

Appendix 3 – Summary of stigma manifestations

Health condition	Study ID	Study design	Country	Disability or health condition	Study population	Stigma manifestations	Risk of bias
Mental health conditions (not specified)	Attitudes towards mental illness in Malawi: a cross-sectional survey (Crabb, 2012)	Cross-sectional survey	Malawi	Mental health	210 patients with mental health conditions and carers	Enacted stigma 63% afraid to have a conversation 34% upset/disturbed about working with them 41% not willing to share a room 8% ashamed if someone knew they were related to them 81% not willing to marry them	High
	Stigmatization of people with mental illness among inhabitants of a rural community in Northern Nigeria' (Adu, 2011)	Cross-sectional survey	Nigeria	Mental health	325 adults aged 18+ in a rural community	Enacted Stigma 9.6% were willing to have a mentally ill person as a friend 12.3% would accept to marry them	High

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	Public stigma against family members of people with mental illness: findings from the Gilgel Gibe Field Research Center (Girma, 2014)	Cross-sectional survey	Ethiopia	Mental health	845 community members	Affiliated stigma Enacted stigma <u>Low stigma score on items</u> Families treated differently to other families Parents of children with mental illness are not as responsible and caring as other parents People should keep their family member with mental illness behind locked doors	Low
	Training needs and perspectives of community health workers in relation to integrating child mental health care into primary health care in a rural setting in sub-Saharan Africa: A mixed methods study (Tilahun, 2017)	Mixed methods	Ethiopia	Mental health	104 extension Workers	Enacted stigma: Negative attitudes from the community	Medium

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	Experiences and effects of psychiatric stigma: Monologues of the stigmatizers and the stigmatized in an African setting. (Egbe, 2015)	Qualitative	South Africa	Mental health	77: 32 health care professionals – 10 nurses, 20 lay counsellors, 2 auxiliary social workers 45 mental health service users	<p>Experienced stigma: Accused of faking their mental illness by family Name calling Whispering as they walked on streets Mocked and pointed fingers at them</p> <p>Perceived stigma: Regarded as not being desirable members of the community and not quite human</p>	Medium

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	Psychiatric stigma and discrimination in South Africa: perspectives from key stakeholders (Egbe, 2014)	Qualitative	South Africa	Mental health	77 – nurses (10), lay counsellors (20), auxiliary social workers (2), and service users with depression or schizophrenia (45)	<p>Enacted stigma: Ill treatment at health facilities – security personnel attacks, being assaulted or ignored Ill treatment from family members – being denied food, laughed at, beaten Ill treatment from community, neighbours, general public, church members, friends and employers Communities provoked and called names Discrimination from employers – inadequately compensated or made to do filthy work</p> <p>Perceived stigma: Seen as a deliberate act Aggressive Weak Caused by witchcraft</p>	High
	Stakeholder perspectives on children's mental	Qualitative	6 LMICs, including Kenya,	Mental health	People living in slum areas and orphanages	<p>Enacted stigma: Negative language</p>	Low

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	health needs and supports in six low- and middle-income countries (Vostanis, 2018)		Pakistan, and Rwanda		(Pakistan), community care homes (Rwanda), slums following displacement (Kenya) Numbers not stated		
	They love me but they don't understand me: Family support and stigmatisation of mental health service users in Gujarat, India (Mahomed, 2019)	Qualitative	India (Gujerat)	Mental health	17 mental health service users (residential patients)	Enacted stigma: Lack of support from families Name calling Left out of the house by family members Avoided by the community	Medium
	Stakeholder perceptions of mental health stigma and poverty in Uganda (Ssebunnya, 2009)	Qualitative	Uganda	Mental health	106 mental health stakeholders	Perceived stigma: Considered to be possessed by evil spirits or paying a price of their bad deeds Enacted stigma: Alienated by family members Socially excluded from activities	Medium

