Stigma

What is Stigma?

The *Lancet* Commission on ending stigma and discrimination in mental health

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Stigma is a

- Complex multilevel societal process that encompasses
  - Labelling - stereotyping
  - Separation
  - Status Loss - devaluing
  - Discrimination in the context of power loss
  - Often arises from
    - Ignorance
    - Prejudice

Labeling → Stereotype

Division Us vs. Them

Lose Social Status

Discrimination

Stigma
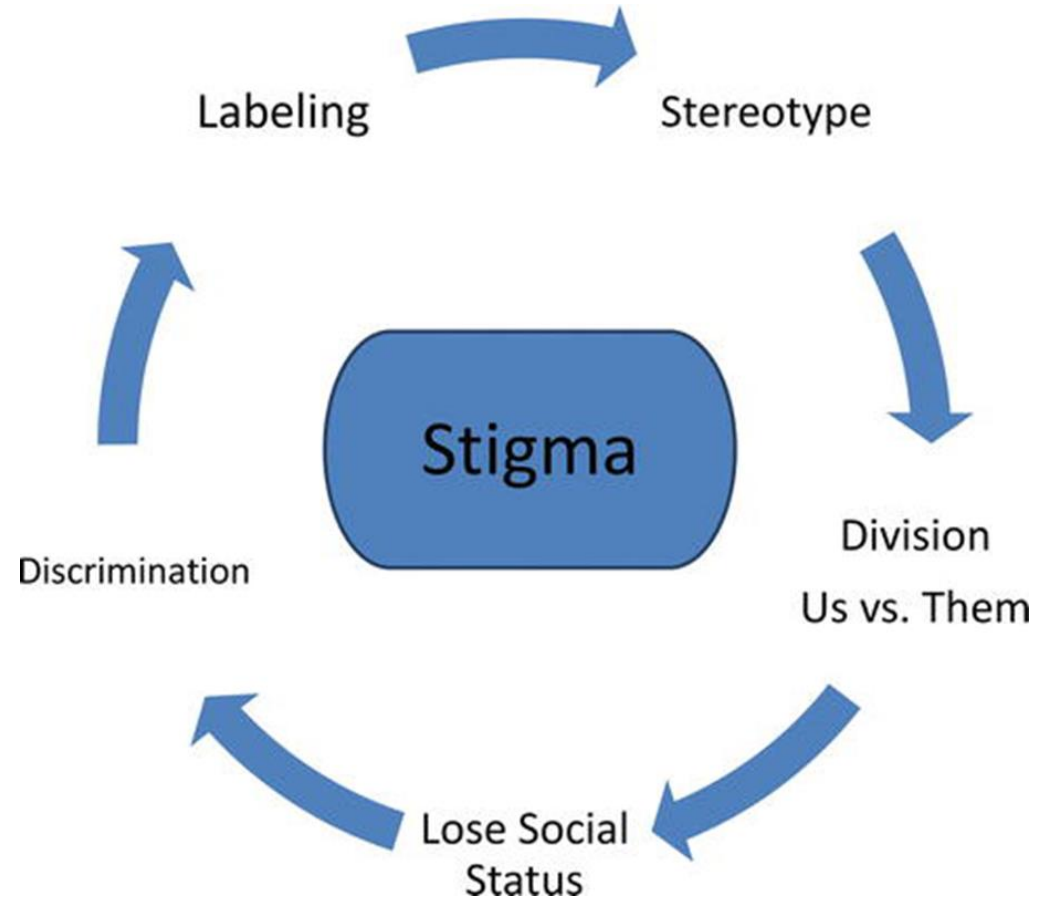
Labelling

- Identification and highlight human differences that matter socially

- Social process

- Linked to negative stereotypes

- Leads to seperation

Separation between 'Us' and 'Them'

- Believe that the labelled people are different from other people

- For example a child with cerebral palsy is called a "Spastic" rather than a child with cerebral palsy

