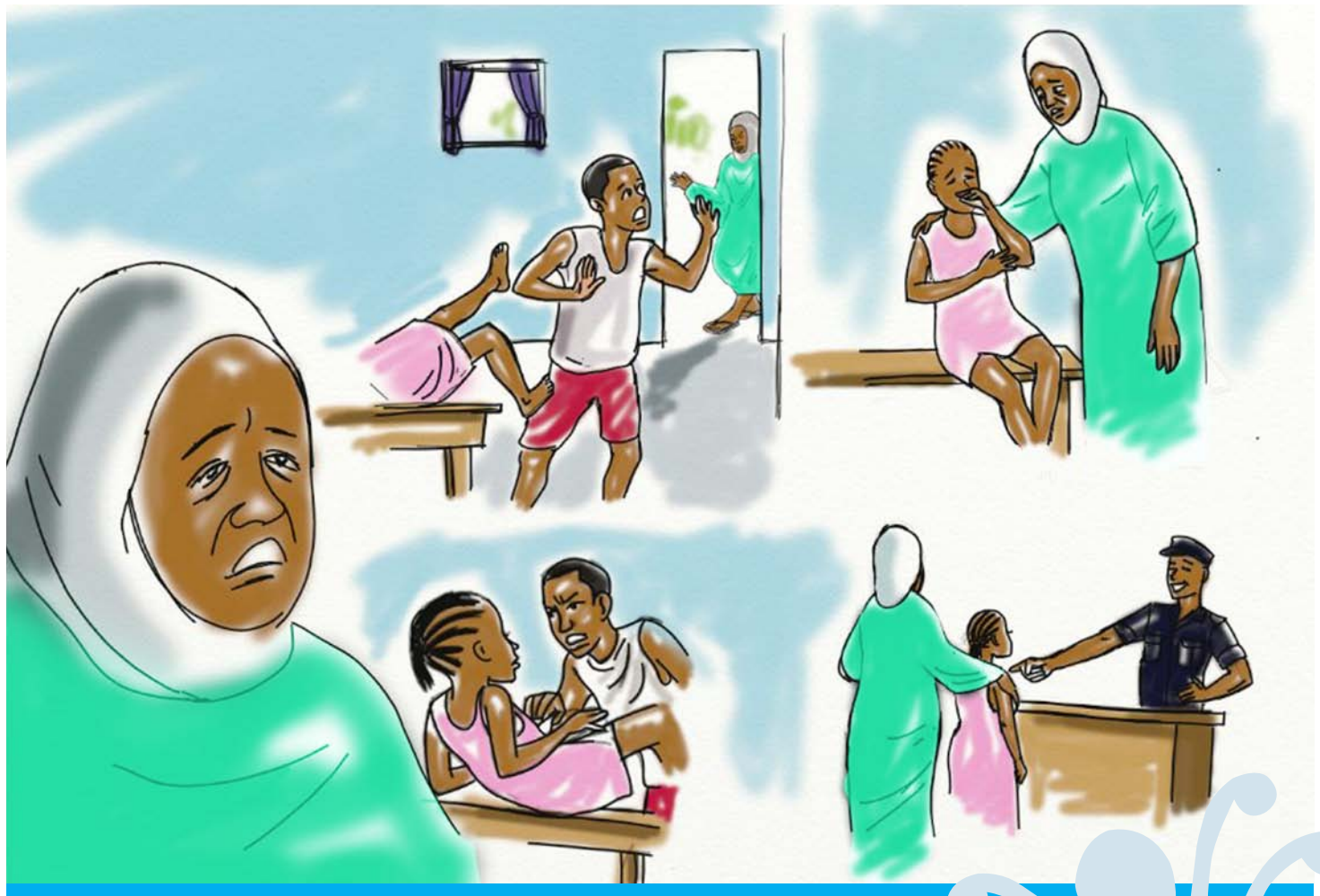


Experiences of Abuse

At today's meeting, Ayishetu is very upset. After we calm her down we ask what has happened. Ayishetu explains that Ama has become quite self-sufficient over time and she can now stay at home for an hour or two at a time while Ayishetu runs errands. But, Ama is now coming of age and she had been worried about making sure she is safe when Ayishetu goes out. The day before, Ayishetu had gone to fetch some water as the supply had been cut off and when she came back, a neighbouring boy was in her house and he had half undressed Ama and was touching her body. Ayishetu screamed at the boy and he ran away, but now Ayishetu doesn't know what to do. She went to the police but they laughed at her when they saw Ama. They said if she can't tell them clearly what happened and that she did not like it then there was nothing they could do.

