

**Using an E-intervention to challenge the current stigma of  
intellectual disability in Kenya**

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**Thesis declaration form**

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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## **Overview**

This thesis focuses on using an e-intervention to challenge the stigma of intellectual disability in Kenya. Part one of the thesis is a systematic literature review examining the attitudes towards people with intellectual disabilities in Africa. The search strategies used to identify the relevant literature are specified. The 22 papers are presented according to the differences in attitudes among various groups including the general public, teachers and families. The findings are then summarised and methodological issues and implications discussed.

Part two is an empirical study using a randomised control trial to assess (1) attitudes towards intellectual disability in Kenya. Attitudes were assessed at baseline, immediately post-intervention and at one month follow-up and (2) the feasibility of a digital intervention in a Kenyan context. The measures used were the *Attitudes Toward Intellectual Disabilities* questionnaire short version (ATTID-SF) reflecting affective, cognitive and behavioural dimensions and the supernatural beliefs subscale of the Intellectual Disabilities Literacy Scale (IDLS). The prevalent attitudes towards intellectual disabilities are described and the effects and feasibility of the intervention discussed. This paper forms part of a joint research study conducted with Deborah Odukoya (2017; Clinical Psychology Doctorate Trainee, University College London) who will report attitudes towards intellectual disabilities in Nigeria. While both projects were conceptualised and planned in parallel, an entirely separate intervention that was appropriate to the respective cultural context was produced by each of us, and data collection and analyses were conducted entirely separately.

Part 3 is a critical appraisal detailing personal reflections and considers methodological issues which arose during the study.

## Table of Contents

<b>Part 1. Literature Review:</b>	<b>8</b>
Abstract	9
1. Introduction	10
2. Method	15
2.1. Search Strategy	15
2.2. Inclusion Criteria	17
2.3. Evaluating the Quality of Studies	17
3. Results	18
3.1. Quality Assessment	25
3.2. Attitudes among the lay public	27
3.3. Attitudes among teachers	31
3.4. Attitudes among family members and carers	39
4. Discussion	42
5. Limitations	48
References	51
<b>Part 2. Empirical Paper:</b>	<b>59</b>
Abstract	60
1. Introduction	61
1.1 People with intellectual disabilities and the social context	62
1.2 Stigma and attitudes	64
1.3 Attitudes towards persons with intellectual disabilities in the African context	66
1.4 Tackling negative attitudes and stigma	68
1.5 Attitudes and contact	69
1.6 Factors related to attitudes	70
1.7 Digital interventions: Helping bridge the gap	71
1.8 Aims and hypothesis	72
2. Method	73

2.1 Joint project	73
2.2 Research design	73
2.3 Setting and participants	74
2.4 Measures	78
2.8 Conditions	82
2.9 Procedure	83
3.0 Data preparation and statistical analysis	85
4. Results	87
4.1 Power analysis	87
4.2 Missing data	87
4.3 Factor analysis	88
4.4 Reliability	92
4.5 Research Question 1	92
4.6 Research Question 2	94
4.7 Level of functioning	95
4.8 Research Question 3	97
4.9 Research Question 4	100
5.Discussion	102
5.1. Limitations	107
5.2 Implications and future research	108
References	111
<b>Part 3: Critical Appraisal</b>	<b>123</b>
Overview	124
Collaboration	124
Methodological issues	126
Recruitment and retention	127
Dissemination	128
Persona experiences	130
References	132
<b>Appendices</b>	<b>133</b>
Appendix 1: Quality appraisal tool	134

Appendix 2: ATTID-SF	137
Appendix 3: IDLS	140
Appendix 4: Process questions	141
Appendix 5: Storyboard	142
Appendix 6: Intervention film	152
Appendix 7: Ethical approval	153
Appendix 8: Information sheet	154
Appendix 9: Flyer	155

## **List of Tables and Figures**

### **Literature Review**

Figure 1: Flow diagram of article selection	19
Table 1: Overview of studies included	20
Table 2: Quality ratings of studies	26

### **Empirical Paper**

Table 3: Participants' demographics	75
Figure 2: Flow diagram of participants in study	77
Table 4: Proportion of variance accounted for by the six ATTID-SF factors and IDLS subscale	88
Table 5: Mean, standard deviation and proportion of participants with a positive, neutral or negative attitude on items reported by the ATTID-SF and IDLS	89
Table 6: Reliability of all 6 ATTIS-SF factors	91
Table 7: Pre-post follow up scores for ATTID-SF and IDLS	92
Table 8: T-tests and ANOVA and effect sizes results for the factors by participant sociodemographic variables	96
Table 9: Reach of the study	99

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## **Part 1**

### **Literature Review**

**Attitudes towards people with intellectual disabilities in Africa: A  
systematic review**

## **Abstract**

**Background:** Despite affecting people across the world, intellectual disabilities (IDs) are still misunderstood by the general public. The attitudes of the general public towards people with ID have a profound impact on social inclusion and provide information for policy development. The present paper presents a systematic review the literature on attitudes towards people with intellectual disabilities in Africa.

**Method:** The literature was searched using the electronic databases PsychINFO, EMBASE, ERIC and SCOPUS. This was supplemented with hand searches reference lists and relevant journals. Scoring criteria were used to evaluate the quality of each study.

**Results:** A total of 22 relevant studies were identified to meet the inclusion criteria. Of these ten studies used quantitative methods, six studies used qualitative methods and six used mixed methodology to investigate attitudes across the African continent.

**Conclusion:** Overall findings indicate negative attitudes towards persons with intellectual disabilities among the general public across African countries. This evidence is limited by the fact that it is mostly based on relatively small unrepresentative samples, unvalidated measures and the quality of studies varies meaning conclusions are difficult to draw and further research is needed.

## **1. Introduction**

Intellectual disabilities are characterised by intellectual impairment and significant deficits in two or more areas of social (adaptive) functioning, which have an onset before adulthood (American Psychiatric Association, 2013, WHO, 1992). The World Report on Disability (World Health Organisation and World Bank, 2011) notes that approximately one billion people across the globe have a disability, 80% of whom live in developing countries. This percentage is substantial yet there is a dearth of data and large gaps in knowledge that exist about different types of disabilities in low and middle income countries (LMICs) (Adnams, 2008), with findings on sub-Saharan Africa largely under-represented when it comes to intellectual disability research (Njenga, 2009).

Over the years, research into intellectual disabilities has been predominantly conducted in and about high-income countries (Townsend, 2011). Generally, this reveals greater investments by high-income governments into research and service provision (Emerson, 2008). Despite progress in policies and service provision in high-income countries, people with intellectual disabilities continue to experience high levels of stigma and discrimination, including reduced employment opportunities, poorer access to education and receive a substandard quality of care (Cummins & Lau, 2003; Emerson, Baines, Allerton, & Welch, 2013; Emerson, Hatton, et al., 2013). Stigma can also result in emotional distress, shame and isolation in individuals with intellectual disabilities and their families (Katbamna et al., 2000). To what extent this holds true or is exacerbated for people with intellectual disabilities in LMICs needs further exploration. Studies suggest that the experience of people with intellectual

disabilities in many LMICs is starkly different to that of people with intellectual disabilities in high-income countries, yet little is known and researched in the global literature on this topic (Townsend, 2011).

Disability remains a complex, dynamic, multi-dimensional and disputed concept (WHO, 2011). As a result, the definition of disability has been an evolving concept and views have shifted from seeing this group as individuals with impairments to seeing them as individuals with disabilities within their social context (McKenzie & McConkey, 2013). The UN Convention on the Rights of Persons with Disabilities (UNCRPD) is based on the premise that 'disability' results from the interaction between people with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society (United Nations, 2006). Thus, disability is seen in terms of the socio-economic, cultural and political disadvantages that result from an individual's exclusion (Government of Canada, 2003). For example, research shows that negative attitudes towards people with disabilities can lead to segregation (Keith et al., 2015; Keller & Siegrist, 2010), rejection (Daruwalla & Darcy, 2005; Hassanein, 2015) and degradation (Panek & Jungers, 2008). By contrast positive attitudes can result in social and psychological acceptance of the individual with a disability (Werner et al., 2015) such as improving social (Kam & Wong, 2008; Keith et al., 2015); medical (Ryan & Scior, 2014); educational (Tindall et al., 2015) and occupational programmes for people with disabilities (Tsang et al., 2004; Uysal et al., 2014). Therefore, society's perceptions and reactions towards individuals with disabilities whether positive or negative are important as they affect the experiences of people with disabilities and those close to them.

Given the difficulties in establishing an agreed definition of disability, it is important to acknowledge that these valuations are culturally specific. Culture has several definitions and it affects the ideas, values and patterns of behaviour in a society. Culture refers to the joint collection of characteristics that are passed from generation to generation which distinguish one society from another in how they think, feel, act and react to people and events (Tindall et al., 2015; Dickson et al., 2000). Further to this, Ravin and Rubin (1983) pointed out that attitudes are not inherited but acquired and learned, with the individual acquiring them from the dominant culture through socialisation. Therefore, cultural influences coupled with individual or group experiences may lead to important consequences and outcomes for people with intellectual disabilities. This highlights the importance of culture not only as it relates to attitudes and stigma towards people with intellectual disabilities, but also, more positively, directs attention to the support that may exist for this group within different communities.

Furthermore, several studies have investigated the cultural influences on attitudes by assessing their effects on a person's behaviour (El-Keshky & Emam, 2015; Scior et al., 2010) and found that in high-income countries attitudes towards people with intellectual disabilities are affected by culture, formal education (Symons et al., 2014), previous contact with people with disabilities and demographic characteristics (Scior et al., 2011). The limited cross-cultural research conducted to date suggests that attitudes towards people with intellectual disabilities tend to be more positive in high than in low and middle-income countries (Florian, 1982; Scior et al., 2015). Other studies have found more positive attitudes towards people with intellectual disabilities in

societies characterised by values of individualism rather than in societies characterised by values of collectivism such as China (Bi, 2010; Rao et al., 2010). For example, stigma in China has been linked with concerns about threats to group status and group harmony, concerns which have been referred to as ‘collectivist’ orientations (Rao et al., 2008). Contrariwise, discourses around individual rights, confidentiality, and privacy are dominant in stigma studies conducted in western countries that have individualistic cultural orientations (Rao et al., 2007). Accordingly, different cultural characteristics may account for the differences in stigmatizing attitudes across cultural groups.

Africa is a large continent consisting of 54 countries with numerous diverse peoples and cultures with different beliefs, values, customs and traditions. Attitudes towards people with intellectual disabilities within its societies has been insufficiently explored and reported. Kisanji (1995) examined Tanzanian proverbs relating to disability and suggested that people with disabilities are feared because they are viewed as curses from gods and ancestors or caused by witchcraft. In regards to intellectual disabilities, these beliefs are not uncommon and have also been described in other African countries such as South Africa (Kromberg et al., 2008), Ethiopia (Mulatu, 1999) and Uganda (Hartley et al., 2005) which may contribute to general apathy and disregard for people with intellectual disabilities (Ihunnah, 1984). However, it is likely that adherence to such beliefs varies with age, education, and also between urban and rural populations. By contrast, some Tanzanian proverbs are used to encourage socially acceptable behaviour towards people with disabilities in the community, for example, by respecting individual differences, helping people in need and

valuing all children and integrating everyone into the community (Kisanji, 1995).

People with intellectual disabilities are among the most vulnerable and marginalised groups in the world. They often face abuse and experience social exclusion on a much greater scale than individuals without disabilities, and this experience is intensified within contexts of poverty such as those on the African continent (Inclusion International, 2006). They are more likely to have poorer health and inadequate access to quality health care (WHO, 2013); less education opportunities with less than 10% of disabled children attending school (World Vision, 2007; ACPF, 2011); fewer employment opportunities, higher rates of abuse and poorer quality of life than those without disabilities (WHO, 2013).

The UNCRPD as recently as 2006, officially recognised the equal rights of people with disabilities and made it obligatory for governments who ratify the Convention to counter discrimination and tackle societal barriers that stop people with disabilities from being valued and seen as equal members of society (United Nations, 2006). In high-income countries, current policies advocate for social inclusion, education, employment, independence and empowerment to improve the lives of people with disabilities within their societies. However, in many African countries barriers such as lack of awareness, negative community attitudes and stigmatising beliefs prevail and people with intellectual disabilities are often denied rights and resources. Thus attempts at greater community integration are difficult (Baffoe, 2013). The importance of understanding the different ways in which intellectual disabilities are perceived lies in the fact that societies conceptualise intellectual disabilities differently (Baffoe, 2013). Therefore, exploring and understanding attitudes and perceptions about persons

with intellectual disabilities not only nationwide but also in different localised African contexts is vital.

A better understanding of attitudes to intellectual disability across African countries may not only shed light on the extent of stigma but also help identify cultural differences and positive ways in which intellectual disabilities are understood and acknowledged.

### *Aims*

The aim of this review was to formally summarise the findings of studies that have investigated attitudes towards individuals with intellectual disabilities in Africa. The review addresses the following questions:

1. What attitudes towards individuals with intellectual disabilities have been observed in studies carried out in African countries?
2. Are there differences in attitudes among different groups, e.g. the lay public, education, health care professionals and families?

## **2. Method**

### *2.1 Search strategy*

Multiple searches were conducted to identify articles focusing on attitudes and beliefs amongst the populations of African countries towards individuals with intellectual disabilities. An electronic search was undertaken across the following databases using the OVID interface: PsycINFO, Scopus, Eric, Embase. A combination of search keywords and their alternatives were used. Search terms were truncated with (\*) to allow for multiple spellings and endings of words and included (intellectual disabil\*, mental\* retardation, mental\*

handicap\*, developmental disb\*, developmental delay OR learning disb\*) AND (attitude\*, stigma, belief\*, prejudice, discriminat\*), in conjunction with terms used to denote different groups (public, general population, teacher\*, educator\*, policy maker\*, judiciary, religious leader\*) AND African countries (Africa\*, Algeria\*, Angola\*, Benin, Botswana, Burkina Faso, Burundi, Cameroon, Canary Islands, Cape Verde, Central African Republic, Chad, Comoros, Democratic Republic of Congo, Republic of Congo, Djibouti, Egypt\*, Equatorial Guinea, Eritrea\*, Ethiopia\*, Gabon, Gambia, Ghana, Guinea-Bissau, Ivory Coast, Kenya\*, Lesotho, Liberia, Libya, Madagascar, Malawi\*, Mali\*, Mauritania\*, Mauritius, Morocco, Mozambique, Namibia, Niger, Nigeria, Rwanda, Sao Tome and Principe, Senegal\*, Seychelles, Sierra Leone, Somalia, South Africa\*, Sudan\*, Swaziland, Tanzania\*, Togo, Tunisia, Uganda\*, Zambia\*, Zimbabwe\*). No date limitations were used for the search.

The results of all searches were collated and duplicates removed. All studies were selected for the review by assessing eligibility through reading the title, abstracts and/ or the full paper where the abstract was not available or sufficient to establish suitability for this review.