- Controversy: "A person with Autism" vs "Autistic"
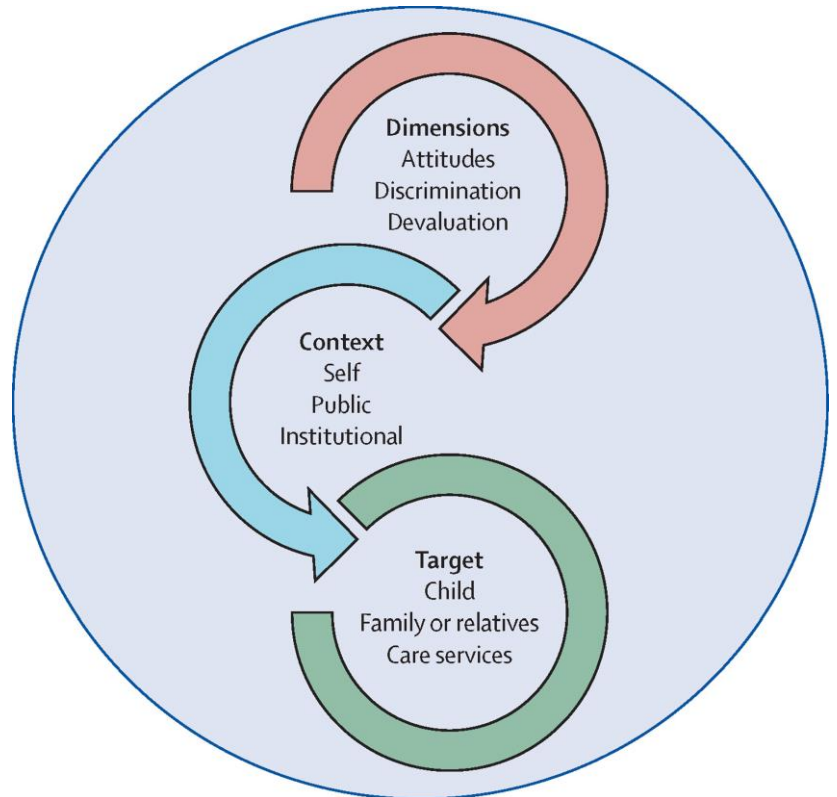 - Neurodiversity

Status Loss

- Associated with discrepancies of the power

- Leads to marginalisation and disadvantage
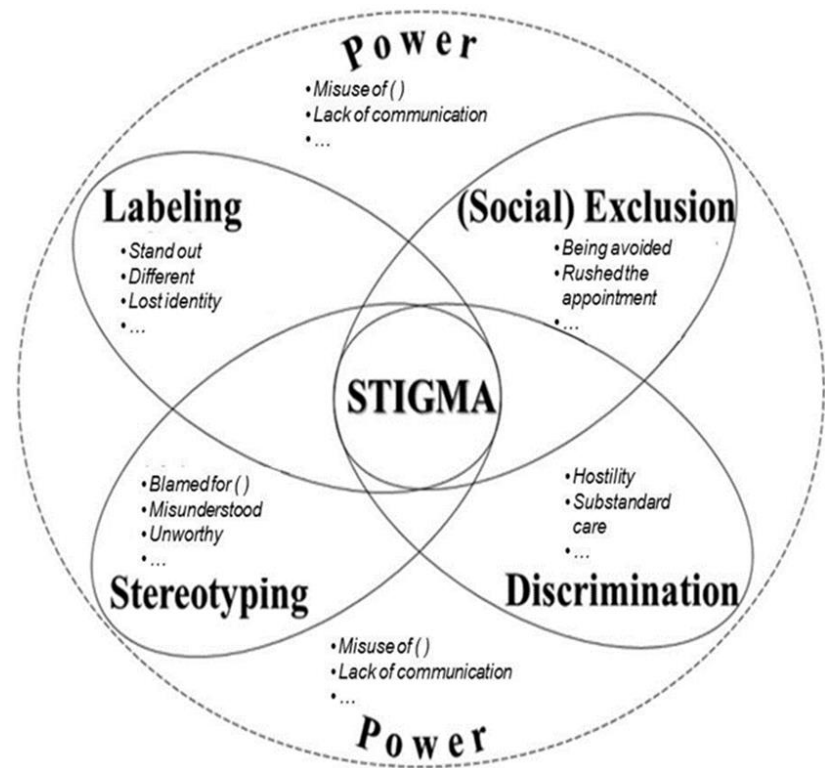
Devalue oneself

- Loss of self esteem leads to mental health issues in the child, the carers and family