Toufic hears this and stands up with rage. He says he will not stand for this, justice must be served and the police must take notice. Ama is a woman with rights, after all. I say that we will all go together with Ayishetu to the police station, so that they take the case seriously and if they don't we will speak to Inclusion Ghana. Ayishetu looks relieved at the offers of support.

Does this situation seem familiar to anyone in your group?




Development and Health

This week we have organized a health professional from the local hospital to come and speak to our group, because we realize that we actually don't know a lot about what causes ID and what we can do as parents/caregivers to help our children. The health professional explains that the medical definition of ID is that it involves impairments of general mental abilities (generally recognised as an IQ below 70) that impact adaptive functioning in skills like language, reading and memory as well as social skills and self-care. Also, a person should experience these symptoms during their developmental years.

Esi asked whether the fact she did not wear the appropriate white clothes after her child was born can cause ID. The health professional explains that ID can be caused by any condition that impairs development of the brain before birth, during birth or in the childhood years. She says that several hundred causes have been discovered, but in about one-third of the persons affected, the cause remains unknown. She says the main causes relate to genetic conditions, problems during pregnancy or birth, health or environmental problems or issues relating to poverty and deprivation. I feel so relieved – my husband left me and my family abandoned me because they thought I had done something to cause my child's condition. Now I see that there are many possible causes of his ID. We thank the health professional and invite her back next week – we still have so many questions!

What else do people in your group know about ID?

How can you find out further information that you would like to know?



Hello, I am a health professional. I am here to speak to you about the causes of ID.

Pls, is it that I didn't wear the appropriate white cloths that's why my child had ID?

No, the main causes relate to genetic conditions, problems during pregnancy, birth, health or environmental problems or issues relating to poverty and deprivation.

Development and Health

This week the health professional is back and we ask her about how we can cure our children. The health professional explains that ID is a lifelong disability and that unfortunately there are no known cures. What is important though for persons with ID, is that with early intervention, they can reach their full potential in life. The professional explains that early identification is very important. She explains some early symptoms can include:

- Rolling over, sitting up, crawling, or walking late
- Talking late or having trouble with talking
- Being slow to master things like potty training, dressing, and feeding himself or herself
- Difficulty remembering things
- Inability to connect actions with consequences
- Behavior problems such as explosive tantrums
- Difficulty with problem-solving or logical thinking

She says that to address these symptoms, various therapies have been shown to be very helpful. For example, occupational therapy is helpful, where the person is slowly taught meaningful activities. Other therapies include speech and physical therapy. At the end of this education, Esi stands up and thanks the health professional for her time. Esi says with this knowledge she feels strong and more confident.

Do any of the children of the parents/caregivers in your group receive therapy for their child?



School

This week our group discusses school and the importance of all of our children going to school. Kwasi and Ayishetu both tell the group that they tried to enroll their children in the local primary school but the school rejected their applications. Ayishetu said the principal was quite rude, saying that you can't teach fools anything. I explain that I have been successful in enrolling my son, Nii in school and since enrolling him he has learned to read and write some words. His communication skills have improved greatly as well and he is more relaxed around new people.

I see all the parents sitting forward on their chairs, listening to me eagerly. They all want their children to attend school as well. But how can we do it? I realize that together as a group we have some power. I suggest that we approach the principal of the school my son attends to ask whether they can take more enrolments of children with ID.

Toufic says it is the right of every child to attend school but until joining this group he had never seen the point of his son attending school. He says that all this is going to change now and he will use his influence to lobby the school as well.

