



Activity report

Name of Activity: Fathers Workshop.

Target Group/Audience: Fathers of children with neurodevelopmental disabilities

Date: 14/09/2022

Venue: Kafue District (Kanyanja Baptist Community Church)

Theme: Awareness raising workshop for fathers with children with neurodevelopmental disabilities.

Objective: To Increase the engagement of Fathers in family care work, knowledge on neurodevelopmental disability and peer support among parents or fathers of children with disabilities.

Attendance Total: M: 26 (26 Fathers: 01 Coordinator)

Activity details

Result Area/ Activity No. B2.1/A04.3

Result 4: The political and social framework for children with neurodevelopmental disorders and their families has improved in the target area

Activity:

A one-day workshop for fathers with children with neurodevelopmental disabilities was conducted in Kafue district in Kanyanja at Baptist Community Church. The workshop aimed at increasing the

engagement of Fathers in family care work, increase knowledge on neurodevelopmental disabilities, increase knowledge on rights of children with disabilities so that they can better advocate for better conditions for their children in all spheres of society and to also peer support among parents or fathers in their communities. The meeting was attended by twenty-six (26) fathers of children with neurodevelopmental disorder and one (1) female coordinator bringing the total number of participants to twenty-seven (27), and the training was facilitated by Madam Precedence Gertrude Kapulisa, the Executive Director from Archie Hinchliffe Disability Intervention (AHDI).

The meeting was opened with a prayer and later participants introduced themselves by stating their names, the location they were coming from though within kanya and mentioned the name and age of child. The organizing team introduced themselves too. They also shared information on the name of the project and how partners worked together.

The facilitator stated the training by asking the participants to state some of the functions of the brain that they knew. The participants stated that the brain was an organ that was responsible for coordinating some functions of the human body maintaining balance and was also in charge of controlling the five senses of human beings. The facilitator then added that the brain was an organ of a human being, and it was responsible for almost everything and that every human being has a brain. She stated that according to research that was done on human beings, it was discovered that the brain had an average weight of 1.4kg and was made up of small tissues that cannot be seen with naked eyes unless under a microscope known as nerve cells. She further said that the brain was functional all the time, however, it was more active during the day and less active during the night as a person was engaged in less activities. The brain was a complex organ that controlled all thoughts, memory, emotions, touch, motor skills, vision, breathing, temperature, hunger, and every process that regulated the body. Together, the brain and spinal cord that extends from it made up the central nervous system.

Moving on, she highlighted that disabilities could come about due of different reasons, such as accidents, born with them and could be due to severe illnesses. She said that when the blood pressure goes up it reaches a level where it would cause rupture of small blood vessels that carry oxygen to the brain and then cause bleeding resulting in damage to the brain tissues, and such situations were referred to as cerebral-vascular accidents (CVA). Added that symptoms and signs of cerebral vascular

accidents included dizziness, numbness, weakness on one side of the body, and problems with talking, writing, or movement. She said it was therefore important to protect the brain, as well as protect the brain of unborn babies by taking the right medication prescribed by medical staff and feeding on nutritious foods during pregnancy to avoid brain damages that may result into a baby being born with a disability (ies).

She then divided the participants in groups and asked them to discuss the types of disabilities they knew and thereafter choose a representative who would present the findings of the group. During the plenary session, fathers were able to identify some of the neurodevelopmental disabilities when they were asked to list those that they were familiar with, and among those listed were, albinism, down syndrome, blindness, fitting, stunted growth, hydrocephalus to mention a few which could come about due to accidents, born with or even Witcraft. However, there were some knowledge gaps among the participants on the disabilities and causes of mentioned conditions. The facilitator therefore closed the knowledge gaps by highlighting some of the causes. These were categorized in three and that they could occur during pregnancy, during childbirth and those that may occur after childbirth. The training further covered on how these disabilities may be prevented and how children with neurodevelopmental disabilities could be taken care of and how they could be handled during physiotherapy sessions to improve their conditions based on type of disability.

After talking about the brain and the effects of brain damage, the facilitator proceeded to talking about different types of disabilities and how they could come about she started with Spina bifida, which she said was a birth defect in which a developing baby's spinal column on the lumber area fails to develop or close properly while in the womb. Symptoms may be seen on the back area where there would be an abnormal tuft of hair, or a protruding watery `sack` of spinal cord tissue. She said this type of disability is usually caused when pregnant mothers do not take folic acid which plays an important role in the production of red blood cells and bone formation. She said when a child is born with such type of disability depending on the severity of the spinal defect, the child may have bladder and bowel problems, and loss of sensation below the defect, inability to move the lower legs (paralysis) and sometimes children born with spina bifida may also have club feet (s). However, she also said

treatment is necessary, it's carried out through surgery to close the defect and therapy / exercises are vital with emphasis on management to prevent complications.

Secondly, she talked about Down Syndrome, which she said was a genetic disorder caused when an extra genetic chromosome was produced instead of only 46. The condition of Down's syndrome had features that helped to identify the children which included distinct facial appearance, intellectual disability (slow to learn), and developmental milestone delays. Further, she added that children with Down syndrome had mental slowness. Just like a person without disability children with down syndrome are also able to learn and pick up new skills, but they may take longer to reach important goals like walking, talking, and developing social skills. She further explained to the participants that in instances where a child is born with such a disability, parents to the child must not blame each other. This was because children belonged to both parents would have contributed to the production of the child. It was the responsibility of both parents to taking care of the baby to promote good health and growth / development.