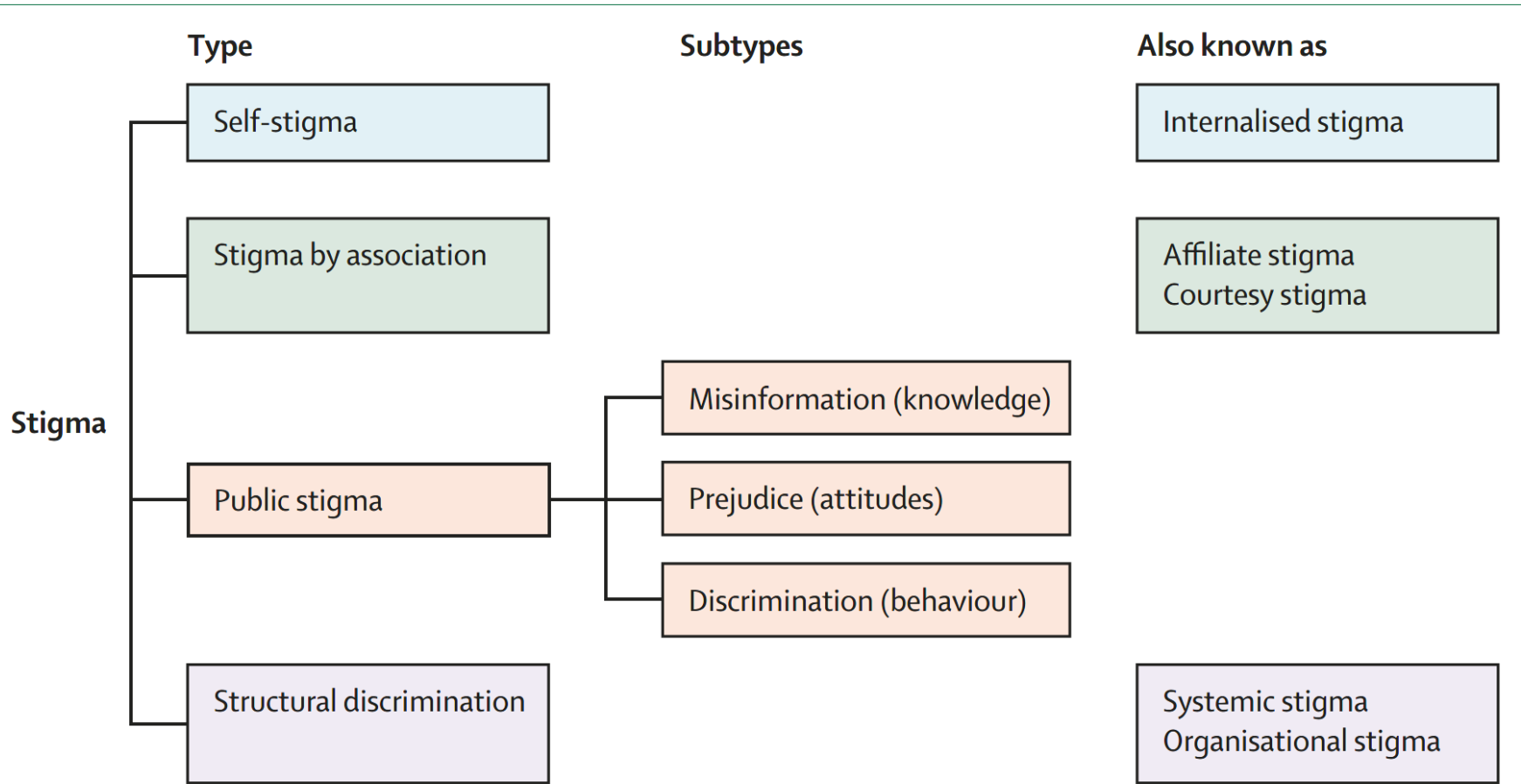- *Kariuki et al Lancet Child and Adolescent Health 2021*

Challenges and coping strategies of parents of children with autism on the Kenyan coast

JK Gona[1], **CR Newton**[2], **KK Rimba**[1], **R Mapenzi**[1], **M Kihara**[3], **FV Vijver**[4], and **A Abubakar**[1]

- Most parents and the professionals from rural and urban settings interviewed viewed parents of children with autism as being stigmatized and sometimes blamed for their child's condition and behavior.