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						done Denied employment/losing jobs Reluctant to send their child to school	
Schizophrenia	Perceptions of a South African schizophrenia population with regards to community attitudes towards their illness (Botha, 2006)	Cross-sectional survey	South Africa	Schizophrenia	100 adults diagnosed with schizophrenia for at least a year	<p>Enacted stigma: 65% agreed that they were discriminated against 48% were subjected to name calling and verbal abuse, 39% were victims of physical abuse</p> <p>Internalised stigma: 16% found it difficult to attend clinics because of fear of disclosure 18% found it difficult to take medicines because it reminded them that they were ill. 44% perceived people with psychiatric illnesses to be dangerous 24% agreed that people with</p>	High

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						schizophrenia should rather not get married	
	Stigma and explanatory models among people with schizophrenia and their relatives in Vellore, South India (Charles, 2007)	Cross-sectional survey	India	Schizophrenia	100 schizophrenia patients and 100 relatives	<p>Perceived stigma: 54% of relatives believed in non-biological causes of illness</p> <p>Internalised stigma: Patients believed that their illness was caused by karma 32%; black magic 24%; evil spirits 29%; punishment by God 35%; 60% listed at least one non-biomedical cause</p>	Medium

Health condition	Study ID	Study design	Country	Disability or health condition	Study population	Stigma manifestations	Risk of bias
	Experiences of stigma and discrimination of people with schizophrenia in India (Koschorke, 2014)	Mixed methods	India	Schizophrenia	282 people with schizophrenia	<p>Enacted stigma: Avoided by others Treated differently or with lack of respect Teasing or negative comments Scolded or shouted at</p> <p>Perceived stigma: 52% had stopped taking up opportunities in past 12 months because they anticipated negative reactions</p> <p>Internalised stigma: 46% reported discomfort to disclose the illness 79% reported sense of alienation</p> <p>Experiences of negative discrimination reported less commonly (42%) than internalised stigma, and significantly less often than in studies carried out elsewhere</p>	Low

Health condition	Study ID	Study design	Country	Disability or health condition	Study population	Stigma manifestations	Risk of bias
	Experiences of stigma and discrimination faced by family caregivers of people with schizophrenia in India (Koschorke,2017)	Mixed methods	India	Schizophrenia	282 patients and their caregivers	Affiliated stigma: 21% (n=59) experienced "caregiver stigma" Caregivers blamed and criticised for the behaviours of people with schizophrenia problems, for example, by 'pampering' him or not taking care of him properly, for not marrying him/her off or making sure he goes for work, or for not noticing the problem before bringing her into the family as a daughter-in-law	Low
	I cry every day and night I have my son tied in chains (Asher,2017)	Qualitative	Ethiopia	Schizophrenia	50 (4 people with schizophrenia, 17 caregivers, 7 community leaders, 22 CBR workers)	Perceived stigma: Seen as unpredictable and dangerous by community leaders and caregivers Seen as insignificant or lacking usual needs Enacted stigma: Restraint of people with schizophrenia	Medium

Health condition	Study ID	Study design	Country	Disability or health condition	Study population	Stigma manifestations	Risk of bias
Bipolar disorder	Stigma and its correlates among patients with bipolar disorder: A study from a tertiary care hospital of North India (Grover, 2016)	Cross-sectional survey	India	Bipolar disorder	185 patients with bipolar disorder	Internalised stigma: 38.9% reported self-stigma alienation (28.6%) and social withdrawal (28.6%)	High
HIV/AIDS	Religion and HIV in Tanzania: influence of religious beliefs on HIV stigma, disclosure, and treatment attitudes (Zou, 2009)	Cross-sectional survey	Tanzania	HIV/AIDS	43 participants (Protestants, Catholic, Lutheran congregations)	Enacted stigma: 54.6% expressed shame-related stigma. Lower among those from Pentecostal churches (64.3%) 53% believe a punishment from God 35% believe those infected have not followed the Word of God	High

Health condition	Study ID	Study design	Country	Disability or health condition	Study population	Stigma manifestations	Risk of bias
	'Dying twice' – a multi-level model of the roots of AIDS stigma in two South African communities (Campbell, 2007)	Qualitative	South Africa	HIV/AIDS	120 community residents, including people with HIV, carers, community volunteers, local leaders, NGO staff	<p>Perceived stigma: Belief that AIDS caused by witchcraft (bewitching of sufferer by someone jealous of them)</p> <p>Enacted stigma: Family members hid away sick relatives, disowned dead relatives, refusing to collect their bodies from the mortuary, no acknowledgement that an individual had AIDS</p>	High