Autism was the next type of disability she talked about. She defined it as developmental disorder characterized by difficulty in social interaction, communication and usually presents with repetitive actions like rocking or hitting the head on to the wall. The facilitator said children could be born with or acquire it after birth. And usually present with different extremes in terms of intelligence. Which could be quite slow in learning, while others could be super intelligent, the cause could be damage to the brain and sometimes the cause would not be known.

Moving forward, she moved on to talk about intellectual disability which said was a term used to refer to a person that had challenges with learning. She said intellectual disability may be caused by various reasons which among many others may include- trauma before birth, an infection or exposure to alcohol, drugs, or other toxins, chromosome abnormalities that result in Down syndrome and sometimes may be due to environmental factors. Children with intellectual disability may be characterized with having trouble following simple instruction, may struggle to develop social skills, struggle to remember things, and might also be unable to carry out personal care like getting dressed or taking a bath.

Last on types of disabilities and possible causes, the Facilitator talked about Cerebral Palsy, which she said was a neurodevelopmental disability that resulted from damage to an immature brain in children between the age of 0 to 5 years and affected movement, postural tone, and sensation. She said children with cerebral palsy usually have associated problems that included difficulties eating and drinking, impaired speech / language, hearing, stunted growth, deformities due to poor positioning and visual / hearing impairments among others. The causes of CP were summarised into causes which included during pregnancy, during delivery and after birth.

Having defined disability, the facilitator asked the participants to go into their groups and discuss the various models of disability. She highlighted that models of Disability were essentially devised by society about persons with disabilities, she added that models revealed ways in which society viewed people with disabilities. The models that were discussed under this session included the Traditional model which, in many cultures around the world perceived people with disabilities as under a spell of witchcraft, possessed by demons, or as penitent sinners, or being punished by God for wrongdoing by themselves or their parents. The Charity Model depicted the fact that the people with disabilities were viewed as having a deviation, helpless and that could never do anything for themselves, deserving of pity. While The rights-based model was discussed lastly, and it was highlighted that the model- was close to the social model and looked at disability as a human rights issue. And that said it recognized the fact that disability was a natural part of human diversity. The problem was not an individual, but society created barriers. Citing an example of the way transport was designed as the problem and not a wheelchair.

After discussing on the models of disability, the training also looked at the barriers that could hinder participation for people with disabilities. She said there were many barriers that people with disabilities faced, and in the end excluded them from fully participating in various activities in society. Among these factors she pointed out that People's perceptions of persons with disabilities was one of the most foundational barriers which included Stigma, stereotyping, discrimination, and prejudice. It made it difficult for a person with a disability to be able to participate in society. Institutional barriers included laws that discriminate. And these are barriers which stops them from accessing activities or programs that they have a right to. Hence it was important for policy makers to formulate policies that were inclusive and remove all society created barriers to accessing services or programs in the

communities / society. While she highlighted that social barriers to disability were related to factors like education, income, and safety in the home. People with disabilities were less likely to get jobs or complete high school and were more at risk of experiencing family violence than those without a disability.

The facilitator concluded the training by talking about child safeguarding and child protection as advocacy. Session on safeguarding and child protection looked into policies and practices that may be followed to ensure that children and adults are safe and promote their wellbeing. The session on safeguarding was aimed at helping fathers to be able to recognize the signs of abuse and raising awareness on the available legislation and safe practices so that- they could be in a position to prevent harm to a child's health and development and ensure that children grow up in safe and effective care. Guidelines such as the local and International Human Rights Laws and Policies like PWD ACT No. 6 of 2012, the Universal Declaration of Human Rights, and the United Nations Convention on the rights of the child (UNCRC) to mention but just a few, were highlighted to raise awareness on the existing guidelines aimed at protecting children including children with disabilities from harm.

She added that, to ensure that children and adults with disabilities enjoy their rights, there were various influential people that parents could work with in their communities to advocate for better condition. For instance, in the village set up parents could work closely with various people like the traditional leaders, ward councilors, members of Parliament among many others. And that it was very important to ensure that their voices were heard, and their concerns were well included in the development planning processes to benefit their children with various disabilities.

Outline achievements:

- 26 Fathers of Children with disabilities trained
- Change of Attitudes towards the causes of neurodevelopmental disabilities
- Gained knowledge on children rights, how to safeguard and protect children with disabilities as well as how to Advocate for better conditions for children with disabilities.
- Actively participated and were involved in all activities during the training

Challenges:

- No major challenges were encountered.

Lessons Learnt:

- Fathers of children with disabilities lack information on various types of neurodevelopmental disabilities and how they may be caused. Most Activities have been centered much on working with women as care givers of children with disabilities. Therefore the need to heighten male engagement so that there can be more participation from the fathers in the various communities.

Recommendations

- Most Activities have been centered much on working with women as care givers of children with neurodevelopmental disabilities thus creating knowledge gaps among men. Therefore, the need to heighten male engagement so that there can be more participation from the fathers in the various communities.

Pictures



Participants listen to the facilitator during the training



Participants during group work



Participant during a presentation



Fathers doing an energizer

Convener/Organizer: Cheshire Homes (CBID) and AHDI

Report compiled by: Ms. Betty M. Mukonka

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