Ayishetu is excited and says that she will do whatever she can. We agree that next week we will make a clear plan of how to approach the school and what each of us can do. We agree that we won't rest until each of our children is in school.

Do any of the parents/caregivers in your group have their children enrolled in school?

I tried enrolling my son in the local school but they rejected my application



I also had a similar experience. The principal was rude, saying that you can't teach fools anything.



It is the right of every child to attend school but until attending this meeting I have never seen the point of allowing my child to school. I won't rest, I am going to use my influence to lobby the school as well.



I will do whatever I can!



Sharing Tips on how to care for your child

I remind the group at the start of the meeting that today we are talking about tips and tricks we have learned that help us to care for our child. Toufic starts the discussion, saying that one of the biggest challenges he faces is toilet training his son. Toufic asks if anyone in the group has had success with toilet training. Ayishetu speaks up, saying that Ama is now able to go to the toilet by herself after a lot of guidance from Ayishetu. While each child is different, Ayishetu says that she broke each step down, beginning with helping Ama recognize that she should urinate in the toilet. She then repeated these steps, removing her clothes, wiping herself and putting her clothes back on. Through this imitation style, Ama gradually learned how to go to the toilet by herself. Ayishetu rewarded Ama when her pants were dry and shook her head when they were wet. Kwasi adds that his child really enjoys playing with an old mobile phone. He has a special phone that he gives his child to play with after he has gone to the bathroom by himself. In this way he ‘rewards’ his child for being independent. Kwasi emphasizes that it was hard, and he had to be very persistent and firm to ensure his son could toilet by himself. Toufic thanks the group, he is ready to try some of these tips out with his child. If he could ensure his child goes to the toilet independently it will be a great success!

I see that the group has much to learn from each other. In our own way, we are all ‘experts’.

What other tips do parents/caregivers in your group have to share?

Today, we will talk about tips and tricks we have learnt that helps us to care for our children with ID



Has anyone in the group had success with toilet training?



Ama is able to go to the toilet after some guidance and steps I broke down to her.



My son enjoys playing with an old mobile phone. I have a special phone I give him after he has visited the bathroom.



I am ready to try some of these tips out with my son and see if my son will be able to go to the toilet independently.



Legal Rights of Persons with ID

This week we have asked a person from Inclusion Ghana to talk to us about the legal rights of persons with ID. Alice has come and starts by explaining what discrimination is. She says it is treating a person, or group of people, less favourably on the basis of an attribute that the person, or group of people, has. The attribute might be the person's intellectual disability or their race or their gender. She explains that there is an international law made by world leaders, called the Convention on the Rights of Persons with Disabilities that says persons with ID must be treated equally and without discrimination. There are many other rights in this Convention which she explains, like the right to health care and education. Alice also tells us about the Ghana Disability Law, which gives further protection to our child.

All the members in our group are very interested in learning about these laws and we agree that for the next two weeks we will explore these laws in more detail.

Do people in your group know about these laws?

How can knowing the law help your child?



Social Activities

The topic for today's meeting is to discuss social activities that we can do for our kids. Ayishetu has said that we, as parents, set the best example for how others should treat our children. She says that if we bring our children with us in public, hug them, love them, treat them with respect and without embarrassment then others will see that the child deserve love and attention, just like any other child. Others in the groups agree.

Toufic looks at the ground while Ayishetu is speaking. He says very quietly that he realizes hiding his son has taught his community that it is right to be ashamed and abusive towards children with ID. Esi Maame nods, saying that she thought she was protecting her daughter by keeping her away from others. She knows that nothing will change if we keep our children hidden.

I tell the group that Alice from Inclusion Ghana has told me about Special Olympics, which is an organization which promotes sporting events for persons with ID. I suggest that we get our children to play a game of football together. Ayishetu is excited at the idea – she has been teaching Ama to kick a ball for many years but he has never had other friends to play with! Toufic looks energized – his eldest son is a football coach. He will be happy to host a game for all the children. We agree that we will play a mixed game with our children with ID (including boys and girls) and their siblings and we will invite our friends and family along as supporters. Everyone is very excited. We begin to plan how we will host this game and the training we will do in the lead up. We agree that for the next two meetings we will plan this activity and report on our progress. In the meantime, Ayishetu says we should always include our children in our activities.