Reference lists of articles that met the review's inclusion criteria were reviewed and six additional relevant studies identified. In addition, a hand search of the African Journals Online database and the following journals was conducted: African Journal for the Psychological Studies of Social Issues, Applied Research in Mental Retardation, Development and Education, Disability and Society, International Journal of Disability, Journal of Intellectual Disabilities, Journal of Intellectual Disability Research, Nigerian Journal of Psychiatry, Research in Developmental Disabilities, Sexuality and Disability and South African Journal of Communication Disorders. Lastly, citation searches of the articles identified for inclusion were conducted in Google Scholar but did not yield any further articles not already identified.

## *2.2. Inclusion and exclusion criteria*

The review included articles that were: (i) published in English; (ii) published in peer reviewed journals to guarantee some measure of quality control; (iii) empirically based; and (iv) explicitly focused on attitudes towards individuals with intellectual disabilities. Studies that examined attitudes towards a spectrum of disabilities and other disorders were included if they reported specific attitudes towards people with intellectual disabilities. Review articles, discussion papers, case studies and unpublished dissertations were excluded.

## *2.3. Evaluating the quality of studies*

A key component of systematic reviews of the literature is the assessment of the quality, or validity of the studies (Oxman & Guyatt, 1988). In order to maintain a structured assessment of the quality of studies in this review, an assessment tool was used. The articles were appraised in terms of the criteria specified in the critical appraisal tool developed by Hawker and colleagues (2002) and subsequently used in papers that assess both quantitative and qualitative research (e.g., Flemming, 2010; Markoulakis & Kirsh, 2013). The tool is used to rate studies on a 4-point scale (1 = very poor to 4 = good) on nine aspects of methodology. The tool is user friendly because it provides clear guidelines for scoring of different aspects of articles reporting empirical studies (see Appendix 1). Previous research has found inter-rater reliability to be ‘high’ for the tool, although specific reliability scores have not been published (Flemming, 2010; Hawker et al., 2002). The majority of the articles were of fair to good quality with the lowest score being 21 out of a possible score of 36. The articles were rated by the first author alone due to resource constraints. In order to check the ratings given, four randomly selected articles were independently rated by the research supervisor using Hawker and colleagues (2002) tool and differences in ratings identified and discussed.

### **3. Results**

The database searches identified 154 articles of which 30 met all of the inclusion criteria. It was not possible to obtain full articles for four of the studies and a further four were excluded as English translations were unavailable. Figure 1 provides an overview of the process by which the articles in the search were identified. A total of 22 publications were included in this review, ten used quantitative, six used qualitative and six used both qualitative and quantitative methodologies. Seven studies investigated the attitudes of the public, nine investigated teachers' attitudes and six investigated family members' and carers' attitudes. Questionnaires were the favoured method of data collection employed in ten studies, while 16 studies employed interviews in addition to questionnaires.

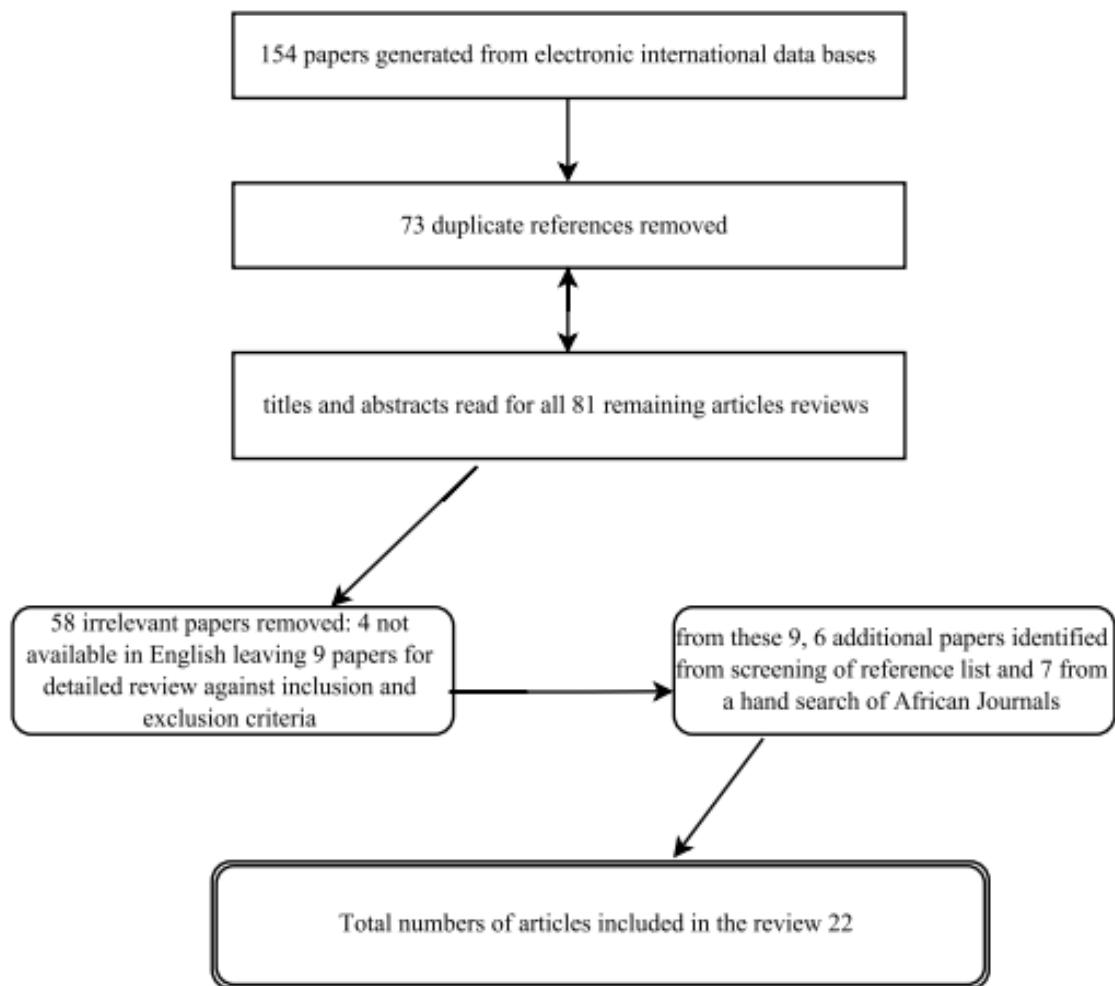


Figure 1. Flow diagram of article selection process

Table 1. Overview of studies included in the review

<b>Study</b>	<b>Country</b>	<b>Sample</b>	<b>Focus</b>	<b>Method</b>	<b>Findings</b>
Aderemi (2014)	Nigeria	12 teachers (9 female, 3 male) aged 29-55	Teachers' opinions and awareness regarding sexuality and exposure to HIV with people with ID	Informant interview based on Integrated Model for Change (de Vris et al., 2003)	1. Negative attitudes; learners considered as hypersexual, incapable of intimate relationships and at risk of exposure to HIV
Agbenyega (2007)	Ghana	50 teachers from inclusive school, 50 from non-inclusive school; 33% males, 67% females	Teachers' concerns and attitudes towards inclusive education	20 item Attitudes Toward Inclusion in Africa Scale (ATIAS) (Agbenyega et al., 2005) and interviews	1. Negative attitudes towards inclusion of children with ID common (limits amount of work that can be done; academic performance of peers would be affected) 2. Teachers felt their knowledge and skills to teach children with ID were inadequate 3. No differences in attitudes between both groups of teachers
Aldersey (2012)	Tanzania	13 family members of people with ID	Family perceptions of ID	Interviews	1. Family members reported that Tanzanians look negatively on people with ID 2. Family members reported their children experience stigma
Bayat (2014)	Cote d'Ivoire	65 professionals working in the field of developmental disabilities; 29 females and 36 males	Understanding ways in which Ivorians view disability	(1) Field observations, (2) surveys; (3) focus groups with professionals, (4) 1 focus group of parents of children with ID, (5) transcribed interviews and (6) examination of government documents	1. Professionals viewed children as 'diseased' in line with a medical model 2. Public viewed children as 'cursed'

Baffoe (2013)	Ghana	80 people with disabilities, 20 family members, 20 others	Examine societal attitudes and barriers for persons with disabilities in Ghana	(1) Interviews (2) Focus groups (3) survey	<ul style="list-style-type: none"> <li>1. Societal stigma, discrimination and their effects most difficult barriers for people with ID to live normal lives</li> <li>2. Myths, superstitions, negative labels contribute to social exclusion of people with ID</li> <li>3. Some parents admitted to hiding children from public view</li> </ul>
Bardon & Corbin (2006)	South Africa	Over 800 adults	Examine the public's knowledge of Special Olympics, their perceptions of people with ID and their beliefs about inclusion in South Africa	(1) Surveys using the Multinational Survey of Public Attitudes towards individuals with Intellectual Disabilities (2002) (2) Face-to-face interviews	<ul style="list-style-type: none"> <li>1. 65% of public have no knowledge of special Olympics</li> <li>2. Majority of public underestimates what people with ID can do</li> <li>3. Majority of public believe that people with ID should not be included with the rest of society</li> </ul>
Barnatt & Kabzems (1992)	Zimbabwe	197 teachers, 66% male, mean age = 28.5, average 4.3 years of experience, 90% lived in urban or suburban areas	Teachers' attitudes towards the integration of pupils with ID into regular classrooms	Survey based on Darovill (1989) using both closed-ended and open-ended questions	<ul style="list-style-type: none"> <li>1. Low levels of acceptance of including children with ID</li> <li>2. Preference ranking for children with different disabilities, with those with ID last</li> </ul>
Benomir et al., (2016)	UK & Libya	University students and professional staff working with children with ID 243 (Libyan, 129 (UK))	Attitudes to people with ID in the UK and Libya	(1) Demographic Questionnaire (2) Community Living Attitudes Scale (CLAS-MR, Henry et al., 1996) translated into Arabic version by authors	<ul style="list-style-type: none"> <li>1. Libyans had less favourable attitudes than UK sample</li> </ul>

Dangor & Ross (2006)	South Africa	10 traditional healers and 10 caregivers from South African Muslim community.	Beliefs and practices of caregivers and traditional healers regarding Down Syndrome	Individual semi-structured interviews including both open and close-ended questions adapted from Bham & Ross (2005) and Badat (2003)	1. Common beliefs were that Down syndrome was genetic and children were perceived as ‘gifts from God’
Eni-Olorunda & Adeboye (2014)	Nigeria	169 teachers; 90 from Oyo and 79 from Ogun States	Investigated why teachers exclude children with ID from regular classrooms	Questionnaire for Exclusion of Children with Intellectual Disability in Regular Classroom (Section A- demographic information, Section B- 15 items)	<ol style="list-style-type: none"> <li>1. Teachers would not want to accept children with ID into their classroom</li> <li>2. Majority stated culture was not responsible for their reasons</li> <li>3. Differences between both groups of teachers</li> </ol>
Gaad (2004)	Egypt, England and United Arab Emirates (UAE)	Unknown number of 6 Egyptian parents and teachers.	Cross-cultural perspectives towards inclusion of children with ID	Interviews	<ol style="list-style-type: none"> <li>1. Negative attitudes towards inclusion of children with ID held by teachers.</li> </ol>
Hartley et al. (2005)	Uganda	51 parents, caregivers and families of children with disabilities	Understand how family members cope with their disabled children	<ol style="list-style-type: none"> <li>(1) Key informant semi structured interviews (Britten, 1995)</li> <li>(2) Non-participatory observation schedules (Mays and Pope, 1995)</li> </ol>	<ol style="list-style-type: none"> <li>1. Carers reported that children encountered negative attitudes; rejection from family members, peers and community</li> <li>2. Parents would like children to attend school</li> <li>3. Parents and caregivers often believed that ID was God’s will, angered spirits or witchcraft was the cause</li> </ol>
Khandel Wal & Workneh (1987)	Ethiopia	100 medical students	Study the change in undergraduate medical students’ attitudes regarding mental disorders	Vignettes adapted from Wig et al (1980) and structured questions	<ol style="list-style-type: none"> <li>1. ID was considered to have most negative outcome of all disorders considered, with marriage and work viewed as impossible</li> </ol>

MacDonald (2012)	Tanzania	32 participants compromised of families, school staff and local leaders	Examines cultural beliefs and values about disability and the influence of these on a school for children with disabilities	(1) Observation (2) document collection (3) interviews using five strategies outlined by McMillan and Schumacher (2006)	<ul style="list-style-type: none"> <li>1. Majority believe that having a child with ID is part of God's plan</li> <li>2. Negative beliefs included shame or burden that children with ID brought to the family</li> </ul>
Mapuranga et al. (2015)	Zimbabwe	10 teachers, 10 children and 10 parents	Investigates impact of inclusive education on the rights of children with ID	(1) Questionnaires (2) Interviews	<ul style="list-style-type: none"> <li>1. Inclusive education recognises the rights of children with ID</li> </ul>
Mapuranga &Nyakudzuka (2014)	Zimbabwe	50 teachers	Teachers' perceptions towards the inclusion of learners with ID	Survey	<ul style="list-style-type: none"> <li>1. 75% agreed that inclusive education is ideal for learners with ID.</li> <li>2. 75% reported people with ID not readily accepted by peers</li> </ul>
McKenzie & Swartz (2011)	South Africa & UK	63 participants (community members, parents of people with disabilities, people with disabilities and teachers); 31 from East London and 32 from Eastern Cape Province, South Africa	Examines viewpoints of two communities on disability in childhood and its implications for sexuality of people with disabilities	Q methodological study; (1) surveys and (2) interviews	<ul style="list-style-type: none"> <li>1. High levels of stigma and negative attitudes towards people with disabilities limit the development of sexuality</li> <li>2. Sexuality of people with disabilities seen as different and impacts on self-esteem of children with disabilities</li> <li>3. Mothers and grandmothers tend to be responsible for sexuality education of children with disabilities</li> </ul>
Menon & Nkhosi (2015)	Zambia	19 mothers	Mothers' perceptions of the needs of adolescent children with ID	(1) Focus groups (2) Observations using the Home Environment Potential Assessment (HEPA) (Serpell & Nabuzoka)	<ul style="list-style-type: none"> <li>1. Mothers reported that adolescents with ID have social and emotional needs just like everyone else</li> </ul>

Mulatu (1999)	Ethiopia	450 adults (mean age 34; 55% males)	Explore causal beliefs about, perceived importance of various treatments attitudes towards 6 disorders and 3 physical illnesses	Semi-structured interview	<ol style="list-style-type: none"> <li>1. ID mainly seen as having a spiritual origin</li> <li>2. Prayer and home/family care strongly suggested for treating mental than physical illnesses</li> <li>3. Negative attitudes towards people whose illnesses are believed to be caused by supernatural origin</li> </ol>
Oluremi (2015)	Nigeria	200 public secondary school teachers	Investigate the attitudes of regular and special teachers to students with special needs in mainstream public secondary schools	Descriptive survey design using (1) Teachers Attitude to Students with Special Needs (TASSN) developed by researcher (2) Examination records	<ol style="list-style-type: none"> <li>1. 76% had positive attitudes, 16% had negative attitudes and 6% had neutral attitudes towards students with ID</li> <li>2. Special teachers had significantly more positive attitudes compared to regular teachers</li> </ol>
Phineas et al. (2013)	Zimbabwe	33 teachers, 3 head teachers from rural primary schools in Zaka	Investigate the effects of inclusion on children with severe ID in regular primary schools	(1) Questionnaires (2) Interviews	<ol style="list-style-type: none"> <li>1. 91% believed that special schools had more to offer students with ID</li> <li>2. All teachers believed inclusion promoted acceptance</li> <li>3. 94% did not want to teach students with severe ID</li> <li>4. 87% thought students with severe ID cannot learn well in mainstream classes</li> </ol>
Walker (1987)	Ghana	146 second year college students	Compared attitudes and knowledge towards people with ID	Questionnaires	<ol style="list-style-type: none"> <li>1. Special education trainees had significantly less favourable attitudes towards people with ID</li> <li>2. Students were more favourable about educating people with ID and less likely to blame the individual/family for the disability compared to non-students</li> <li>3. Neither students or non-students favoured interaction with people with ID</li> </ol>

### **3.1. Quality Assessment**

The quality appraisal ratings for the studies are included in this review and presented in Table 2. Overall the studies were appraised as being of fair to good quality according to the Hawker and colleagues (2002) appraisal tool. No study scored below 21 out of 36 possible points, and none were excluded on the basis of methodology. Of note, 15 of the 22 studies had low scores on item six: ethics and bias. These 15 studies did not make any explicit statements of whether ethical approval was gained or only briefly acknowledged issues around confidentiality and consent and were poor in considering possible sources of bias within the studies.