Health condition	Study ID	Study design	Country	Disability or health condition	Study population	Stigma manifestations	Risk of bias
	HIV/AIDS-related stigma and discrimination: A study of health care providers in Bangladesh (Ahsan Ullah 2011)	Mixed methods	Bangladesh	HIV/AIDS	41 17 HIV-positive patients (12 male and 5 female), 10 general staff, 8 doctors, and 6 nurses	<p>Enacted stigma: 58% reported experiencing stigma 75% reported partners' threatening to abandon 88% reported distancing from friends and relatives Health care professionals disclosed confidential information to other people without patient's consent 29% refused patients with HIV/AIDS admission to private clinics 43% of patients with HIV/AIDS were refused admission in government hospitals Refused care by health professionals 67% experienced delays in receiving treatment</p> <p>Perceived stigma 46% reported fear of being infected 38% feared that helping is sin</p>	High

Health condition	Study ID	Study design	Country	Disability or health condition	Study population	Stigma manifestations	Risk of bias
Leprosy	Community stigma and desired social distance towards people affected by leprosy in Chandauli district, India (Ballering, 2019)	Cross-sectional survey	India	Leprosy	371 community members without leprosy	<p>Perceived stigma: 94% expressed negative attitudes to people with leprosy Muslims and Buddhists had a significantly lower SDS score than Hindus ($p > .04$ and $p > .01$, respectively) Those with lower total leprosy-specific knowledge scores, had significantly lower SDS scores ($p > 0.002$). 31.8% and 7% had an accepting attitude of having a person with leprosy caring for their children; over 60% of participants were willing to let a room, become colleague of or liking next door to a person cured from leprosy 55% thought people with leprosy would, or possibly would, conceal their disease 85% thought people would, or possibly would, avoid a person in their community affected</p>	Low

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						by leprosy 87% envisage problems for person with leprosy getting married and 59% in an ongoing marriage	
	The quality of life, mental health, and perceived stigma of leprosy patients in Bangladesh (Tsutumi, 2007)	Case-control study	Bangladesh	Leprosy	189 leprosy patients	Internalised stigma: Approximately half of the patients had internalised stigma	Low

Health condition	Study ID	Study design	Country	Disability or health condition	Study population	Stigma manifestations	Risk of bias
	Health-related stigma related to leprosy: What can be learned from nurses in Ghana? (Bergman, 2017)	Qualitative	Ghana	Leprosy	4 nurses	<p>Affiliated stigma: Nurses working in leprosy setting subjected to negative remarks from peers</p> <p>Enacted stigma: Perceived to be lowly contagious, creating fear and discrimination Denied physical contact and closeness</p>	High

Health condition	Study ID	Study design	Country	Disability or health condition	Study population	Stigma manifestations	Risk of bias
Leprosy & HIV/AIDS	Stigma and social participation in Southern India: differences and commonalities among persons affected by leprosy and persons living with HIV/AIDS (Stevelling, 2011)	Cross-sectional survey	India	Leprosy and HIV/AIDS	190 people living with leprosy or HIV/AIDS (numbers not specified for each condition)	<p>Enacted stigma: Around 10% of people with leprosy reported that they did not receive the “same respect” as their peers, while this was around 30% among people with HIV/AIDS ($p < 0.001$)</p> <p>Internalised stigma: More than 50% of people with HIV/AIDS thought that others were thinking less of their family and that their condition causes problems for their children, compared to 40% of the people with leprosy 60-70% of respondents were disappointed in themselves for contracting the disease and felt embarrassed Significant differences between people with HIV/AIDS and people with leprosy, present on the mean items scores of "affected people should not marry", "stay away from social</p>	High

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						<p>situations to protect family" (p<0.001); "the condition has spoiled my life", "nobody get close" and patronising behaviours from others; "ignore or take me less serious" (p<0.001) Those with HIV-AIDS more likely to "feel ashamed" and experience "less respect from others" compared to people with leprosy (p<0.001)</p>	