What other social activities can you do with your children?

What are the benefits that doing social activities can bring, for your child, you and the community?

As parents we should treat our children with love and set good examples for others



I realize I'm hiding my son



I thought i was protecting my daughter by keeping her away from others



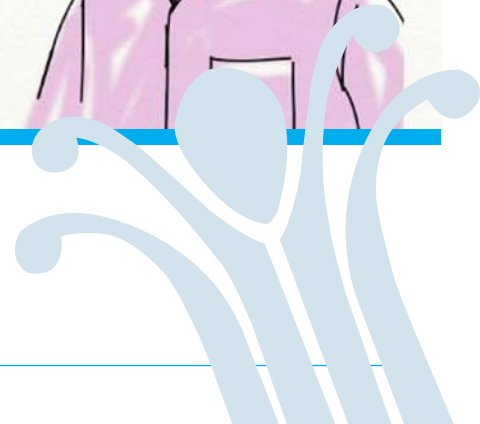
There is a special olympic game organised for children with ID.



I have been teaching Ama how to kick a ball but she has no one to practise with.



My eldest son is a football coach, he will be happy to host the game



Group Project

After all the success around our group football game, the group is excited to think about the next project we could undertake. At our last meeting we decided this would be our new meeting topic. We start by thinking about what activities we had already started doing together, without really planning for it to happen. Ayishetu explains that Kwasi has helped her a lot by offering to pick her up and take her to meetings. I tell the group that Esi and I have been sharing child minding, to allow us to work more often. We start to think about the possibilities. Touif suggests starting a small business that our children can be involved in. He has some extra land at his place and says we could plant a small garden for the children to tend. I am so excited! This is something that our children can build together for their future. It will take some planning but we are ready to get started.

What other group projects can you undertake together?

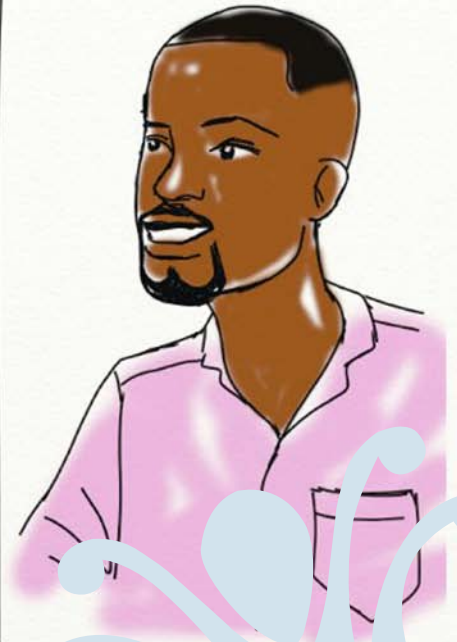
Kwesi has helped me a lot by bringing me to meetings everyday



Esi and I have been sharing child minding to allow us work more often



We start a small business that our children can be involved in.



Awareness Raising and Advocacy

Today our group has agreed we will discuss advocacy projects. Alice has explained that advocacy is a process of trying to influence the opinions of people in the community and government. Our group has all agreed that advocacy is very important to ensuring the lives of our children improve. We think of ways that we can influence people and I say that most people who treat our children poorly don't understand what an ID is and what causes it. I suggest that we could increase awareness of these facts as a way of changing opinions. Kwasi says that we could use the church to hold a community meeting where we can gather people and tell them the true information. Toufic suggests that he can take some pictures of our children playing like all other children do to put up at the meeting. He says this will help to show they are regular children that deserve our love.

Our group is excited. There is a lot to do and we agree to allocate specific jobs. We also decide to let Alice know our plan, in case she has some resources we can use.

What are some other advocacy project that your group would like to do?