Table 2. Quality ratings of studies

Author(s) & date	Methodological items (0-4)	Intro & aims (Q2)	Method & data (Q3)	Sampling (Q4)	Data analysis (Q5)	Ethics & bias (Q6)	Findings & results (Q7)	Transferability/generalizability (Q8)	Implications & usefulness (Q9)	Overall score (0-36)
	Abstract & title (Q1)									
Benomir et al .(2016)	4	4	4	3	4	3	4	4	3	34
Dangor & Ross (2006)	4	4	4	4	4	4	3	3	3	33
Hartley et al. (2005)	4	4	4	4	3	2	4	4	4	33
Mckenzie & Swartz (2011)	4	4	4	3	4	4	4	3	3	33
Walker (1982)	4	4	4	4	4	3	4	3	3	33
Aderemi (2004)	4	4	3	4	4	4	3	3	3	32
Aldersey (2012)	4	4	4	3	4	3	3	3	3	31
Bayat (2014)	3	4	3	4	3	1	4	4	4	30
MacDonald (2016)	4	4	4	3	4	2	3	3	3	29
Mulatu (1999)	4	4	4	3	3	1	4	3	3	29
Eni-Orlunda & Adeboye (2014)	3	4	4	3	4	1	3	3	3	28
Menon & Nkhosi (2015)	4	3	4	3	4	1	3	3	3	28
Baffoe (2013)	3	4	4	4	1	1	3	4	3	27
Bardon & Corbin (2006)	4	4	3	2	1	1	4	4	4	27
Oluremi (2015)	3	4	3	3	3	2	3	3	3	27
Agbenyega (2007)	3	3	3	4	3	1	3	3	3	26
Mapuranga et al. (2015)	4	4	3	2	1	1	3	3	4	25
Barnartt & Kabzems (1982)	3	2	3	4	1	1	3	3	4	24
Phinias et al. (2013)	3	4	3	3	1	1	3	3	3	24
Gaad (2004)	1	2	2	2	2	3	2	3	3	22
Mapuranga & Nyakudzuka (2014)	3	4	2	3	1	1	3	2	3	22
Khandel Wal & Workneh (1987)	3	2	3	2	2	1	3	2	3	21

### **3.2. Attitudes among lay people towards people with intellectual disabilities in Africa**

In African society, traditional concepts of intellectual disability have been insufficiently explored. Seven studies examined public attitudes towards people with intellectual disabilities. However, it is important to note that like studies conducted in high-income countries, much of what we know about attitudes in different African contexts is derived from student samples thus their generalisability to the wider population may be limited.

A South African study based on questionnaires and face-to-face interviews investigated the public's knowledge of Special Olympics, their perceptions of people with intellectual disabilities and their beliefs about inclusion (Bardon & Corbin, 2006). The sample comprised of over 800 adults from both urban and rural areas. Overall, the public underestimated the capabilities of people with intellectual disabilities in completing self-help tasks, interacting with others and carrying out complex tasks such as handling emergencies. Only 44% of the public believed that individuals with intellectual disabilities can play sports on a team with other people with intellectual disabilities, and 20% believed that people with intellectual disabilities can play sports on a team with people without intellectual disabilities. Furthermore, the majority of the public believed that individuals with intellectual disabilities should live, work and go to school in separate environments from the rest of society and less than 40% of the public knew about Special Olympics. However, it is important to mention that the study was conducted in 2006 a few years before the 2012 Paralympics that had a seismic effect in shifting perceptions towards intellectual disabilities globally. Although the authors reported the public's negative attitudes towards

people with intellectual disabilities, their article does not provide details of the sample, such as, age, gender, race or context nor did they comment on how the data analysis was conducted.

A study by Bayat (2014) using surveys, interviews and observations on 69 participants examined the public's views toward people with disabilities in Cote d'Ivoire. The findings showed that professionals working in the field of disabilities viewed intellectual disability as a pathological condition, that is, that the affected child was diseased and a strong conviction for inclusion seemed to be lacking. Whereas parents believed that children with intellectual disabilities were cursed by gods. In either case both views proposed that children with intellectual disability should at best, be isolated, or, at worst, killed for the fears of harming others. The author noted such views are interwoven within African cultural beliefs and religious practices. This study was rated as good quality and adhered to all criteria on the Hawker scale.

An interview-based study explored the causal beliefs about perceived importance of various treatments for, and attitudes towards six mental disorders and three physical illnesses (Mulatu, 1999). The sample consisted of 459 adults from north-western Ethiopia. The results indicated that intellectual disability was believed to have spiritual origins, and holy water, family care and consultations with traditional healers were the preferred treatments. Overall, negative attitudes were found towards individuals with disorders whose causes were believed to be supernatural. Mostly these negative attitudes included unwillingness to have romantic relationships and work with people with intellectual disabilities due to fear of contamination through physical and/or spiritual contact. Although these studies provided insight into the negative

attitudes in Ethiopia, the sample was made up predominantly of men and these negative views may not be representative of the women in this community. This study was rated to be of fair quality.

A Tanzanian study using interviews, observation and documents examined the beliefs and values of this community and their influences on children with disabilities (Stone-MacDonald, 2012). The sample comprised of 32 families, school staff and local leaders. They found that in this community, people believed that a child with an intellectual disability is part of God's plan. However, many people also believed that such children brought shame to their family. The generalisability of the results are limited because recruitment was confined to a Lutheran Church school located in a rural town in Tanzania.

Benomir and colleagues (2016) conducted a study using the Community Living attitudes Scale for Mental Retardation (CLAS-MR) (Henry et al., 1996) on 367 participants. This study investigated attitudes towards people with intellectual disabilities in Libya and compared them with those in the UK. They found differences in attitudes toward people with intellectual disabilities between Libyan and British students and teachers. Libyan participants had lower ratings on Empowerment (which relates to policies and decisions that affect the lives of people with intellectual disabilities; and a belief that they should be able to make their own decisions); Similarity (which assesses participants' view on how similar people with intellectual disabilities are to typically-functioning people) and Sheltering (which assesses the extent to which the participant believes the daily lives of people with intellectual disabilities must be supervised and/or that they must be protected from community dangers).

Additionally, the Libyan students gave more favourable ratings for Exclusion (which assessed the desire to exclude persons with intellectual disabilities from community life) than Libyan staff that worked at schools for children with intellectual disabilities whereas UK students gave higher ratings than the UK staff. The author highlighted the similarity between the findings in this study and those reported by Patka and colleagues (2003). Benomir's results support the notion that people from a collectivist culture (Libya) hold less favourable attitudes towards individuals with intellectual disabilities compared to those from an individualist culture (UK). However, most of the participants in this study were female and largely drawn from universities and the education professions and therefore reflect attitudes of a more educated class that may be unrepresentative of the general public. It is also important to acknowledge that the self-report measure used was developed in the USA, which may fail to recognise the cultural, political and religious differences in the Libyan society compared to those in the USA. The internal consistency of the scale was satisfactory, but other aspects of reliability and validity were not tested.

A questionnaire-based study examined changes in attitudes regarding mental illnesses before and after a six-week psychiatric course (Khandel Wal & Workneh, 1987). The study included 100 undergraduate medical students in Addis Ababa, Ethiopia. The findings showed that intellectual disabilities were believed to be a serious condition with less favourable, pessimistic outcomes even after the course. For persons with intellectual disabilities, the students thought that marriage and the ability to continue with their occupation was an impossibility. However, details of the sample were not described, the sample

size was not justified and a clear description of how the analysis was carried out was not discussed.

Walker (1987) carried out a study comparing attitudes and knowledge towards individuals with intellectual disability. The sample compromised of 146 second year college students majoring in general education in Ghana. They found that special education trainees had significantly less favourable attitudes towards individuals with intellectual disabilities compared to the general education and administration students. Surprisingly, a negative correlation between greater knowledge and attitudes towards people with intellectual disabilities was observed. Compared to non-students, students were more favourable about educating people with intellectual disabilities and were less likely to blame the individual or family for the disability. Neither the students nor non-students favoured interaction with people with intellectual disabilities. However, the sample only looked at the attitudes of students and is unrepresentative of the attitudes of the majority of Ghanaian society.

### **3.3. Attitudes amongst teachers**

It has been argued that teachers' attitudes towards inclusion are very important variables in the implementation of successful inclusive practices (Avramidis & Norwich, 2002; Parasuram, 2006). That is, for effective inclusive education, teachers should hold positive attitudes regarding inclusion, including a willingness to teach children with intellectual disabilities and take responsibility for their learning (Titone, 2005). Whereas negative attitudes and prejudice towards students with intellectual disabilities are detrimental to

establishing and maintaining inclusive education programmes (Agbenyega, 2005).

Nine studies investigated teachers' attitudes towards intellectual disabilities. Of these, six reported negative attitudes whereas three reported more positive attitudes. A study conducted with 100 teachers from inclusive and non-inclusive schools in Ghana, found no significant differences between the attitudes of teachers from both schools. In both types of schools, negative attitudes prevailed; the teachers did not regard students with intellectual disabilities as belonging in regular classes and preferred them to be in special schools (Agbenyega, 2007). They also believed that including students with intellectual disabilities in mainstream classrooms results in a failure to complete the syllabus as well as negatively affecting academic performance of pupils without intellectual disabilities.

Furthermore, both teacher groups also expressed concerns for their professional competency and lack of resources available which the authors believe may explain the negative attitudes and beliefs found. Material and human resources and professional knowledge are found to positively influence teachers' attitudes' and willingness to embrace inclusive education (Loreman et al., 2005). It is important to note that in this study, the teachers were not involved in the initial planning and implementation of the programme and thus may have resented efforts by policy makers to enforce inclusive education. This can be inferred from their comments where they regarded inclusive education as an imposition from outside. This study was rated to be of fair quality and benefited from no attrition.

In Egypt, inclusion has not yet been adopted and teachers responded negatively to the idea of accepting children with intellectual disabilities in their classroom (Gaad, 2016). In this study, structured interviews were conducted on six teachers and parents in Egypt, United Arab Emirates (UAE) and England. Egyptian parents reported concerns about how society views their children and how this affects their education. In Egypt, inclusion is not yet an option and such children have only been recently offered placement in special schools, therefore, many parents accepted this choice and appreciated it. A mother from UAE reported that her son was in inclusive education. However, he was in a special classroom with other students with intellectual disabilities. Whereas a mother from England reported that options other than full inclusion were not considered.

The teachers in this study exhibited a variety of attitudes. In England, one reported that teaching a student with intellectual disabilities was demanding despite beliefs of the children's rights whereas another teacher from England reported that regardless of challenges, inclusive practices were beneficial for the student with intellectual disabilities. In UAE, teachers showed less acceptance for the notion of including students with intellectual disabilities. Egyptian teachers responded negatively to accepting children with intellectual disabilities into their classrooms. Although these findings offer some insight into attitudes towards inclusion of students with intellectual disabilities in three different cultures, there were some limitations and had one of the lowest quality ratings. There was a very low sample size and the sampling strategy in this study was not described, that is, no details such as total number, age, gender and context and how they were recruited was provided. Details about the structured interviews,

data collection, recording and analysis were also not adequately described. Therefore, the findings would be difficult to generalise and compare to other studies.

In 2003, Phinias and colleagues conducted a study using the descriptive survey method and examined the effects of inclusion on children with severe intellectual disability in Zimbabwe. The study included 33 teachers and three head teachers from mainstream or regular rural primary schools in rural Zaka central cluster that included children with severe intellectual disabilities. They found that whilst all 33 teachers believed that students with severe intellectual disabilities should be taught by specialist teachers, all 33 teachers agreed that ordinary schools are appropriate settings for students with severe intellectual disabilities. However, thirty teachers (91%) believed that special schools had more to offer and were better equipped for such students. All teachers believed that inclusion promoted acceptance and valued the students' human rights and can be successful with support whilst 88% reported it was burdensome to ordinary teachers. A substantial number of teachers (94%) did not want to teach children with severe intellectual disabilities whereas 6% reported they would be comfortable to teach such children. Only one (3%) of the teachers felt they can learn well in ordinary classes while 87% thought that they cannot learn well in the mainstream classes and need special education in separate classes. All the teachers believed that such children have the same rights as other children and should be treated equally. However, these findings are difficult to generalise across the wider Zimbabwean population as they had a small sample size from only one rural cluster. Additionally, there was little description of the questionnaires and analysis used by the authors.

A questionnaire-based study investigated why teachers exclude children with intellectual disability from their classrooms (Eni-Olorunda & Temitayo, 2014). The study included 169 teachers from Oyo and Ogun urban states in Nigeria. They found that 57% of teachers agreed that children with intellectual disabilities should not be in regular schools and they would not accept them in their classroom. This was because the teachers believed such children would not be able to learn anything and also because they were not special educators. The majority of the teachers (62%) agreed that having a large class would hinder them from paying attention to children with intellectual disabilities. There was also a significant difference in responses between both groups with teachers in Oyo state more willing to accept such children in their classroom. Surprisingly, in both groups 84% reported that culture was not the reason why they would not accept such children in their classrooms. The author noted that this was in contrast to Brown's (1991) findings that teachers' attitudes towards inclusive education for children with special needs may be associated to attitudes prevailing in the respective culture. Furthermore, a significant negative relationship between teachers' years of experience and their attitudes towards inclusion was reported, that is, interestingly those with more experience were more likely to support inclusion of such children in their classroom. This study was rated as good quality according to the Hawkes and colleague's (2002) rating tool.