- *People end up blaming me saying that I am raising my child in a bad way. I'm seen as an irresponsible mother. I feel ashamed of myself.* (Interview, parent, rural county)

- *They are suffering because as Africans, in any society, you know your hope is to get a normal child. These parents are disregarded.* (Interview, teacher, rural county)

- *There are those people like in a church. When they see a child moving up and down and disturbing people, they blame the parent. Then you are banned from church services.* (FGD, parent, urban county)

Types of Stigma

| Type	Subtypes	Also known as
Self-stigma		Internalised stigma
Stigma by association		Affiliate stigma / Courtesy stigma
Public stigma	Misinformation (knowledge) / Prejudice (attitudes) / Discrimination (behaviour)	
Structural discrimination		Systemic stigma / Organisational stigma

Types of Stigma

- ## Self Stigma
  - People with the condition view themselves and therefore of lesser value
- ## Stigma by Association
  - Internalisation of stigma by close associates of the person with the condition e.g. Family members
- ## Public Stigma
  - Community views and/or acts towards the person with the condition
- ## Structural Stigma
  - Discrimination in
    - Cultural and organizational practices
    - Laws
    - Policies

Consequences of Stigma

Stigma can cause

- Feelings of
  - isolation
  - hopelessness
  - low self-esteem
- Create problems with employment
- Harassment
- Physical violence
- Negatively impact community participation
- Reduce resource opportunity access
- Cause a person to
  - deny the illness
  - refuse treatment
- Cause there to be inadequate coverage of mental health treatment by health facilities
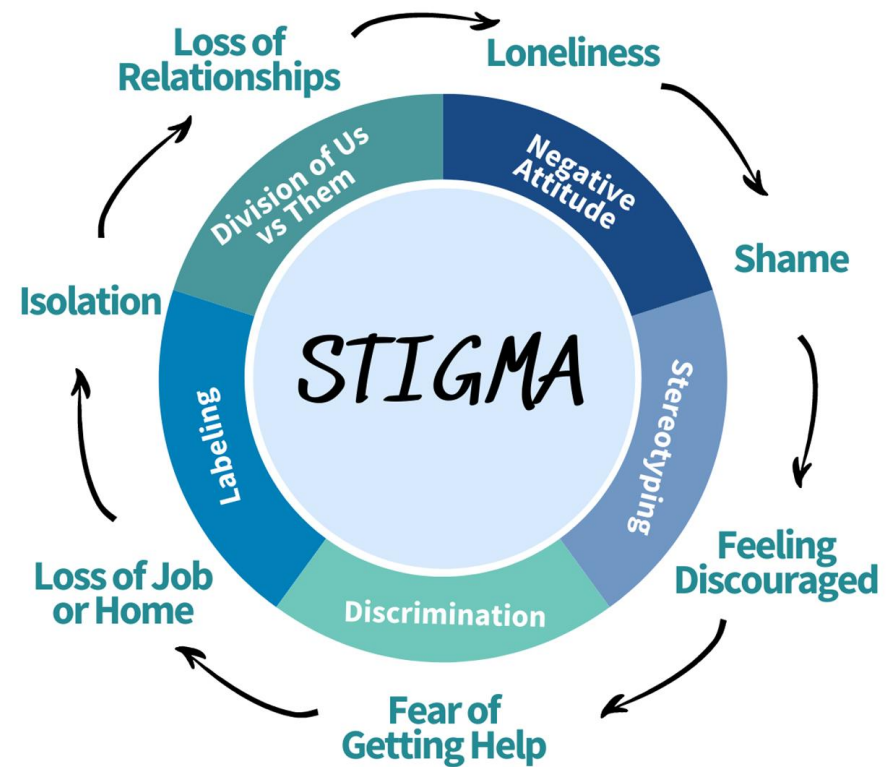
What can you do about it?

Use of Language

Lancet Commission on ending stigma and discrimination in mental health
Language is important to break down stigma

"Language is an important aspect when dealing with mental health issues. Some words can be stigmatising to those with lived experiences and this has an effect on how those with lived experience are treated by society at large."

"It is important that the words/terms do not devalue my illness and do not lead to feelings of shame that I have a mental illness."