Foreword Awareness raising and advocacy

Today, we will discuss advocacy projects



We can use the church to hold community meetings.



I can take pictures of our children playing like all other children



Our group is excited. There is a lot to do and we agree to allocate specific job.



Potential Challenges within the Group

Now that we know how to run our PSHG, Alice from Inclusion Ghana tells us that it is important to remember that, while nobody joins a group to create problems, it is good to prepare for some challenges in the group. Alice explains one common issue is that parents/caregivers use the group as a place to ‘dump’ their problems and that rather than offering support or solutions they offer more complaints. Esi suggests that for each issue that is brought to the group, we should try to find a solution or some advice before we move on, so that we don’t just talk about problems. We agree with this suggestion.

Alice says another issue is that parents/caregivers might feel reluctant to talk or contribute to the group. Toufic states that to overcome this we should encourage one another and ask questions to bring the views of everyone out. An opposite problem, says Alice, is that some parents may dominate the conversation. To overcome this I suggest that we ensure we take turns and if someone speaks too much we can thank them and ask to hear from someone else in the group.

What are other challenges your group might face?

How will your group overcome these challenges?

Nobody joins a group to create a problem but it is good to prepare for some challenges in a group

We should try and find solutions to each issue before we move on, so that we don't just talk about problems

Another issue is that parents may feel reluctant to talk or contribute to the group.

To allow this, we should encourage one another and ask questions to bring the views of everyone out.

Some parents may dominate the conversation. In order to avoid this everybody should be given talk turns.