Barnartt and Kabzems (1992) conducted a survey based questionnaire examining Zimbabwean teachers' attitudes towards the integration of pupils with disabilities into classrooms. The sample consisted of 197 teachers from three groups. The findings showed low levels of acceptance of integrating pupils

with intellectual disabilities in ordinary classrooms. Only 12% of the teachers felt that students with intellectual disabilities should always be included in regular classrooms and less than 15% were willing to accept such children in their own classroom in contrast to 42% and 80% respectively for students with physical disabilities. Forty percent of the teachers would refuse to teach a child with intellectual disabilities and would refer the child to a special school.

When comparing teachers' attitudes towards pupils with different types of disabilities, physical disabilities were viewed as most acceptable and intellectual disabilities as least acceptable. Some of the responses indicated that this may be because changes in teaching methods would be needed, lack of resources, over population of pupils and lack of knowledge or training. These results were consistent with attitudinal studies which reported physical disabilities to be the most acceptable (Alghazo & Naggar Gaad, 2004; Glaubman & Lifshitz 2001). Avramidis and Norwich (2002) found that teachers' attitudes towards inclusion were influenced by the type and severity of the child's disability and by the teachers' access to instructional support. More positive attitudes were related to the inclusion of children who had less severe disabilities or with physical or sensory impairments. Moreover, more experienced teachers were more accepting of pupils with disabilities in their classrooms than in classrooms in general. The authors suggested that social and attitudinal factors may account for the results, but it may be worth considering that the teachers may perceive teaching and motivating a child with a physical disability easier than a child with an intellectual disability. However, the generalisability of these results is limited as the sample was primarily male secondary teachers.

By contrast, two studies in Zimbabwe conducted by Mapuranga et al. (2014; 2015) and one study from Nigeria (Oluremi, 2015) generated more positive findings. One study based on questionnaires explored 50 teachers' perceptions towards inclusion of learners with intellectual disabilities. They found that 75% of teachers agreed with the idea that inclusive education is the ideal placement for learners with intellectual disabilities. The same proportion of teachers noted though that learners with intellectual disabilities are not readily accepted by their peers in inclusive settings and 64% agreed that such pupils benefit educationally and socially from inclusion (Mapuranga & Nyakudzuka, 2014). These findings support previous studies that have reported that most teachers in inclusive classrooms recognise the positive social benefits that can be achieved through inclusion for both special and general education students (Downing & Peckham-Hardin, 2007; Matzen et al., 2010) and that inclusion can present with challenges such as peer exclusion. The researchers noted that teachers noted lack of expertise, time consumption and inadequate resources as challenges to inclusion. These results are congruent with previous findings mentioned in this review and others (Ainscow, 2004; Avramidis & Norwich, 2002; Chimdeza & Peters, 2001). This study had lower quality ratings because the methodology was not adequately described and no details of the data analysis was provided.

The second study from Mapuranga and colleagues (2015) used both questionnaires and interviews to investigate views on the rights of children with intellectual disabilities with regards to inclusive education among teachers and parents in Zimbabwe. The results indicated that inclusive education recognised the rights of children with intellectual disabilities. However, they also reported that such children experienced discrimination from their peers and teachers

which violated their dignity. Furthermore, the findings also reported common beliefs held about intellectual disabilities include curses or punishments from ancestral spirits for wrong doing which affected how children with intellectual disabilities are cared for. A questionnaire-based study examined the attitudes of 200 regular and special teachers to learners with intellectual disabilities in mainstream public secondary schools in Nigeria (Oluremi, 2015). The results showed that 76% of teachers had positive attitudes, 16% had negative attitudes and 6% had neutral attitudes towards students with intellectual disabilities. Compared to the regular teachers, special teachers had significantly more positive attitudes to integration. The study was rated as good quality, however, the study failed to provide details of questionnaires and data analyses used.

Aderemi (2014) conducted an interview-based study to examine the views of 12 teachers on sexuality of Nigerian students with intellectual disabilities and awareness of their risk of HIV infection. The results revealed that while the teachers acknowledged the sexuality of students with intellectual disabilities, their attitudes were negative, they considered them ‘hypersexual’, to have no understanding of sex and facing risk of HIV exposure. These results are congruent with other studies that reported individuals with intellectual disabilities are susceptible to sexual abuse, lack access to sex education and are often perceived as hypersexual (Aderemi et al., 2013; Rohleider & Swartz, 2009; Rohleider et al., 2012). Similarly, to discourage students with intellectual disabilities from engaging in sexual activities, the use of corporal punishment, misinformation and fear was commonly used as a deterrent and further reflected teachers’ negative attitudes towards sexuality of this group. Furthermore, four teachers suggested that such students engage in sexual intercourse without

emotional attachments and are incapable of intimate relationships. This study was rated as good quality.

### **3.4 Attitudes among family members and carers**

In most countries across the globe, the family is seen as the first and most enduring unit of society and is usually the primary source of influence behind personality development and the growth of an individual (Macionis, 2011). For people with intellectual disabilities, family members often provide ongoing invaluable support throughout their lifespan (Chou et al., 2007; Hill & Rose, 2009; McConkey, 2005). In attempting to understand different attitudes towards intellectual disability in diverse contexts, discourse with family members and carers has proven to be insightful.

Six studies looked at the attitudes of family members and carers towards people with intellectual disabilities. A qualitative study using interviews, focus groups and surveys examined societal views towards persons with disabilities in Ghana (Baffoe, 2013). The study included 120 persons consisting of parents of people with disabilities, teachers, public officials and people with disabilities. They found that some parents of children with intellectual disabilities hid their children from public view because families were shunned because of prevailing myths and superstitions in their society. The study was rated as fair quality, however, the study provided no details about the data analysis used. Negative attitudes towards persons with disabilities have also been reported in Uganda. Hartley and colleagues (2005) conducted a qualitative study using semi-structured interviews and observations with 51 caregivers/parents/families of

children with disabilities in Uganda. Caregivers reported that a major barrier encountered by children with intellectual disabilities, and those close to them, is rejection by family members, peers or teachers and other members of the community who believe that they are shameful and should be hidden away. Caregivers also identified beliefs that God's will, angered spirits or witchcraft were the cause of the child's disability. Despite these negative attitudes reported, many families accept and include such children with intellectual disabilities. These results must be treated with caution because the parent group primarily included female carers and small sample size.

A South African study examined the viewpoints of two communities on disability in childhood and its implications for sexuality of people with disabilities using interviews and surveys (McKenzie & Swartz, 2011). The sample was made up of two groups, one from the UK and the other from South Africa. The UK group comprised of 31 persons, five community members, 12 parents of children with disabilities, seven adults with disabilities and seven teachers who work with children with disabilities. The South African group was made up of 32 persons of whom 10 were parents, eight people with disabilities, 10 community members and four teachers. They found that some believed children with intellectual disabilities were a gift from God. Mothers thought that such children should be perceived the same as everyone else with regard to their sexuality. However, the sexuality of these individuals was also viewed as different from normal sexual development. The negative attitudes and high levels of stigma have limited the development of healthy sexuality among children with intellectual disabilities that were found to negatively impact their self-esteem. This study was rated as good quality.

An interview based study conducted on 19 mothers of adolescent children with intellectual disabilities in Zambia reported their children have social needs and emotional feelings like other people (Nkhosi & Menon, 2015). However, the mothers also noted that their children faced challenges when it came to getting their needs met that may lead to emotional difficulties and social isolation as found in other studies. The generalisability of the study is limited as there was no evidence that the children were diagnosed with an intellectual disability and had all received physiotherapy services. Family perceptions of intellectual disabilities in Tanzania were investigated by interviewing 13 family members of individuals with intellectual disabilities (Aldersey, 2012). They found that all family members accepted their child with intellectual disability. However, family members reported that the Tanzanian culture held a negative view towards this group and labelled them as a ‘bad omen’ for the family. On an individual level, parents reported that their children ‘live a subhuman life’ and are not acknowledged in the community. Furthermore, parents also identified stigma was expressed through abandonment of the children by other families. The sample size in this study was too small to generalise its findings but has important implications for healthcare providers and practitioners in supporting and encouraging families with children with intellectual disabilities.

In a South African Muslim community, cultural beliefs and practices in regards to Down syndrome among ten caregivers and ten traditional healers were investigated by Dangor and Ross (2006). The researchers conducted interviews and found that both groups believed that the condition was genetic and caregivers believed that affected children were gifts from God. Some of the caregivers and traditional healers attributed Down syndrome to a punishment

from God or curses from people. Common treatment/management approaches mentioned by both groups included the use of inscriptions from the Quraan, water that had been prayed over and herbal medicines. The main reasons for consulting traditional healers were cultural beliefs and pressure from family members, a preference for their holistic approach and the personal nature of their interventions. However, it is important to note the interviews were not recorded and instead the same researcher took hand written notes for all interviews, which may have affected both the flow of the interviews and data collection. The study would have benefited from the use of triangulation to add depth and rigor to the investigation. Moreover, the findings lack generalisability because of the small sample size.

#### **4. Discussion**

This systematic review considered the results of 22 peer-reviewed studies, which examined attitudes towards persons with intellectual disabilities among a range of populations (e.g. fellow students, teachers, parents) in Africa over a period of over three decades (1987-2016). Ten of the studies reviewed used quantitative, six used qualitative and six used mixed methodologies. Further to this, nine studies reported attitudes among teachers, seven reported attitudes of the general public and six reported attitudes among family members and carers towards people with intellectual disabilities. Overall, this review of the literature suggests that in Africa, attitudes towards persons with such disabilities are generally negative and associated with stigma.

The seven studies that focused on public attitudes concluded that the samples believed that people with intellectual disabilities were incapable of self-

help tasks, interacting with others or unable to make decisions. The findings also revealed that intellectual disabilities were either viewed as a result of supernatural causes (e.g. curse from god or a result of witchcraft) or a medical condition that can be cured with medication. Moreover, most of the public's attitudes favoured the exclusion of people with intellectual disabilities (e.g. they should live, work and go to school) away from the rest of society. A few of the studies reviewed suggested that the desire of exclusion may be due to viewing them as different to others and fear of 'contamination' through contact. These findings are congruent with Scior (2011) where lay people wanted greater distance from people with intellectual disabilities and the global review by Scior and colleagues (2015), where in many low and middle income countries public attitudes perceived such people as unable to contribute to society and there is still a desire to separate this group from society due to prejudice and stigmatising beliefs about the causes of intellectual disabilities. More research into public causal beliefs about intellectual disabilities and their effects on stigma in different cultures should be conducted to identify targets for interventions aimed at reducing stigma towards people with intellectual disabilities.

Out of the nine studies that reported teachers' attitudes, six studies reported negative attitudes towards people with intellectual disabilities. These studies revealed that generally teachers held negative attitudes towards inclusive education and preferred children with intellectual disabilities to attend special schools and taught by specialised teachers because they were unable to learn well in inclusive settings. They believed that including these children would lead to failure to complete the syllabus and negatively affect students without

disabilities. This is congruent with other studies that report children with intellectual disabilities are still segregated in learning institutions and in some places denied the right to education (Scior et al., 2015). Additionally, a few of the studies found that teachers believed that this group were hypersexual and unable to have sexual relationships with emotional attachments, teachers also differentiated their attitudes according to type of disability with greater willingness to include children with physical disabilities than intellectual disabilities as found in other studies (Glaubman & Lifshitz, 2001). Furthermore, teachers with more experience had more favourable attitudes towards inclusive education. The negative attitudes observed among teachers may be due to a lack of professional preparedness, available resources, sufficient orientation and specialist assistance, and no involvement in policy making (Agbenyega, 2007). Furthermore, inclusive education is a fairly new initiative in African education and how it is implemented is constantly evolving.

Nevertheless, because teachers' attitudes towards inclusion have been found to be a key factor that impacts the attendance of children with intellectual disabilities in regular classrooms, positively changing their attitudes should be a key target. Teachers should be encouraged to undergo regular training in teaching children with intellectual disabilities and universities should spend resources in changing attitudes among students as they may have significant influence on services and community views towards people with intellectual disabilities. Importantly, teachers should be involved in all stages of policy development and decision making that would affect them in their schools. Recent studies have indicated that teachers' attitudes and beliefs directly affect their behaviour with students and so have a great influence on classroom

environments and student outcomes (Cook, 2002; Silverman, 2007). Therefore, a synchronisation of support systems and involvement of teachers would help in reducing teachers' negative attitudes and concerns about inclusion and integration. This would facilitate a positive environment for children with intellectual disabilities, ensuring that the education system as a whole enables children with different needs and learning abilities to receive schooling.

Six studies revealed family members' and carers attitudes towards individuals with intellectual disabilities. These findings showed that negative attitudes are not just held by the wider communities but also within families. A common response is to hide children away from society to avoid stigmatization, ridicule and shame for the wider family. In line with findings from previous research (Essop; 2012), this further reinforces shamefulness associated with intellectual disabilities that is still prevalent in many African countries. Moreover, the belief that this disability is associated with different sexual development compared to those without disabilities has resulted in denial of sexual education and exclusion from health initiatives and a discourse of fear and protection (McKenzie & Swartz, 2011), resulting in a heightened vulnerability to sexual abuse and HIV (Rohleder et al., 2009), low levels of self-esteem and avoidance of sexual expression (Shakespeare, 2006). The exclusion of people with intellectual disabilities reduces their chances in learning about sexuality and finding sexual partners (Rembis, 2010).

Additionally, because the disability is traditionally viewed as a religious issue, family members and carers often seek divine intervention through traditional healers. However, it is important to note that some studies reported positive attitudes towards people with intellectual disabilities. Three studies

reported teachers' favourable attitudes towards inclusive education as they recognised the positive social benefits despite the rejection and discrimination from peers and teachers. Parents accepted their children with intellectual disabilities and believed them to be a gift from God, having the same social and emotional needs as everyone else. This highlights that more needs to be done to assert the rights of children with intellectual disabilities to education. Research and interventions should target, encourage and support families to challenge negative perceptions and continue to provide support they provide loved ones with intellectual disabilities and extend to the wider communities in many low and middle-income countries.

Furthermore, some of the findings reported in this review may be bound not only by border but also by time. For example, the study by Gaad (2004) reported findings from Egypt before the revolution and the study by Benomir and colleagues (2016) took place in 2011, the last year of the Gadaffi regime in power and hence the last year of stability in Libya. Additionally, global internet usage has grown significantly and accordingly, access to information and education has increased exponentially. Hence it is possible that further studies investigating attitudes towards people with intellectual disabilities in Africa and around the world may reveal different findings.

Moreover, the limited data gleaned from studies with community, student and parent samples suggest that actions to improve attitudes towards individuals with intellectual disabilities are needed at multiple levels. Such actions should provide more information and promote greater acceptance of individuals with intellectual disabilities and challenge traditionally highly stigmatising beliefs, such as intellectual disability being viewed as a 'curse'. While there is a large

amount of literature on public attitudes toward people with disabilities in high-income countries, very little has been written about attitudes towards people with disabilities in low-income countries. Overall, given the paucity of data about people with intellectual disabilities and their experiences in different African countries, more research is needed not only to contribute to the limited existing literature but to inform governmental agencies, professional associations, community-based support services and advocacy suited to these contexts.

