

# SOCIAL ISSUES AND SOCIAL MANAGEMENT OF EPILEPSY

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## 60 NAMES FOR EPILEPSY IN AFRICA (WITH LANGUAGE & COUNTRIES SHOWN)

Epilepsy is found in all communities of the world. It affects both males and females, black people and white people, children and adults, rich and poor, educated or not. Below are some names given to epilepsy in Africa, in alphabetical order. Please note that some of the names are no longer appropriate now because they label, devalue and stigmatise.

1. Akwukwu na-ado - Igbo - Nigeria
2. Bolwetsi bja go wa - Northern Sotho - South Africa
3. Botlhokuo gowa - Setswana - South Africa
4. Khunyu - Nyanja - Zambia
5. Chipumputu - Bemba - Zambia
6. Chitutwane - Bemba - Zambia
7. Chithu cha waka - Tumbuka - Malawi
8. Danu rap - Wolof - The Gambia - Possessed by evil spirit or fallen animal
9. Motlotlwane - Setswana - Botswana
10. Dikotlo - Setswana - Botswana
11. Ensimbu - Luganda - Uganda
12. Epilepsia - Portuguese - Mozambique & Angola - Mkn sickness (Mozambique)
13. Epilepsie - French
14. Epilepsie - Afrikaans - South Africa
15. Epilepsy - English
16. Igicuri - Kinyarwanda - Rwanda - Working upside down abnormal brain
17. Isithuthwane - Zulu - South Africa
18. Sokuwa - Zulu - South Africa
19. Izithuthwane - Ndebele - Zimbabwe -
20. Izifafa - Ndebele - Zimbabwe - A disease of fainting or dying
21. Kasuntu - Tonga - Zambia
22. Khunyu/Matenda okugwa - Chichewa - Malawi
23. Chifufu - Chichewa - Malawi
24. Kifafa - Katanga - DRC
25. Kifafa - Swahili - Kenya & Tanzania
26. Kifutu - Balubakat - DRC
27. Kihona - Hona/Manono - DRC
28. Kissinkiri - Moré - Burkina Faso
29. Koukonbolo - Gourounsi Réo - Burkina Faso
30. Krikriksen - Dioula /Bobo - Burkina Faso
31. Kukuxhuzula - Isixhosa - South Africa
32. Maladi ya denke - Bas - Congo/DRC
33. Mavague ya weti - Xangana - Mozambique
34. Ndulme - Luo - Kenya
35. Njirijiri - Nyanja - Zambia
36. Njirinjiri - CiSena - Mozambique
37. Nthenda yakugua - Nyungwe/Nyanja - Mozambique
38. Zvipusha - Shona - Zimbabwe - Contagious disease
39. Pfarí - Shona - Zimbabwe - Jerking
40. Nhuta - Shona - Zimbabwe - Shaking disease
41. Tsviyo - Shona - Zimbabwe - Whistling disease
42. Kudonha - Shona - Zimbabwe - Falling disease
43. Kufaifa/Zvifaifa - Shona - Zimbabwe - A disease of dying/fainting
44. Sethwathwa - South Sotho/Sesotho - South Africa
45. Sifo sekuwa - Swaziland
46. Wa'ah - Yemba - Cameroon
47. Warapa - Yoruba - Nigeria
48. Wayoo - Mandinka - The Gambia
49. Yemiti'ili/ ʾየሚቲሊ - Amharic - Ethiopia
50. مرض كهربائية الدماغ - Arabic - Brain electrical shock
51. الصرع سابقا - Arabic - Brain electrical shock
52. Msetti - Morocco - Crazy
53. Maskoune/Fihleriah - Morocco - Obsessed by an evil spirit
54. صرع - Morocco
55. ايبلسيا - Arabic - Brain electrical shock
56. توقف سلوك - Arabic - Behavioral arrest
57. مرض السقوط - Arabic - Falling disease
58. Intandara, Burundi - Generalised contractures
59. Adingbe - Fon, Benin
60. Mblisimbaama - Gulmancema - Burkina Faso

Epilepsy is not contagious

“epilepsy is derived from the Greek word *epilambanein* and means **to be seized.**”