"It can shape public impression towards mental health condition. It can empower/discourage individuals with lived experiences to seek help/influence their recovery journey."

"Important, language habits can affect how we understand something, and language use has the power to hurt or build others."

"Terms like 'crazy' and some other obsolete or offensive terms can negatively affect the course of mental illness."

"Language matters very much. There are many insulting words that are used as a routine, also there are words that are paternalistic and contribute to medicalisation of the problem. The language is the fuel for stigma, and media representatives as well as public speakers should be cautious about what terminology they use."

"Language becomes a medium which further promotes stigma and discrimination. Further, the use of inappropriate language and terms leads to labelling, may trigger persons with lived experience or make them feel marginalised. This further impacts help-seeking behaviour and the active participation of persons with mental illness in decisions concerning themselves."

"It's very important because different terms have different implications. Some language can be disempowering and hurtful. It's not about political correctness. But how we express in a way that is aligned with our values with the careful choice of words."

Interaction with the person and family

Person with lived experience (of a mental health condition)

Person with a mental health condition

Person with a psychosocial disability
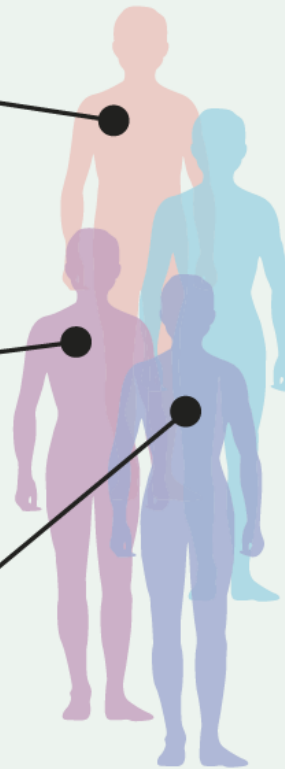
The key principle: Address the individual as a **person** rather than a condition. There may not always be common preferred terms on how individuals would like to be addressed, it is best to **ask the person**.

Avoid any **derogatory** phrases

What Matters Most approach

Structural barriers and facilitators
Societal level conditions, cultural norms, and institutional practices that limit opportunities, resources, and wellbeing of a stigmatised population[36]
- Discriminatory policies against PWLE
- Lack of availability of resources for mental health
- Infrastructures not suitable in health facilities for treatment of PWLE

Explanatory models of mental illness
- Causal beliefs
  (eg, supernatural causes)
- Stigmatising terms
- Symptoms (eg violence, loss of functioning)
- Gender, poverty, etc
  (intersectionality)

Locations and manifestations
- Self-stigma, public stigma
- Discriminatory behaviours
- Health facilities, community spaces