Finally, despite international agreements and policies aimed to raise awareness of intellectual disability and tackle stigma and discrimination towards people with intellectual disabilities, limited action has been taken in low income countries compared to high-income countries (Scior, 2015). This is surprising as 80% of people with disabilities live in developing countries where stigma is very high and people with disabilities still experience unrelenting difficulties and poorer quality of life.

The limited research suggests that the general public has a limited understanding of intellectual disabilities (Mulatu, 1999), and want greater social distance from people with intellectual distance that has led to this group hidden away from society. Numerous interventions that vary in target group, content and methodologies have been reported to tackle attitudinal barriers in different societies have shown promising results. Some evidence from these studies have consistently reported contact with people with disabilities as an effective way to challenge negative stereotypes. This is in line with Allport (1954) intergroup contact theory that suggests direct contact between members of different social

groups can help reduce prejudicial attitudes and can be a helpful way to improve attitudes and ultimately reduce stigma.

However, these results should be taken with caution as most reported methodological and conceptual limitations (e.g. small samples, poor measurements of attitudes) and have failed to ensure wider implementation and collaborations globally. Therefore, moving forward, interventions at a multi-level that are sensitive to different contexts and cultures, informed by theory are needed to tackle stigma in African countries.

## **5. Limitations**

The findings in this review were largely based on self-report questionnaires and interviews rather than direct observations of the samples, e.g. teachers. It is conceivable that teachers may support inclusive education in general but may be unwilling to make specific adaptations for pupils with intellectual disabilities, possibly due to lack of resources. Furthermore, observations would be necessary to assess to what extent and how teachers' attitudes, feelings and behavioural intentions affect their actual behaviour towards pupils with intellectual disabilities. Additionally, some cultural beliefs may be associated with divinity or viewed as offensive and not voiced in research, for example, beliefs in disability resulting from curses and past sins. Therefore, research participants may have been reluctant to admit to holding such beliefs and instead given socially desirable responses.

Another limitation concerns the relatively small samples in most of the studies, rendering their findings of low generalisability. Furthermore, the samples were mostly either predominately male or female rather than balanced, which may have affected the studies' findings. In six of the quantitative studies, details of the methodology were not provided. Therefore, one needs to be cautious about the extent to which the reliability and validity of the measures are acceptable and whether the constructs they assessed were appropriate and relevant to capture attitudes towards individuals with intellectual disabilities within these cultures.

It is important to note that some of the investigators' narrow understanding of the language, history and cultures of the sample limited some of the studies. Although some were carried out in consultation with local professionals, Western influence on the interpretation of data was inevitable (Miles, 1983). Each culture is unique and is usually best understood by indigenous people. However, as Maclure (2006) highlights, African educational research is heavily dependent on foreign funding making it difficult to ensure that the process and results are truly reflective of the sociocultural context in which they originate. A few further sources of potential bias need to be acknowledged, namely the fact that the author carried out a thorough assessment of the identified articles against the inclusion or exclusion criteria alone. However, although final judgements of whether articles should be included or not were made in discussion with the supervisor, this was done after the initial sorting of articles. Quality assessment of the articles were done alone, the supervisor cross-checked ratings for the first four articles to calibrate the ratings but due to resource constraints it was not possible to independently double rate each article. One of

the criteria for inclusion was that articles had to be published in English which excluded four articles from French speaking countries such as Togo that were not translated into English. Some full text versions of articles could not be found and were thus excluded. Additionally, although the literature searches were done on the well-known databases, it is possible that the author could have missed some African databases that might have resulted in relevant articles being excluded. Moreover, the measures used in some of the studies were not standardised or even named or described in any detail and therefore made it difficult to compare the findings or assess the quality of the studies. By contrast, some of the studies used standardised tools and provided cross-cultural validations of these and thus paved the way for future studies in these countries (e.g. Benomir 2016 who produced an Arab version of the Community Living Attitudes Scale for Mental Retardation (CLAS-MR) that is culturally sensitive and valuable).

In conclusion, there is only very limited research on attitudes toward intellectual disabilities in African countries; (2) findings of existing studies and generalisability of their results are severely limited by small and selective samples, and by poorly articulated methods that would make replication next to impossible; (3) more extensive, well designed studies are needed to shed light on attitudes to intellectual disabilities in different African countries. For example, using standardised measures, conducting comprehensive interviews and recruiting samples that include a mix of rural and urban environments and different groups including religious leaders to assess which factors drive stigma and highlight target areas for interventions.

## **References**

- Aderemi, T. J. (2014). Teachers' perspectives on sexuality and sexuality education of learners with intellectual disabilities in Nigeria. *Sexuality and Disability*, 32(3), 247-258.
- Adnams, C. M. (2008). Poverty and intellectual disabilities. *Journal of Intellectual Disability Research*, 52(8), 639.
- Agbenyega, J. (2007). Examining teachers' concerns and attitudes to inclusive education in Ghana. *International Journal of Whole Schooling*, 3(1), 41-56.
- Ainscow, M. (2004). Special needs in the classroom: a teachers' guide, University of Michigan: Unesco.
- Aldersey, H. M. (2012). Family perceptions of intellectual disability: understanding and support in Dar es Salaam: original research. *African Journal of Disability*, 1(1), 1-12.
- Alghazo, E. M., Gaad, N., & El, E. (2004). General education teachers in the United Arab Emirates and their acceptance of the inclusion of students with disabilities. *British Journal of Special Education*, 31(2), 94-99.
- American Psychiatric Association. Task Force on DSM-IV. (1993). *DSM-IV draft criteria*. Amer Psychiatric Pub Incorporated.
- Avramidis, E., & Norwich, B. (2002). Teachers' attitude towards integration/inclusion: a review of the literature. *European Journal of Special Needs education*, 17, 129-147.
- Baffoe, M. (2013). Stigma, discrimination & marginalization: Gateways to oppression of persons with disabilities in Ghana, West Africa. *Journal of Educational and Social Research*, 3(1), 187-198.

Bardon, J. N., Siperstein, G. N., Parker, R. C., & Corbin, S. (2006). Attitudes of the public in South Africa toward people with intellectual disabilities, Special Olympics Report.

Barnartt, S. N., & Kabzems, V. (1992). Zimbabwean teachers' attitudes towards the integration of pupils with disabilities into regular classrooms. *International Journal of Disability, Development and Education*, 39(2), 135-146.

Bayat, M. (2014). Understanding views of disability in the Cote d'Ivoire. *Disability and Society*, 29(1), 30-43.

Benomir, A. M., Nicolson, R. I., & Beail, N. (2016). Attitudes towards people with intellectual disability in the UK and Libya: a cross-cultural comparison. *Research in Developmental Disabilities*, 51, 1-9.

Bi, H. (2010). *Chinese graduate students' attitudes toward persons with intellectual disabilities: An acculturation approach* (Doctoral dissertation, Bowling Green State University).

Brown, R. I. (1991). Changing concepts of disability in Developed and Developing communities. In Mitchell, D and Brown I(Eds) *Early Intervention Studies for Young Children with Special Needs*, New York; Chapman and Hall.

Cook, B. G. (2002). Inclusive attitudes, strengths, and weaknesses of pre-service general educators enrolled in a curriculum infusion teacher preparation program. *Teacher Education and Special Education*, 25(3), 262-277.

Cummins, R. A., & Lau, A. L. (2003). Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of applied research in intellectual disabilities*, 16(2), 145-157.

Dangor, T., & Ross, E. (2005). Western and traditional medicine: cultural beliefs and practices of South African Muslims with regard to Down syndrome. *The South African Journal of Communication Disorders (Die Suid-Afrikaanse tydskrif vir Kommunikasieafwykings)*, 53, 27-38.

Daruwalla, P., & Darcy, S. (2005). Personal and societal attitudes to disability. *Annals of Tourism Research*, 32(3), 549-570.

- Dickson, M. W., Aditya, R. N., & Chhokar, J. S. (2000). Definition and interpretation in cross-cultural organizational culture research: Some pointers from the GLOBE research program. *Handbook of Organizational Culture and Climate*, 447-464.
- Downing, J. E., & Peckham-Hardin, K. D. (2007). Inclusive education: What makes it a good education for students with moderate to severe disabilities?. *Research and Practice for Persons with Severe Disabilities*, 32(1), 16-30.
- El-Keshky, M., & Emam, M. (2015). Emotional and behavioural difficulties in children referred for learning disabilities from two Arab countries: A cross-cultural examination of the Strengths and Difficulties Questionnaire. *Research in Developmental Disabilities*, 36, 459-469.
- Emerson, E., McConkey, R., Walsh, P. N., & Felce, D. (2008). Intellectual disability in a global context. *Journal of Policy and Practice in Intellectual Disabilities*, 5(2), 79-80.
- Emerson, E., Baines, S., Allerton, L., & Welch, V. (2013). Health inequalities and people with learning disabilities in the UK: 2012. *Durham: Improving Health & Lives: Learning Disabilities Observatory*.
- Eni-Olorunda, T., & Temitayo, K. A. (2014). Exclusion of children with intellectual disabilities from regular classroom: Nigeria perspective. *African Journal for the Psychological Studies of Social Issues*, 17(3), 99-109.
- Essop, F. (2012). Parents' and special care workers' understanding of "acceptance" and "denial" in relation to a child's intellectual disability. Unpublished Master's Thesis. University of Cape Town, Disability Studies Division, Cape Town, South Africa.
- Gaad, E. (2004). Cross-cultural perspectives on the effect of cultural attitudes towards inclusion for children with intellectual disabilities. *International Journal of Inclusive Education*, 8(3), 311-328.
- Glaubman IV, R., & Lifshitz, H. (2001). Ultra-orthodox Jewish teachers' self-efficacy and willingness for inclusion of pupils with special needs. *European Journal of Special Needs Education*, 16(3), 207-223.

- Hartley, S. O. V. P., Ojwang, P., Baguwemu, A., Ddamulira, M., & Chavuta, A. (2005). How do carers of disabled children cope? The Ugandan perspective. *Child: Care, Health and Development*, 31(2), 167-180.
- Hawker, S., Payne, S., Kerr, C., Hardey, M., & Powell, J. (2002). Appraising the evidence: reviewing disparate data systematically. *Qualitative health research*, 12(9), 1284-1299.
- Henry, D., Keys, C., Jopp, D., & Balcazar, F. (1996). The community living attitudes scale, mental retardation form: Development and psychometric properties. *Mental Retardation*, 34(3), 149.
- Katbamna, S., Bhakta, P., & Parker, G. (2000). Perceptions of disability and care-giving relationships in South Asian communities. *Ethnicity, Disability and Chronic Illness*, 12-27.
- Keller, C., & Siegrist, M. (2010). Psychological resources and attitudes toward people with physical disabilities. *Journal of Applied Social Psychology*, 40(2), 389-401.
- Keith, J. M., Bennetto, L., & Rogge, R. D. (2015). The relationship between contact and attitudes: Reducing prejudice toward individuals with intellectual and developmental disabilities. *Research in Developmental Disabilities*, 47, 14-26.
- Kisanji, J. (1995). Attitudes and beliefs about disability in Tanzania. *Innovations in Developing Countries for People with Disabilities*, 51-70.
- Khandelwal, S. K., & Workneh, F. (1987). Change in perception of mental illnesses by under graduate medical students of Addis Ababa following psychiatric attachment. *Indian Journal of Psychiatry*, 29(1), 57.
- Kromberg, J., Zwane, E., Manga, P., Venter, A., Rosen, E., & Christianson, A. (2008). Intellectual disability in the context of a South African population. *Journal of Policy and Practice in Intellectual Disabilities*, 5(2), 89-95.
- Loreman, T., Forlin, C., Sharma, U. (2007). An international comparison of pre-service teacher attitudes towards inclusive education. *Disability Studies Quarterly*, 27(4).

- Maclure, R. (2006). No longer overlooked and undervalued? The evolving dynamics of endogenous educational research in sub-Saharan Africa. *Harvard Educational Review*, 76(1), 80-109.
- Macionis, J. J & Gerber, L. (2011). Sociology. 7th Canadian Edition.
- Mapuranga, B., Dumba, O., & Musodza, B. (2015). The Impact of Inclusive Education (IE) on the Rights of Children with Intellectual Disabilities (IDs) in Chegutu. *Journal of Education and Practice*, 6(30), 214-223.
- Mapuranga, B., & Joyline, N. (2014). The Inclusion of Children with Mental Disabilities: A Teacher's Perspective. *International Journal of Humanities Social Sciences and Education*, 1(2), 65-75.
- Matzen, K., Ryndak, D., & Nakao, T. (2010). Middle school teams increasing access to general education for students with significant disabilities: Issues encountered and activities observed across contexts. *Remedial and Special Education*, 31(4), 287-304.
- Mckenzie, J. A., & Swartz, L. (2011). The shaping of sexuality in children with disabilities: AQ methodological study. *Sexuality and Disability*, 29(4), 363-376.
- Miles, M. (1983). Attitudes towards people with disabilities after IYP (1981) with suggestions for promoting positive changes. *Peshawar Mental Health Center*.
- Mulatu, M. S. (1999). Perceptions of mental and physical illnesses in north-western Ethiopia causes, treatments, and attitudes. *Journal of Health Psychology*, 4(4), 531-549.
- Nkhosi, J. K., & Menon, J. A. (2015). Mothers' perceptions on the needs of adolescent children with intellectual disabilities at George Clinic, Lusaka, Zambia. *Medical Journal of Zambia*, 42(4), 164-169.
- Oluremi, F. D. (2015). Attitude of teachers to students with special needs in mainstreamed public secondary schools in southwestern Nigeria: The need for a change. *European Scientific Journal*, 11(10).

- Oxman, A. D., & Guyatt, G. H. (1988). Guidelines for reading literature reviews. *CMAJ: Canadian Medical Association journal*, 138(8), 697.
- Panek, P. E., & Jungers, M. K. (2008). Effects of age, gender, and causality on perceptions of persons with mental retardation. *Research in Developmental Disabilities*, 29(2), 125-132.
- Parasuram, K. (2006). Variables that affect teachers' attitudes towards disability and inclusive education in Mumbai, India. *Disability & Society*, 21(3), 231-242.
- Phinias, T., Jeriphanos, M., & Kudakwashe, M. (2013). Inclusion and the world of disability: A case study of Zaka Central Cluster, Masvingo, Zimbabwe. *Journal of African Studies and Development*, 5(8), 241.
- Rao, D., Horton, R. A., Tsang, H. W., Shi, K., & Corrigan, P. W. (2010). Does individualism help explain differences in employers' stigmatizing attitudes toward disability across Chinese and American cities?. *Rehabilitation Psychology*, 55(4), 351.
- Rembis, M. A. (2010). Beyond the binary: rethinking the social model of disabled sexuality. *Sexuality and Disability*, 28(1), 51-60.
- Rohleder, P., Braathen, S. H., Swartz, L., & Eide, A. H. (2009). HIV/AIDS and disability in Southern Africa: a review of relevant literature. *Disability and Rehabilitation*, 31(1), 51-59.
- Ryan, T. A., & Scior, K. (2014). Medical students' attitudes towards people with intellectual disabilities: A literature review. *Research in Developmental Disabilities*, 35(10), 2316-2328.
- Scior, K., Kan, K. Y., McLoughlin, A., & Sheridan, J. (2010). Public attitudes toward people with intellectual disabilities: A cross-cultural study. *Intellectual and Developmental Disabilities*, 48(4), 278-289.
- Scior, K. (2011). Public awareness, attitudes and beliefs regarding intellectual disability: A systematic review. *Research in Developmental Disabilities*, 32(6), 2164-2182.