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Various impairments	Violence against Children with Disabilities in Africa: field studies from Cameroon, Ethiopia, Senegal, Uganda and Zambia (the African Child Policy Forum, 2011)	Mixed methods	Cameroon, Ethiopia, Senegal, Uganda and Zambia	Different impairments – sensory, physical and cognitive	956 young people with disabilities aged 18-24, as well as parents and carers	<p>Perceived stigma: Children with disabilities are not considered like other children (Senegal) Child being born with a disability is thought to be punishment by God for a family member’s wrongdoing (Ethiopia) Punishment assists the growth and obedience of disabled children who are otherwise difficult (Ethiopia) Intellectual disabilities are “worse” than physical or sensory disabilities and children with intellectual disabilities are “problem makers” (Ethiopia)</p> <p>Enacted stigma: Children with disabilities not to be believed when they report violence (Ethiopia) Social exclusion</p>	Medium

Health condition	Study ID	Study design	Country	Disability or health condition	Study population	Stigma manifestations	Risk of bias
	Knowledge, attitudes and practices in eye health and disability in Sierra Leone: Study report 2014 (Sightsavers, 2014)	Mixed methods	Sierra Leone	Disability (WGSS definition)	1,099 community residents aged 18+ years from four districts	<p>Perceived stigma: Fear of negative attitudes, stigma and rejection</p> <p>Enacted stigma: Provocations or mockery from community Abuse from community, mistreated by family members (for example, being pushed) Separation/divorce health care personnel disrespectful and inattentive Excluded from community life</p> <p>Internalised stigma: Feeling ashamed because of looking or behaving differently Negative feelings Low self-esteem</p>	High
	Can anything good come out of this mouth? Female experiences of disability in Malawi (Braathen, 2008)	Qualitative	Malawi	Different impairments – albinism, hearing, physical and intellectual impairment	18 females with disabilities	<p>Enacted stigma: People without hearing impairment given priority over people with hearing impairments Excluded/ignored by and from society</p>	High

Health condition	Study ID	Study design	Country	Disability or health condition	Study population	Stigma manifestations	Risk of bias
	Childhood disability in Turkana, Kenya: Understanding how carers cope in a complex humanitarian setting (Zuurmond, 2016)	Qualitative	Kenya	Different physical, (sensory, visual, hearing), intellectual, (multiple)	31 carers of children with disabilities and 16 key informants	<p>Affiliated stigma: Described as a social construct defined as a mark of shame or discredit, characterised by guilt or disgrace</p> <p>Enacted stigma: Labelling, stereotyping, separation resulting in hiding children with disabilities away from public life</p>	Low
	Outside the circle: A research initiative by Plan International into the rights of children with disabilities to education and protection in West Africa (Plan International)	Qualitative	West Africa – Guinea, Niger, Sierra Leone and Togo	Disability (unspecified)	630 government and civil society stakeholders, community stakeholders, children aged 10+	<p>Enacted stigma: Negative language used as form of abuse Identification by type of impairment, rather by name Hiding/concealing, as well as neglect and marginalisation by family members Denial of existence and abandonment Name calling, violence and ostracization by peers</p> <p>Perceived stigma: Parents of other children did not want their children interacting with children with disabilities Teachers and</p>	High

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						education leaders – inclusive education only regarded as feasible for those with physical disabilities	
	From the day they are born: a qualitative study exploring violence against children with disabilities in West Africa (Njelesani, 2018)	Qualitative	West Africa – Guinea, Niger, Sierra Leone and Togo	Disability (unspecified)	410 children with disabilities (10+ years), community members and disability stakeholders	Perceived stigma: impairment a punishment or curse from God, consequence of an undesirable act, result of a curse, witchcraft or reincarnation	Low