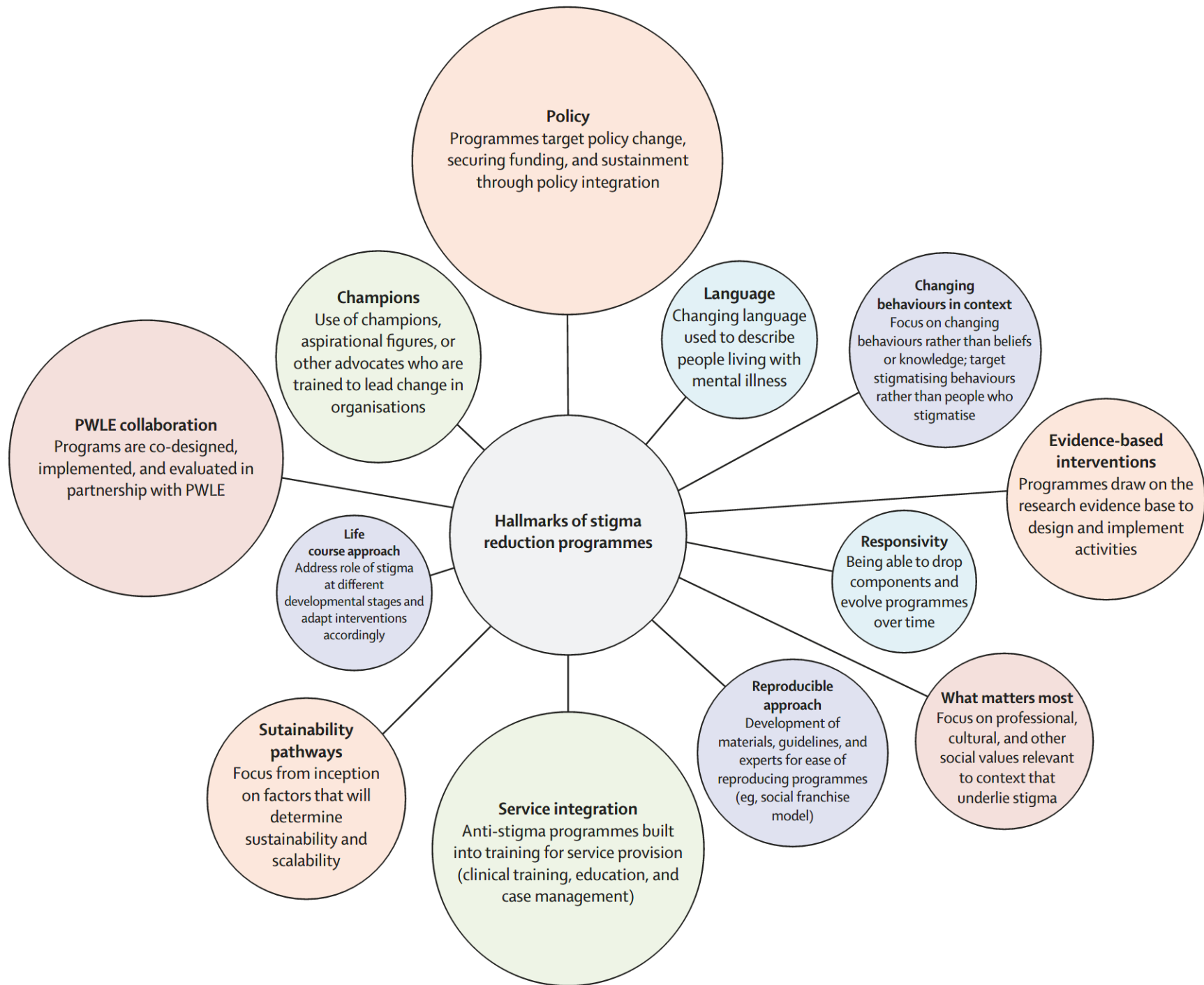### Consequences and impacts of stigma
- Alternative help-seeking
- Services not accessible
- Lack of quality of care

What matters most
Cultural norms and dimensions that influence meanings, practices, and outcomes of stigma[46]
- Social acceptance
- Productivity
- Prestige or social status
- Marriage
- Privacy

Policy
Programmes target policy change, securing funding, and sustainment through policy integration

Champions
Use of champions, aspirational figures, or other advocates who are trained to lead change in organisations

Language
Changing language used to describe people living with mental illness

Changing behaviours in context
Focus on changing behaviours rather than beliefs or knowledge; target stigmatising behaviours rather than people who stigmatise

PWLE collaboration
Programs are co-designed, implemented, and evaluated in partnership with PWLE

Evidence-based interventions
Programmes draw on the research evidence base to design and implement activities

Hallmarks of stigma reduction programmes

Life course approach
Address role of stigma at different developmental stages and adapt interventions accordingly

Responsivity
Being able to drop components and evolve programmes over time

Sustainability pathways
Focus from inception on factors that will determine sustainability and scalability

Service integration
Anti-stigma programmes built into training for service provision (clinical training, education, and case management)

Reproducible approach
Development of materials, guidelines, and experts for ease of reproducing programmes (eg, social franchise model)

What matters most
Focus on professional, cultural, and other social values relevant to context that underlie stigma

What can we do to reduce stigma in SPARK?

Validating measures of stigma against those with mental illness among a community sample in Kilifi Kenya

Mary A. Bitta[1,2], Judy Baariu[1], Elias Fondo[3], Symon M. Kariuki[1,2], Belinda Lennox[2] and Charles R. J. C. Newton[1,2]

- Community Attitudes Toward the Mentally Ill Scale (CAMI), Reported and Intended Behaviors Scale (RIBS) and Mental Health Awareness Knowledge Schedule (MAKS)

- Results support validity of the original MAKS and RIBS scale and a modified CAMI scale and suggest that stigma is not an enduring trait in this population