- Silverman, J. C. (2007). Epistemological beliefs and attitudes toward inclusion in pre-service teachers. *Teacher Education and Special Education*, 30(1), 42-51.
- Shakespeare, T. (2006). Disability rights and wrongs. Routledge, London.
- Symons, A. B., Morley, C. P., McGuigan, D., & Akl, E. A. (2014). A curriculum on care for people with disabilities: Effects on medical student self-reported attitudes and comfort level. *Disability and Health Journal*, 7(1), 88-95.
- Titone, C. (2005). The philosophy of inclusion: Roadblocks and remedies for the teacher and the teacher educator. *The Journal of Educational Thought (JET)/Revue de la Pensée Educative*, 7-32.
- Tsang, H. W., Chan, F., & Chan, C. C. (2004). Factors influencing occupational therapy students' attitudes toward persons with disabilities: A conjoint analysis. *American Journal of Occupational Therapy*, 58(4), 426-434.
- Uysal, A., Albayrak, B., Koçulu, B., Kan, F., & Aydın, T. (2014). Attitudes of nursing students toward people with disabilities. *Nurse Education Today*, 34(5), 878-884.
- United Nations (2006). Convention on the Rights of Persons with Disabilities. New York: UN.
- Walker, S. (1982). A comparison of attitudes and knowledge of Ghanaian college students relative to the mentally retarded. *Applied Research in Mental Retardation*, 3(2), 163-174.
- Werner, S., Peretz, H., & Roth, D. (2015). Israeli children's attitudes toward children with and without disabilities. *Early Childhood Research Quarterly*, 33, 98-107.
- Wong, D. K. P. (2008). Do contacts make a difference?: The effects of mainstreaming on student attitudes toward people with disabilities. *Research in Developmental Disabilities*, 29(1), 70-82.
- World Health Organisation. (1992). *ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva: World Health Organisation.

World Health Organization. World Report on Disability. Geneva: World Health Organisation, World Bank; 2011.

## **Part 2: Empirical Paper**

**Using an E-intervention to challenge the current stigma of intellectual  
disability in Kenya**

## Abstract

**Background:** Around the world people with intellectual disabilities (IDs) are exposed to stigma and discrimination. However, there is limited knowledge about attitudes to people with intellectual disabilities from low to middle-income countries, particularly in sub-Saharan Africa. This study set out to assess (1) attitudes towards people with ID in a Kenyan sample; (2) the impact of a brief e-intervention that combined indirect contact and education about ID on such attitudes; and (3) the feasibility of this e-intervention in terms of reach and acceptability of the study.

**Method:** Using a web-based questionnaire study across three time points, 457 participants were randomised to watch either a 6-minute film based on intergroup contact theory or a control video. Their attitudes were assessed at baseline and again on completion of the intervention. Ninety-two of the participants also provided one-month follow-up data. The measures used were the *Attitudes Toward Intellectual Disabilities* questionnaire short version (ATTID-SF) (Morin et al., 2012) reflecting affective, cognitive and behavioural dimensions and the supernatural beliefs subscale of the *Intellectual Disabilities Literacy Scale* (IDLS) (Scior & Furnham, 2011).

**Results:** The findings indicate that this Kenyan sample had positive attitudes towards people with ID regarding a measure on the three attitude dimensions (cognitive, affective and behavioural). More positive attitudes post-intervention on the *discomfort, interaction, knowledge of rights* and *knowledge of capacity* factors was observed, while attitudes changed in a more negative direction on the *sensitivity/tenderness* factor and the *IDLS* supernatural beliefs subscale. Attitudes varied according to frequency and quality of participants' prior contact with a person with ID and demographic characteristics, as well as the severity of ID depicted in the measures. More positive attitudes were associated with higher education, frequency and quality of contact. Negative attitudes were revealed towards lower functioning people with ID. The ATTID-SF yielded a six-factor structure and had good internal consistency. **Conclusion:** Brief e-interventions that involve indirect contact and education may make a positive contribution to efforts to challenge ID stigma in Kenya. The ATTID-SF shows

promise as a measure that is suitable to assess attitudes in ID in diverse cultural context in Kenya.

## **1. Introduction**

Intellectual disabilities (IDs) affect around 2% of the world's population (WHO, 1992). They are characterised by intellectual impairment and significant deficits in two or more areas of social (adaptive) functioning, which have an onset before adulthood (American Psychiatric Association, 2013; WHO, 1992). Currently, there is little knowledge about this group in low and middle-income countries. The World Health Organisation (WHO) estimates that 10% of Africans have a disability, but there is limited data from African countries as to the actual prevalence (Fujiura at el., 2005).

The Republic of Kenya is a country in East Africa with a population of approximately 38.6 million people (results of the 2009 consensus) with approximately 6 million living in urban areas. Kenya has a young population with 73% of its residents aged below 30 years (Central Intelligence Agency, 2012). It is bordered by Tanzania, Uganda, Ethiopia, South Sudan and Somalia. Kenya's two official languages are Swahili and English. Kenya has a diverse population with 47 different ethnic groups each with its own rich culture and local language. According to the 2009 census, people with ID make up approximately 20% of the Kenya's population (Kenya Bureau of Statistics, 2009). In most cases in Kenya and Africa in general, disability issues are compounded by the impact of disease and poverty where medical and educational services are not accessible (Eide & Ingstad, 2011; Mukira & Korir, 2006).

## **1.1 People with intellectual disabilities and the social context**

Disability has been recognised as an evolving concept that varies from one community to another (UN, 2006). The International Classification of Functioning Disability and Health (ICF) takes a balanced approach and integrates medical and social models of disability to adequately define disability and address the needs of people with disabilities. The ICF defines disability as a complex relationship between an individual's impairment and their environment or contextual factors (WHO, 2001). Consequently, the individual is either empowered or disabled through societal treatment (Llewellyn & Hogan, 2000) which may fail to meet their needs based on the social expectation of 'normalcy' (Hosking, 2008, p. 7).

Since the mid-twentieth century, there has been a growing international disability movement that has advocated for equal rights, inclusion and changes in policy and service provision for this population within society. This has led to the development of and support from international agreements and programmes such as the 2006 UN Convention on the Rights of Persons with Disabilities (UN, 2006) and the African Decade of Disabled Persons, 2000-2009 (African Union, 2005) to improve opportunities and the position of individuals with disabilities. However, the extent to which these changes have been implemented varies greatly across the nations. For example, high-income countries present a different social context for individuals with ID through the provision of established educational, health and social care systems compared to

low and middle-income countries that have poorly developed education, health and social services. Despite attempts to improve conditions for people with ID, they are still amongst the most marginalised groups globally (McKenzie et al., 2013). They often experience stigma and discrimination within their local communities that are very different to the principles set out in government policies and legislation (e.g. Department of Health, 2001).

Research has reported that individuals with IDs are socially excluded and have limited social relationships, access to education, information, employment and opportunities within society as a result of physical, organizational and attitudinal barriers (Baffoe, 2013; Culham & Nind, 2003; Emerson & Baines, 2011). They are more likely to be victims of hate crimes such as abuse, harassment and bullying (Fyson & Kitson, 2010; Sheikh et al., 2010) and condemned to a poorer quality of life. The Department of Health (2005) reported that 32% of people with ID in the UK did not feel safe using public transport and 32% experienced others being offensive towards them the previous year. In the studies, key issues indicated by people with ID were the negative attitudes held by fellow citizens and the failures in social integration (Cummins & Lau, 2003). Negative attitudes influence societal responses and have been highlighted as one of the most pertinent disabling factors for people with ID (National Disability Authority, 2011; WHO, 2001) that affects their community integration, daily living and social participation (Burge et al., 2007; Findler et al., 2007; Verdonschot et al., 2009). Therefore, in this context, societal attitudes and the factors that influence them are an important avenue for stigma research since they largely determine the extent to which an individual with ID needs are met.

## **1.2 Stigma and attitudes**

Goffman (1963) described stigma as an “attribute that is deeply discrediting” reducing the individual “from a whole and usual person to a tainted, discounted one” (p.3). More recently social psychologists have defined stigma as comprised of cognitive, emotional and behavioural aspects known as stereotypes, prejudice and discrimination (Ditchman, 2013). Hilton and von Hippel (1996) define stereotypes as knowledge structures known to most members of a group. Prejudice concerns emotional reactions and is the endorsement of negative evaluations of stereotypes (Eagly & Chaiken, 1993), which lead to the behavioural reaction of discrimination (Crocker et al., 1998), including avoidant, hostile behaviour (Weiner, 1995), increased social distance (Corrigan, 2002) and withholding of help towards the stigmatised group. Power must be exercised for stigmatisation to occur, that is, members of the stigmatised group are disempowered by not having opportunities and access to rights and resources determined by those with more power in the social hierarchy like the situations faced by individuals with ID. Thus, stigma is seen as a behavioural chain that starts from the stigmatising mark, progresses through the attitude structures and results in discrimination and social exclusion that may lead to loss of opportunities (Scior & Werner, 2015; Walker and Scior; 2013). Therefore, one way to approach stigma is to assess negative attitudes and understand their nature.

Attitudes motivate how we choose to act and respond to others (McCaughey & Strohmer, 2005). Attitudes can be defined as a psychological construct that refers to positive or negative evaluations of people, objects, places or activities (Corrigan & Lundin, 2001) that influence our feelings, thoughts and actions (Byron & Dieppe, 2000; Carter & Markham, 2001; Tervo & Palmer, 2004). Two distinct types of attitudes have been identified, including explicit (evaluations which are consciously accessible and controllable) and implicit attitudes (evaluations which are automatically activated and occur without effort or intention) (Prestwich et al., 2008).

Attitudes are a complex phenomena to understand and multiple definitions, perspectives and theories are constantly evolving (Rao, 2004; Seccombe, 2009). However, a common understanding that has emerged is that attitudes are comprised of three dimensions including the affective, cognitive and behavioural dimensions (Findler et al., 2007). The affective dimension refers to positive and negative emotions about a group of people, in this case, people with ID. The cognitive dimension refers to thoughts, perceptions, beliefs and mental conceptualisation of this group. Lastly, the behavioural dimension is the tendency to act a certain way towards or in the presence of this referent (Findler et al., 2007).

Measuring attitudes accurately is a complicated task for researchers in this field. For example, it has been noted that the use of unidimensional measures overly simplifies attitudes and may be unrepresentative of the constructs of attitudes (McCaughey & Strohmer, 2005; Findler et al., 2007). Instruments that consider the multidimensional components of attitudes have been described as more representative and useful (Findler et al., 2007). One example of a

validated and reliable measure is the Attitudes Toward Intellectual Disability Questionnaire (ATTID; Morin et al. 2012). It measures attitudes based on the three dimensions, affect, cognitive and behavioural.

### **1.3 Attitudes towards persons with intellectual disability in the African context**

Over the years, attitudes towards persons with ID have notably changed due to changes in the definition of disability, societal changes, and novel approaches to treatment (Ouellette-Kuntz et al., 2003; 2010). One of the most significant changes has been towards community-based care for persons with ID (Hastings et al., 1998; Schwartz & Rabinovitz, 2001), while societal attitudes in many places continue to negatively affect their participation in community life and to limit their independence (WHO, 2001). For example, as mentioned in the literature review, African beliefs, cultures and traditions greatly hamper provisions for people with ID and generally view individuals with ID as hopeless and helpless (Desta, 2005; Kiarie, 2004).

Myers and colleagues (1998) found that lack of awareness about people with ID has been associated with negative attitudes and linked to stigmatising beliefs being more prevalent in some cultures. For example, many African religions believe ID to be a curse or punishment from God (Sousso & Yogtiba, 2009) or due to possession of spirits (Kisanji, 1995; Kromberg, 2008). Such beliefs and superstitions contribute to the exclusion, disregard and general apathy towards individuals with ID (Sousso & Yogtiba, 2009).

Similar to the rest of the continent, attitudes towards individuals with ID in Kenya are generally negative (Muchiri & Robertson, 2000; Mutua & Dimitrov, 2001; Oriledo, 2003) with Swahili terms such as *mjinga* (fool), *wazimu* (mad/insane) commonly used among the general public. The labels of people with ID, coupled with the beliefs that disability is a retribution for past sins or witchcraft (UDPK, 2003) held by the majority of people in Kenya, these negative attitudes towards people with ID are somewhat rational. These labels and stigmatization may account for parents of children with disabilities often hiding them from the rest of society to avoid shame and ridicule (UNESCO, 1994). Most children and adults with ID live in poverty and do not have access to educational and medical services (Mukuria & Korir, 2006). In fact, even where services are available, people with ID are often neglected, in part due to a dearth of advocacy by and for them (Njenga, 2009). For example, the Kenyan government has failed not only to make provisions for people with ID in terms of the human and capital resources necessary to improve the lives of individuals with ID but also to realise the rights of individuals with disabilities.

Furthermore, Africans tend to be very much a religious people. In both Christian and Muslim traditions people with ID may be perceived as a “gift from God”, sent to test the faith and strength of their family members but innocent in themselves, or conversely as a punishment from God for wrongdoings (Rohleeder & Leslie, 2009; Mckenzie & Swartz, 2011). These responses may negatively affect the acceptance of the individual within their families and communities, and limit the opportunities available to them, such as employment and healthcare. The majority of these negative attitudes are mere misconceptions that stem from lack of understanding of disabilities and how

they affect functioning resulting in fear and lack of accessibility. At the same time, beliefs that people with ID are gifts from God, may be used as coping mechanisms and a source of strength and support to families experiencing challenging situations such as stigma and inadequate emotional and financial support (Gara, 2011). Whilst there is fear and stigma attached to IDs, there are also resources in communities that can be encouraged in accepting individuals with ID. This highlights the need for further research into the understanding of IDs to reflect the Kenyan and generally African perspectives and how these may differ significantly from Western concepts.