Both the nouns epilepsy and seizures can result in stigma

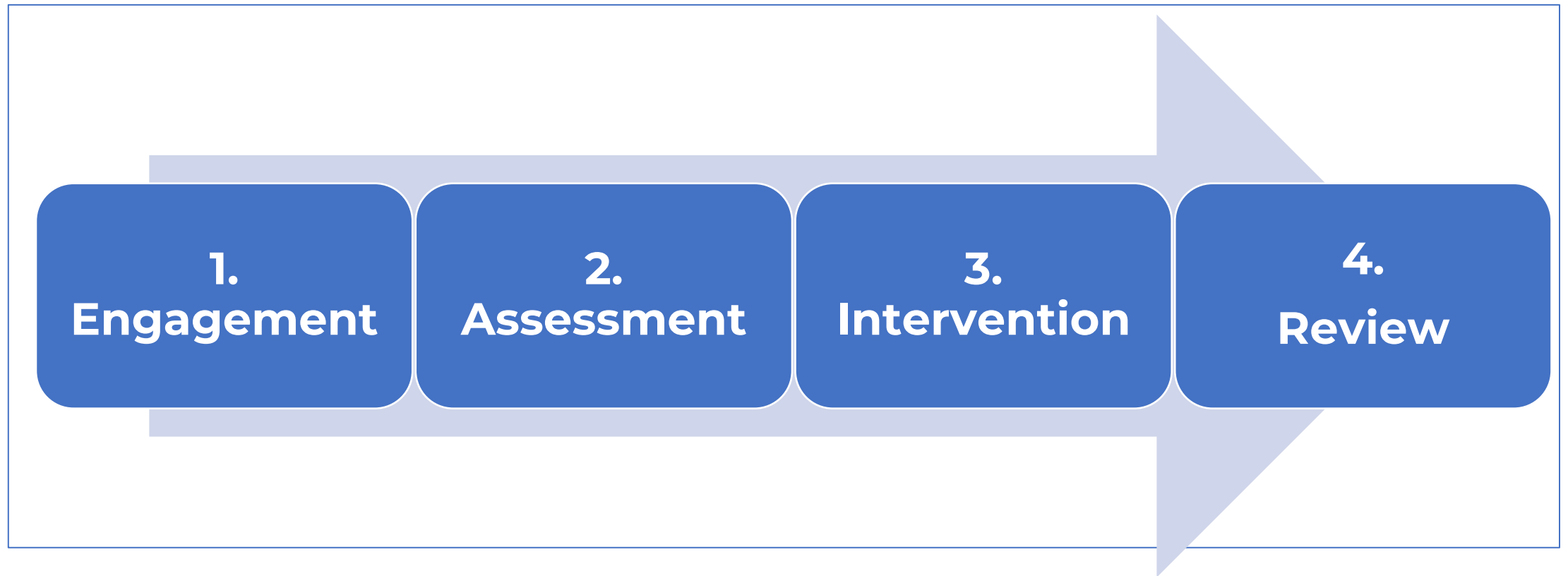
# SOCIAL PROBLEMS OF LIVING WITH EPILEPSY

1. Chronic, life condition – epilepsy is not curable, not all epilepsies can be treated medically or it takes time to get treated
2. It is expensive to get medical treatment – resulting in large treatment gap
3. Different understandings of the condition – resulting in huge information gap
4. It is difficult to learn with uncontrolled epilepsy – resulting in poor educational, training and employment
5. There is limited welfare and development support – resulting in poor lifestyles

# SOCIAL PROBLEMS FROM SOCIETY

Problem	Examples
<b>Labeling</b>	You are not human, you are unworthy You are evil, evil condition You or family are responsible for your condition You are seized
<b>Exclusion</b>	You will not get services You will get less You will get last
<b>Stereotyping</b>	You spoil us You have a contagious condition You will never succeed
<b>Discrimination</b>	You don't go to school You don't marry You will not have children
<b>Neglect</b>	You will not be cared for You are not my child or wife or husband

# PROCESS OF SOCIAL MANAGEMENT



# ENGAGEMENT

- Build a helping or professional relationship with the person so that they trust you
- They are the expert of their life, you are only a catalyst that helps them
- Show them that you care about their condition and you want them to do better
- Do not judge them for what they think
- Focus on the person's strengths not weaknesses
- Agree when to meet for the first meeting to assess social problems

# SOCIAL ASSESSMENT

- You assess by asking questions and observing the person. Basic questions are:
  - Tell me about yourself?
  - Tell me about your family and community?
  - Tell me how you understand epilepsy?
  - Tell me how you are managing epilepsy?
  - What social problems is epilepsy causing you and your family?



# SOCIAL ASSESSMENT TOOL

Questions	Response	
	Yes	No
Does your family know that you experience seizures?		
Are you getting support from the government?		
Are you getting support from the community, including organisations and helping groups?		
Are you getting support from your family?		
Are you getting support from your school, college or university?		
Are you getting support from your employer or co-workers, if employed or self-employed?		
Do you know enough about your condition?		
<b>Total points</b>	Yes responses	
<b>0-3 - Immediate support is required, refer for assistance</b>		
<b>4 - Optimum level, support may be required</b>		
<b>5-7 - Adequate, no support required</b>		

Mugumbate J. R., Kissani, N., Acevedo, K. ... (2022). First Aid (FA) and First Guidance (FG) for epilepsy seizures: key considerations and recommendations for the developing world. *Journal of Social Issues in Non-Communicable Conditions & Disability*, 1(1), 11-24.

# INTERVENTION

- Create a plan of action working with the person and their family
- Record the plan of action and file it for future use
- Implement the plan
- The plan may include:
  - Family or community visit for epilepsy awareness
  - Referring to a support group or income making group
  - Referring to a counsellor or for mental health support
  - Referring to a social worker or to social services unit
  - Referring to epilepsy association or organisation

# REVIEW

- After about two weeks, read the plan and notes and review it
- Check progress, discuss with the person and record it
- Determine if any changes are needed
- You can do a review over the phone, family visit, case conference or a meeting with the person
- Also check how they are doing with their medical management
- Review is a continuous process

# UBUNTU SOCIAL CARE VALUES AND ETHICS



- Relationships (**ukama**)
- Family (**mhuri**)
- Respect (**girmamawa**)
- Justice
- Community/collective (**ujamaa**)
- Wholism/holistic (**mzima/phelele**)
- **A person is a person through others** – accepting people with epilepsy
- **It takes a village to raise a child** – the whole village is responsible for managing epilepsy not just the family