Health condition	Study ID	Study design	Country	Disability or health condition	Study population	Stigma manifestations	Risk of bias
	The abuse of children with disabilities in the Northwest region of Cameroon (The Cameroon Baptist Convention Health services, 2019)	Qualitative	Cameroon (North-west)	Disability (unspecified)	100+ children with disabilities, parents, carers, stakeholders	<p>Perceived stigma: Children with disabilities considered as curse to family and community Some considered them as retribution for crimes committed by ancestors Regarded as witches and subsequently abandoned</p> <p>Enacted stigma: Being kept out of school, often not fed or given food last</p>	Medium
	Combatting Intellectual Disability Stigma: Testing an E-Intervention with Nigerian Internet Users	Randomised controlled trial	Nigeria	Intellectual impairments	198 adults aged 18+	<p>Perceived stigma: Negative attitudes, including pity, sadness and being moved by people with moderate and severe levels of intellectual disability</p>	Low
Albinism	Albinism in Malawi: knowledge and beliefs from an African setting (Braathen, 2008)	Qualitative	Malawi	Albinism	25 people with albinism	<p>Perceived stigma: Albinism seen as a punishment from God</p> <p>Enacted stigma: People with albinism reported spat at.</p>	High

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	Albinism, stigma, subjectivity and global-local discourses in Tanzania (Brocco, 2016)	Qualitative	Tanzania	Albinism	8 people with albinism	Enacted stigma: Albinism represented by denigrating labels, including 'ghost', 'white person' and 'deal' (refers to the trade of body parts on the black market)	High
Epilepsy	Knowledge, Attitude and Practice among patients of epilepsy attending tertiary hospital in Delhi, India and review of Indian studies. (Gourie-Devi 2010)	Cross-sectional survey	India	Epilepsy	120 patients with epilepsy	Enacted stigma: Stigmatising behaviours by teachers, school mates, and by spouse reported by 14%, 16% and 15%, respectively. Internalised stigma: 16% attributed the disease to supernatural powers 21% thought that the disease is a result of sins committed by them or their parents 19% believed that epilepsy can be treated by faith healers.	High

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	Perception of epilepsy among the urban secondary school children of Bareilly district (Joshi, 2012)	Cross-sectional survey	India (Bareilly district)	Epilepsy	798 students from the 9th and 10th standard	Perceived stigma: Epilepsy is a psychiatric disorder (64%) Belief that an average IQ of person with epilepsy lower (40%) Epilepsy is transmitted by eating non-vegetarian diet	Low
	Effect of health education on trainee teachers' knowledge, attitudes, and first aid management of epilepsy: An interventional study (Eze, 2015)	Before and after study (no control)	Nigeria	Epilepsy	226 trainee teachers	Perceived stigma: Over 60% had negative attitudes towards people with epilepsy	Medium
	Perceptions, social life, treatment and education gap of Tanzanian children with epilepsy: A community-based study (Mushi, 2012)	Qualitative	Tanzania	Epilepsy	38 children with epilepsy	Enacted stigma: Isolated and rejected by friends and community	High

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Autism	Challenges and coping strategies of parents of children with autism on the Kenyan coast (Gona, 2016)	Qualitative	Kenya (coastal countries)	Autism	103 parents of children with autism and professionals	Enacted stigma: Non-acceptance/social exclusion of the child with autism by peers, family members, relatives and wider community	Medium
Spina bifida and hydrocephalus	Community knowledge, beliefs, attitudes, and practices towards children with spina bifida and hydrocephalus in Uganda (Banninka, 2015)	Qualitative	Uganda	Spina bifida and hydrocephalus	481 parents of children with the disease, service providers, policy makers and donors	Enacted stigma: 45% reported community members called them names, gossiped about them	High
Cerebral palsy	Understanding the lives of care givers of children with cerebral palsy (Zuurmond, 2015)	Mixed methods	Bangladesh	Cerebral palsy	135 caregivers of children with cerebral palsy	Affiliated stigma: Lack of support in caring for their child Accused of having sinned, hence having a child with cerebral palsy Isolation and lack of wider support Neglect	Low

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Stroke	Stroke-related stigma among West Africans: Patterns and predictors (Sarfo, 2017)	Cross-sectional survey	Ghana	Stroke	200 stroke survivors	<p>Internalised stigma:</p> <p>13% 'always' felt embarrassed because of their physical limitations</p> <p>10% 'always' felt embarrassed about their stroke</p> <p>14.5% 'always' thought it was their fault that they had a stroke</p>	High