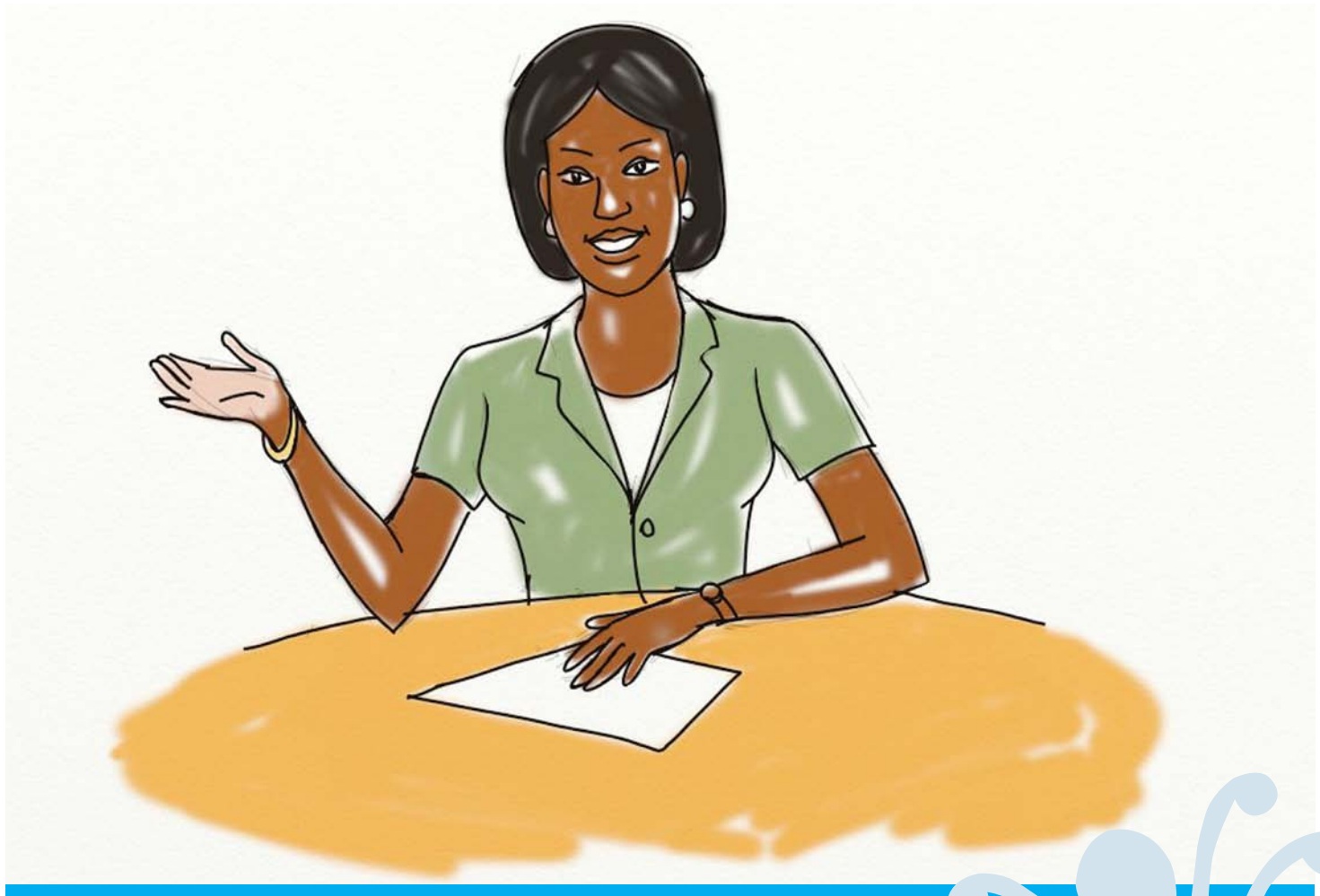


Group is Growing in Size

By now the group has grown in size, as more parents/caregivers in our area learn about the PSHG and see what we have been doing for our children. We now have 13 people in our group and Alice encourages us to invite new members if any are interested, as the more parents/caregivers that are supported and strong, the better the lives of persons with ID will become.

Alice has also told us that PSHGs should be a maximum of 10 people, as keeping the group small will ensure everyone has a chance to speak. We have today made the decision to split our group into two smaller groups, based on where people live. This way some people have to travel less to meet. We also agree that every two months the two groups will come together to hear what has been happening.

How will you decide to divide your group if it becomes too large?



Benefits of Forming a Parents Self Help Group

Today at the end of the meeting we start to share the benefits we have noticed as a result of joining the group. After several months together we now reflect on our successes. I tell the group that I no longer feel angry with my child and am feeling accepted and included in the community because of the support from the group. I also feel like I trust people again and am more confident, since my husband left me. Esi agrees, saying that she no longer feels alone, she has found a place in the group and likes being able to help with shared child-minding. Toufic says that he also feels this way, and he is also amazed at the things he has learned. Now his son is toilet trained and this is a huge success for his family. He is also now taking his son out and introducing him to neighbours. Toufic thanks Ayishetu, Kwasi and the group for their valuable advice and support. Kwasi says that the group farm has helped him greatly, because now Kofi has a place he can go and contribute.

More than this though, Ayishetu reminds us that together our group has begun a journey of changing attitudes in our community. Our group football game was a great success. The community saw our children playing and having fun for the first time. Our advocacy project where we raised awareness at a meeting at the church also opened the eyes of many of our neighbours. We have achieved more than we ever thought we would before joining the group.

What are the other benefits of joining a PSHG?



What support can Inclusion Ghana and its Members provide?

Well, it has been quite a journey sharing these past few months with you. I hope that by now you understand the PSHG concept, how to form a group and the benefits that joining a group can have. To ensure our group continues to be strong into the future, Alice tells me that Inclusion Ghana can give our group support. She says they can do the following:

- ✿ Provide members and group leaders with training on how to lead a group and facilitate a meeting;
- ✿ Give advice and suggestions on specialists to involve in your group meetings;
- ✿ Give you ideas on participatory exercises and energizers that you can use during your meetings;
- ✿ Link you to other support groups that are at a similar stage as your group, groups that have really worked well or groups that have been through similar challenges that your group is currently facing; and
- ✿ Identify and link groups to opportunities that may benefit them.

After so many years of worry and sadness, I am now excited for the future of my child. This PSHG has given me this hope and strength and I hope that it can do the same for you. Together, we can create a change.