#### **1.4 Tackling negative attitudes and stigma**

Effective ways to challenge negative attitudes have gained increasing attention among researchers. Few interventions have targeted the general public for research and those that have explored public stigma have mostly not drawn directly on accepted theories of attitudinal change. This has led to the development of approaches to challenging public stigma: education and contact (Corrigan & Penn, 1999). Educational approaches challenge inaccurate information about mental illness with factual information or data to replace them and benefits include their low cost and broad reach. This may include the use of books, flyers, movies, web pages and other visual aids (Finkelstein et al., 2008; SAMHSA, 2011). However, evidence suggest that on their own, educational approaches only produce short-term improvements on attitudes (Corrigan et al., 2012) and therefore may need to be combined with contact

approaches for longer term changes. Lastly, contact facilitates exchanges between the stigmatized group and the general population.

### **1.5 Attitudes and contact**

Allport's (1954) intergroup contact theory suggests that direct contact between members of different social groups can help reduce prejudicial attitudes and can be a helpful way to improve attitudes. Numerous studies have found that attitudes toward people with ID become more positive after direct contact (Henry et al., 2004; McConkey et al., 1993; Rillotta & Nettleback, 2007), with people who have more contact with this group reporting more positive attitudes than those with less frequent contact (Yazbeck et al., 2004). Studies have reported factors that moderate contact effects, including one-to-one contact, so people engage with one another and can learn of similar interests and cultivate a friendship (Herek & Capitanio, 1996; Levin et al., 2003), interaction with an individual who moderately disconfirms prevailing stereotypes (Blanchard et al., 1975; Reinke et al., 2004), and contact that includes a common goal (Cook, 1985).

In many instances, it may be difficult to provide direct contact on a large scale and to control its quality. This has led to the use of indirect contact interventions, for example, through the use of photographs or film based interventions delivered in various ways, including the internet. These approaches have the advantage of being easily delivered, rely less on specialists and have the possibility of reaching larger audiences as part of combating stigma. Studies that have evaluated indirect contact interventions have yielded

positive results (Carsrud et al., 1986; Smedema et al., 2012) with some showing positive footage of people with ID integrated and participating in communities.

## **1.6 Factors related to attitudes**

Research shows that factors such as demographic variables (gender, age, educational level, religious affiliation and place of residence) as well as contact/experience with people with ID are associated with attitudes towards people with ID. Some studies show that females, younger people, and those with higher educational achievement expressed more positive attitudes towards people with ID (Akarami et al., 2006; Burge et al., 2007; Findler et al., 2007; MacDonald & MacIntyre, 1999). However, other studies have found no effect of gender (Nagata, 2007; Ouellete-Kuntz et al., 2010), or age (Lau & Cheung, 1999). Therefore, results have not been consistent as to the directions and the strength of the associations of these factors on attitudes (Scior, 2011).

One factor that has consistently been shown to be associated with positive attitudes is contact with individuals with ID (Antonack et al., 1995; Werner et al., 2012; Lau & Cheung, 1999). Interactions between the public and people with ID have been shown to be an effective way to increase knowledge and acceptance and challenge negative beliefs and attitudes of people with ID (Lau & Cheung, 1999). However, the majority of these studies were conducted in western countries and little is known about how these factors might influence attitudes in Kenya and other African countries.

## **1.7 Digital interventions: Helping bridge the gap**

Increasingly, governments all over the world are turning to Information and Communication Technology (ICT) to enhance service delivery in the so-called knowledge economy. The goal of the Kenyan National e-Health Strategy (2011) is to provide equitable and affordable healthcare at the highest achievable standard to Kenyan citizens. One of its main objectives is to create links between health research and information technologies with e-learning being a key strategic area of implementation. In Kenya, there are high levels of awareness of ICT among the general population with 57% of the general population using the Internet (Kenya National E-Health Strategy, 2011). The availability of affordable, reliable internet access through mobile phones and fibre optic infrastructure provides a powerful platform to deliver effective and adequate awareness raising on ID using (social) media and other forms of information dissemination amongst the Kenyan urban population. Walker and Scior (2013) and Seewooruttun (2013) conducted the only e-intervention studies to date to tackle stigma associated with ID and found that indirect contact was effective at changing attitudes and reducing social distance in the general public. Therefore, considering the findings described above, cultural contexts and contact may be important influences in attitude formation that warrant future exploration.

## **1.8 Aims and hypotheses**

The present study aimed to: (1) describe prevalent attitudes towards people with ID in a sample of Internet users in Kenya with regard to the three attitude dimensions; (2) assess whether attitudes vary according to prior contact with people with ID and other participant characteristics such as age, gender, sex, education; (3) explore the impact of a digital intervention, via the medium of film, on their attitudes; and (4) assess the validity and reliability of the methodology adopted in this study by examining the reach and acceptability of the study. It was hoped that the study would serve to inform future efforts to increase awareness and challenge stigmatising beliefs towards people with ID that are reportedly held in Kenya and within other African countries.

The following hypotheses were put forward:

1. At baseline, attitudes towards people with ID would not be favourable, and would remain so in the control group at all three time points.
2. Attitudes would be more favourable among participants with prior contact with individuals with ID.
3. There would be a relationship between demographic variables (such as age, gender, religion and education) and attitudes towards people with ID. That is, (i) there would be a positive association between age, education and attitudes towards people with ID and (ii) there would be a negative association between gender, religion and attitudes towards people with ID.
4. Post intervention, there would be more favourable attitudes with regards to the affective, cognitive and behavioural attitude dimensions towards people with ID in the treatment group compared to the control group.

5. Favourable changes in attitudes towards people with ID in the treatment group would be maintained at one month follow-up, albeit reduced in magnitude as reflected in the attitude scores across three dimensions.

## **2. Method**

### **2.1 Joint project**

The empirical study reported here was a joint project with Deborah Odukoya, Trainee Clinical Psychologist at University College London. The current study examined; (1) attitudes towards people with ID on a Kenyan convenience sample, and (2) the impact of a brief e-intervention on lay people's attitudes towards IDs in this Kenyan sample. Deborah Odukoya assessed the same questions in relation to a Nigerian sample. While both projects were conceptualised and planned in parallel, an entirely separate intervention that was appropriate to the respective cultural context was produced by each of us, and data collection and analyses were conducted entirely separately.

### **2.2 Research Design**

The design of this study was informed by Walker and Scior's (2013) study which tested the effects on an e-intervention on attitudes to ID and compared two different interventions. Their design has been adapted to address the aims of this project. In this study, a randomised control trial with a repeated measures design was used. Qualtrics was used to set up the web-based survey. Using this research tool, data was collected at three time points; baseline (T1),

immediately after the intervention (T2) and at one-month follow-up (T3) to assess whether a brief e-intervention can produce changes in attitudes and behavioural intentions and most importantly, whether these changes can be maintained over time. Participants were randomly allocated to either the experimental group or the control group through a randomisation command integrated within Qualtrics.

### **2.3 Setting and participants**

The data for this study were drawn from a convenience sample of internet users of both genders. A total of 457 participants were recruited over a six-month period from October 2016 to April 2017. The inclusion criteria were as follows: 18 years of age or older, English speaking, and a Kenyan resident. Schulze et al (2003) suggested that a young educated sample includes an important age group to target for two reasons: (1) they are at a stage of development where attitudes can easily be influenced, and (2) that as the future generation, they can sustain or change stigma. Participants were excluded if they were below the age of 18 and not Kenyan residents. Of the 457 participants, 70.1% were female. By level of education, over half of the participants had a university degree (54.5%) or a post-graduate degree (35.4%). The majority were Christians (85%) followed by those who were non-religious (9.1%). A large proportion of the participants reported knowing someone with an ID (79.9%) either as a family member (38.6%), friend (17.7%) or other (43.7%). Of those reporting contact, 39.5% saw them occasionally during the year, 32.4% saw them less than once a year and 16.2% on a weekly basis.

In order to test for the effectiveness of randomisation, independent samples t-test and chi square tests were conducted on all demographic variables and all T1 factor attitude variables between the control group and the intervention group.

There were no significant differences between the two groups in relation to participants' age ( $t(317)=-.282, p=.778$ ), whether their main residence was Kenya or another country ( $X^2(1, N=319)=.608, p=.435$ ), their highest level of education ( $X^2(3, N=319)=4.86, p=.183$ ), their religious affiliation ( $X^2(5, N=319)=10.20, p=.07$ ), and whether they knew someone with an intellectual disability ( $X^2(1, N=319)=.226, p=.635$ ).

There were no significant differences for T1 attitudes between the control group and the intervention group for factor 1 ( $t(432)=-.059, p=.953$ ), factor 2 ( $t(432)=-.429, p=.668$ ), factor 3 ( $t(455)=-.903, p=.367$ ), factor 4 ( $t(432)=-1.095, p=.274$ ), factor 5 ( $t(455)=-.186, p=.853$ ), factor 6 ( $t(455)=-.036, p=.971$ ), and factor 7 ( $t(455)=-1.446, p=.149$ ).

Fig. 2 shows the number of participants that completed each stage of the research and where drop-out occurred. No significant differences in the drop-out rates was observed between both the intervention and control group. Socio-demographic information for the 457 participants is presented in Table 3.

Table 3. Participants' demographics

	N	%
<b>Age (years)</b>		
18 - 24	34	10.7
25 - 34	212	66.5

35 - 44	33	10.3
45 - 54	21	6.6
55 - 64	17	5.3
65 - 74	2	.6
N = 137 missing		
<b>Gender</b>		
Male	95	29.9
Female	223	70.1
N = 139 missing		
<b>Religion</b>		
Christian	271	85.0
Muslim	10	3.1
Traditional religion	4	1.3
Buddhist	1	.3
Hindu	4	1.3
Non-religious	29	9.1
N = 138 missing		
<b>Education level</b>		
Secondary school	13	4.1
Vocational	19	6.0
University degree	174	54.5
Post-graduate	113	35.4
<b>Know someone with ID</b>		
	255	79.9
N = 138 missing		
<b>Contact relationship</b>		
Family	98	38.6
Friend	45	17.7
Other	111	43.7
<b>Frequency of contact</b>		
Weekly basis	41	16.2
Several times a month	30	11.9
Occasionally during the year	100	39.5
Less than 1xyear	82	32.4
N = 204 missing		

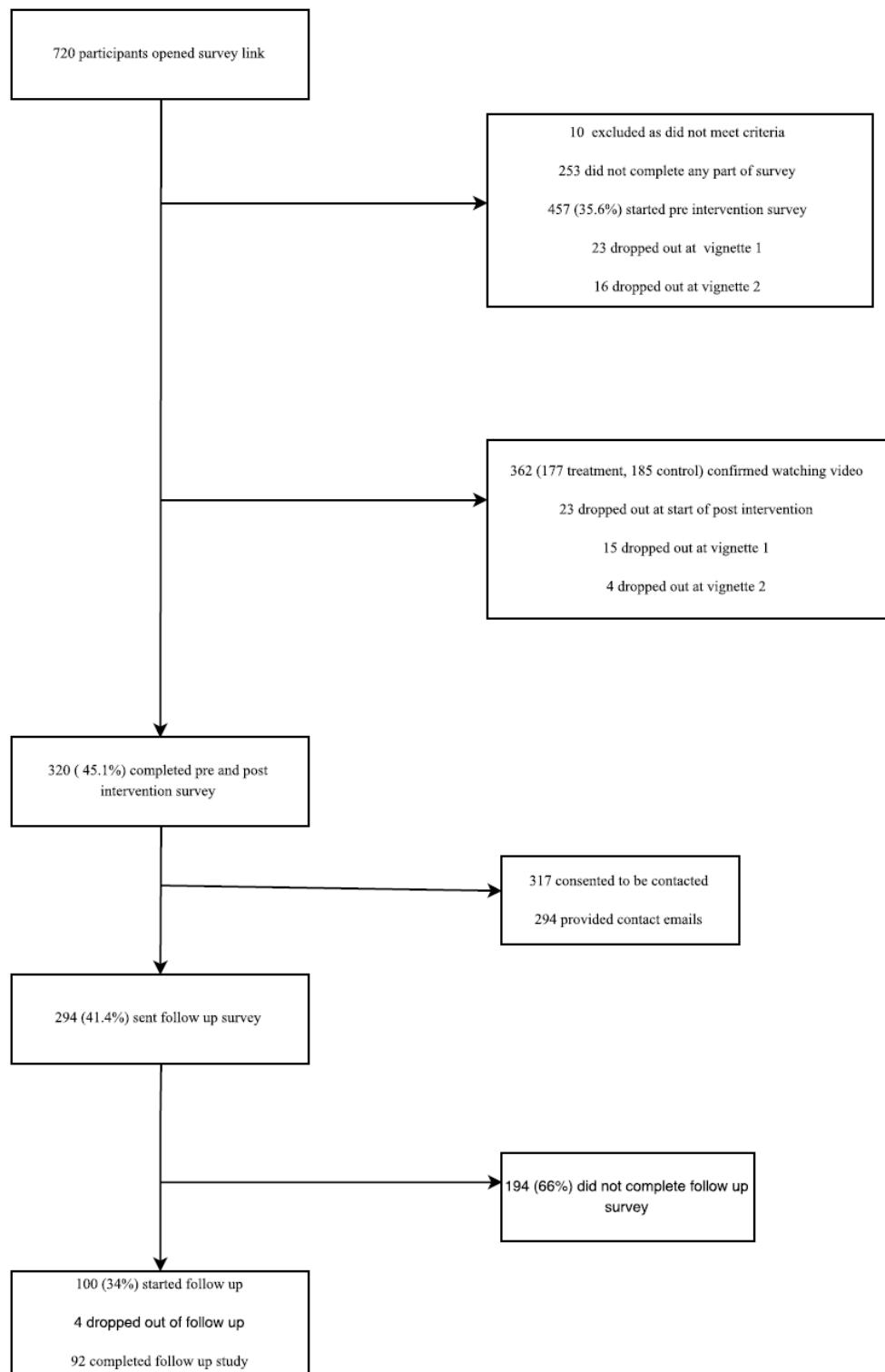


Fig. 2 Flow diagram of participants through each phase of the study.

## **2.4 Measures**

Self-report measures were utilised, with two measures to assess attitude change, as detailed below. The measures were completed at all three time points.

### **2.5 Attitudes towards Intellectual Disabilities Questionnaire (AATID: Morin et al., 2012)**

The ATTID uses a three-dimensional model of attitudes (cognitive, affective and behavioural dimensions), in line with current conceptualisations of attitudes (Findler et al., 2007). Its original form consists of 67 items using a Likert-type scale, ranging from 1 (completely agree) to 5 (disagree completely). Higher scores indicate more negative attitudes. The ATTID was validated with 1605 participants that were representative of the Quebec (Canada) adult population. Analyses yielded a five-factor structure along the three aforementioned dimensions: two factors on the affective dimension of discomfort (17 items) and sensibility/tenderness (six items); two factors on the cognitive dimension of knowledge of causes (seven items) and knowledge of capacity and rights (20 items); and the remaining factor on the behavioural dimension, namely willingness to interact with people with ID (17 items) (Morin et al., 2012). The first 33 questions examine general attitudes; whilst the last 34 are based on two vignettes describing individuals with ID (with different levels of functioning, see below). The original ATTID has been assessed for test-retest reliability, yielding correlations from 0.62 to 0.83 on the five factors and had reasonable to high internal consistency (Cronbach's alpha = 0.92 for the overall questionnaire). In addition to Canada, the ATTID has also been

validated in two other countries: Singapore (Pooh, 2015) and the United Kingdom (Patel & Rose, 2013).

Due to possible problems with internet connectivity and need for a short measure in a cultural setting where there is little familiarity with lengthy surveys, a shortened version of the ATTID was developed in collaboration with Morin and colleagues (see Appendix 2). This was done by retaining the two original vignettes and a reducing the number of items (17 questions for general attitudes, whilst 11 based on vignettes); four selected items with the highest factor loadings on each subscale were selected. Some items were slightly adapted to suit a Kenyan context for example, the names in the original vignettes were replaced with common first names in Kenya and the phrase ‘sweeping the floor’ added. The construct validity of the shortened version was examined by Morin and colleagues and deemed acceptable with Cronbach’s alphas between 0.52 and 0.75 (personal communication).

The questions related to the vignettes allowed the researchers to assess potential differences in attitudes according to level of functioning.

#### *Vignette 1 (high level of functioning)*

*Peter is an adult with an intellectual disability. He lives at home with his parents. He dresses himself and is able to go out without getting lost but cannot take public transportation on his own. He will go on errands to the nearby shop but will not know if he has been given the right change. Peter helps with household chores such as tidying up his room, setting the table and sweeping the floor. He is able to carry on a conversation but has difficulties discussing*

*things that are abstract or complex. Peter knows how to use the telephone and can write.*

*Vignette 2 (low level of functioning)*

*John is an adult with an intellectual disability. He communicates using sounds and gestures. He is able to show by gestures that he needs to go to the toilet. Since John has major coordination problems, he requires constant assistance when he moves around and always has to be accompanied on outings. He also has trouble with various movements. He is able to feed himself with an adapted spoon, but he drops food.*

## **2.6 Intellectual Disabilities Literacy Scale (IDLS, Scior & Furnham, 2011)**

The IDLS uses a vignette methodology to assess knowledge and beliefs about a range of mental health problems amongst diverse cultural groups (Angermeyer & Dietrich, 2006). The measure presents vignettes containing diagnostically unlabelled case stories for mild intellectual disability. Participants are asked a series of questions to assess their recognition of the condition in the vignette, their beliefs about causes and suitable interventions, stigmatising attitudes and contact with people with intellectual disabilities and mental health problems and socio-demographic characteristics. Participants rate their level of agreement on a 7-point Likert scale (1=strongly disagree to 7=strongly agree). In this study, only the supernatural causal beliefs subscale about causes of ID was used based on the majority of beliefs held within the Kenyan and African context described in the literature review and this study.

The IDLS has good psychometric properties and has been tested in a range of cultural contexts (Scior & Furnham, 2011) with high internal consistency (Cronbach  $\alpha = .87$ ) and yields a test-retest reliability score of  $>0.7$  for all items. For the supernatural beliefs subscale, the Cronbach's  $\alpha$  values were  $\alpha=.76$  and assessed for test-retest reliability score, yielding correlations from 0.52 to 0.74. The scale has also been used in pre-post-test design similar to this study and has been shown be sensitive enough to capture attitude change (Walker & Scior, 2014). See Appendix 3 for this scale.

## **2.7. Socio-demographic characteristics and process evaluation questions**

Socio-demographic information including the participants' age, gender, educational attainments and religious affiliation was collected. Participants were also asked whether they knew anyone with ID, and if so, the nature of the relationship and the frequency of contact. Scior & Furnham (2011) reported that the beliefs individuals hold are influenced by their demographic characteristics and cultural background and thus it is important to understand these factors as they may improve service delivery that consider different values. Finally, the components of the process evaluation were intended to augment our understanding of the acceptability and reach of the study in this Kenyan sample. This was done by collecting information about their experiences of the study (see Appendix 4) to inform the best route for disseminating interventions such as the present one in Kenya in future.

### **Scoring**

Scores for each factor were summed and divided by the number of items,

and the overall ATTID score was computed by adding the average of all the five factors. For this study, scores below the scale midpoint (3) were considered as indicating positive attitudes and above 3 considered as indicating negative attitudes. Scores for the IDLS items were reversed and a mean score of the three statements was calculated, with higher scores associated negative beliefs.

## **2.8 Conditions**

A storyboard was developed in discussion with the fellow trainee and my supervisor (See Appendix 5). Using this as the basis for the intervention film, I then travelled to Nairobi, where the stigma change video was filmed with the help of local collaborators and a local workshop of people with ID.

### **2.8.1 Intervention condition**

The stigma change video was six minutes long and comprised of three parts. Firstly, an educational segment adopted from Seewooruttun (2013) study that included an introduction delivered outlining how ID is defined, its causes, and the impact it may have on individuals affected. This approach has been shown to successfully challenge existing stigma and misconceptions of intellectual disability in a South Asian sample (Seewooruttun et al., 2013) known to have similar stigmatising beliefs as many African countries. To increase the credibility of the information provided, an expert in the field delivered it. This was followed by a segment involving individuals with moderate ID who vary in life roles, capabilities and challenges they faced. This was to challenge stereotypes and increase their empathy with this group by demonstrating they have similar goals, dreams and aspirations that stigma may prevent them from achieving (Scior & Werner, 2014). The intervention film can

be viewed using the following link  
[https://www.youtube.com/watch?v=ZSi\\_DJxGPrs&t=15s](https://www.youtube.com/watch?v=ZSi_DJxGPrs&t=15s) (Appendix 6).

### **2.8.2 Control condition**

The film used in the control condition was also six minutes long. It was unrelated to ID and was about the challenges children in rural Kenya face in receiving an education. This condition controlled for exposure to a video and reactivity to the outcome measures in the study.

### **2.9 Procedure**

The full procedure for this study was approved by the Ethics Committee of University College London (Appendix 7). Advice was sought from local contacts and researcher institutions in Kenya and informed that further permission for a web based study was not needed.

The treatment of participants was in accordance with the ethical standards of the British Psychological Society (2010), including guidance with regard to deception (not being aware at the beginning that the study was measuring a change in attitudes). At the beginning of the survey, an information page was presented and the participants were instructed to read it carefully and invited to ask questions of the researcher. The information page stated the purpose of the study, participant criteria, guarantee of confidentiality, data protection and the right to withdraw from the study and included the researcher's contact address (See Appendix 8). The risks of participation in the study were minimal and no psychological distress was expected among participants.

Details of the study including that it is a scientific research study conducted by University College London that was investigating the personal difficulties

that people in Kenya were facing. If consent for participation was given, the participants were directed to the baseline measures (T1). Following completion of the baselines measures, participants were randomised to the stigma change condition or the control condition using a randomisation code embedded within the Qualtrics survey. Following the intervention, participants completed post-intervention measures and socio-demographic variables were collected at this point. Participants were given the opportunity to provide their contact details if they wished to take part in the follow-up and/or the prize draw. Their contact details allowed for matching of baseline and follow-up responses. After a one month interval, all 294 participants who provided their contact details and consented to being contacted again were invited to complete the follow-up survey.

The study was advertised and shared online via email promotion and social media (Facebook, Twitter, Instagram, Snapchat; see Appendix 9) and word of mouth. The author's contact details were on the flyer alongside a link to the Centre for Intellectual and Development Disability Research (CIDDR) site on the UCL website to help ensure the author's credibility. Participants were also recruited with the help of service providers working with people with intellectual disabilities. Incentivised snowballing (Gardner, 2007; 2009) was also used to aid participant recruitment. The incentives used to sustain snowballing included vouchers redeemable at leading restaurants and outlets in Kenya ranging from £10-20, won through a prize draw. In order to be within the prize draw participants were required to complete the web survey at all three time points. Gardner (2007; 2009) provided evidence for incentivised snowballing and proposed it was a cost-effective and accessible approach to

participant recruitment through internet mediated research.

Participants clicked on an electronic link in the email or social media advertisement which re-directed them to the data collection website where they completed the study. Research suggests that data collection through web based recruitment procedures is as valid or at least comparable to data collection through alternative methods such as paper and pen based (Krantz & Dalal, 2000). To reduce the impact of poor internet connectivity on the study, settings within Qualtrics allowed participants to return to the survey at a later point and continue from where they stopped.

To ensure that all participants would have a similar representation of what ID is, a description was provided at the beginning of the survey:

“For the purposes of the questionnaires, the term ‘intellectual disabilities’ refers to people who have difficulties with thinking (intellectual function) and coping on their own on a day-to-day basis (social functioning). These difficulties would have started before adulthood (18 years old). In the past the term ‘mental retardation’ has also been used. Some specific syndromes and conditions like Down syndrome, Fragile X and Autism may in some cases be associated with having an intellectual disability. Intellectual disabilities are different from specific learning difficulties such as Dyslexia, which are NOT the focus of this study.”

### **3.0 Data preparation and statistical analysis**

Firstly, the data were cleaned by removing blank data and all participants who did not meet inclusion criteria ( $N=10$ ). All the IDLS and ATTID reverse-worded items were recoded. Items endorsed as “don’t know” (score of 6) were

recoded to a neutral score (3) as recommended in the literature (Krosnick, 2002; Graham & Hofer, 2000) so as to retain these participants within the final sample. The pattern of missing data was identified using the Littles MCAR test.

Data were analysed using the Statistical Package for Social Sciences (SPSS) version 24. The psychometric properties of the shortened ATTID were analysed and the Estimation Maximum method was used to replace missing data (Graham, 2009), the measure was evaluated against a total of 457 participants. An exploratory analysis was then carried out to identify the structure of the instrument using the principle component factor analysis (PCA) with Varimax rotation as conducted by Morin et al (2013). The internal consistency of the subscales was validated using Cronbach's alpha. Assumptions of normality were met and the outliers identified were included as recommended by Verma (2015).

Mean scores, standard deviations and the proportion of participants with a positive, neutral or more negative attitudes were computed to describe the sample's baseline (T1) attitudes towards persons with intellectual disabilities on *the six factors*. The general linear mixed model (GLMM) for repeated measures was used to test for intervention effects. To assess attitudes and socio-demographic variables (age, gender, education, religious affiliation) and level of functioning, t-tests and ANOVAs were carried out. Lastly, to examine the acceptability and reach of the study frequency statistics were computed.

## **4. Results**

### **4.1 Power analysis**

For this study a power analysis was conducted informed by Lapinski and Nwulu (2008) and Walker and Scior (2013). The former study of Nigerian adults tested a film based anti-stigma intervention and found a small effect size,  $d=0.25$ . Werner and Scior's study used a similar methodology to the proposed study with a UK population and reported a small effect size of  $d = 0.16$  for changes in social distance, the primary outcome. Additionally, Lindau and colleagues (2016) conducted a study using a brief web-delivered film and found positive changes in social distance with an effect size of  $d = 0.25$ . To ensure feasibility of recruitment yet avoid the study being underpowered, an effect size of  $d = 0.25$  was assumed for the power analysis. An a priori power analyses was calculated through the G\* Power programme (Faul et al., 2007). At an alpha of 0.05 and a desired power of 80%, a total of 398 participants (199 in each group were required. The required sample size was achieved.

### **4.2 Missing data**

The GLMM for repeated measures was used to test for intervention effects. This method accounts for the dependency between repeated measures collected for each participant across time and the missing data presented in the data. The GLMM does not depend on participants providing data at each assessment point, instead it uses all the data present at each assessment point. Elobeid and colleagues (2009) reported that this method for accommodating missing data

exceeds traditional methods of replacing data. An assumption of using this approach is that the data are missing at random. Little's MCAR test was non-significant,  $\chi^2$  (39, N=457) = 40.45,  $p = .406$  indicating that the assumption was satisfied.

### 4.3 Factor analysis

Given the overall Kaiser-Myer-Olkin index of 0.81 is considered to be very good (Hutcheson & Sofroniou, 1999), a factor analysis was carried out at T1. The PCA revealed nine components with eigenvalues above one. Stevens (1992) proposed that the scree test is a reliable benchmark for factor selection and can be used to determine the number of factors to retain (Catell, 1966). The scree test yielded a curve inflection point after the seventh factor, justifying a six-factor solution. This was in contrast to Morin and colleagues (2013) analysis that yielded a five factor solution. The six ATTID-SF factors were: (1) discomfort towards ID; (2) knowledge of rights; (3) interaction; (4) sensibility or tenderness; (5) knowledge of capacity and (6) knowledge of causes. The first factor, *Discomfort*, consists of *eight* items related to situations that can create discomfort. The second factor termed *Sensitivity/Tenderness* consists of six items under the affective component. The third and fourth factors *Knowledge of rights* and *Knowledge of capacity* are within the cognitive component (knowledge). *Interaction* consists of 7 items and *Knowledge of causes* has six items and sits within the cognitive component. The IDLS supernatural beliefs subscale consisted of three items.

The proportion of variance accounted for by the six factors was 55.74% (Table 4).

Table 4. Proportion of variance accounted for by the six ATTID-SF factor and IDLS subscale

Factor	% of variance	Cumulative %
Discomfort	19.29	19.29
Sensitivity and tenderness	11.30	30.59
Knowledge of rights	8.94	39.53
Interaction	6.51	46.05
Knowledge of capacity	5.09	51.14
Knowledge of causes	4.61	55.74
IDLS supernatural beliefs	3.76	59.50

Attitudes were separated into three categories for ease of presentation: more positive (scores of 1 and 2), more neutral (score of 3) and more negative (scores 4 and 5). Table 5 presents all items, their mean scores, standard deviations and percentage of participants by responses (positive, neutral and negative attitude) for each factor.

Table 5. Mean, standard deviation and proportion of participants with a positive, neutral or negative attitude on items reported by the 6 ATTID-SF factors and IDLS subscale

Factors (sample range)	Sample average (SD)	Positive attitude (1and 2)	Neutral attitude (3)	Negative attitudes (4 and 5)
<b>Factor 1 - Discomfort</b>				
Experience anxiety towards Peter	2.54 (1.15)	56.7	15.0	28.4
Experience anxiety towards John	2.73 (1.19)	50.5	13.4	36.1
Feel insecure towards Peter	2.12 (0.96)	74.2	13.6	12.2

Feel insecure towards John	2.22 (0.99)	73.2	12.4	14.3
Feel afraid of Peter	1.96 (0.89)	80.6	12.9	6.4
Feel afraid of John	2.25 (1.03)	72.2	12.2	15.5
Be wary of Peter	2.65 (1.22)	52.1	13.6	34.3
Be wary of John	2.64 (1.18)	52.6	15.3	32.1
<b>Factor 2 – Sensitivity/Tenderness</b>				
Feel sad toward Peter	3.15 (1.15)	33.9	15.7	50.4
Feel sad toward John	3.62 (1.09)	19.9	10.5	69.6
Feel pity toward Peter	3.10 (1.17)	36.2	14.3	49.5
Feel pity toward John	3.59 (1.11)	19.6	11.5	68.9
Feel touched, moved by Peter	3.89 (0.95)	9.4	13.1	10.8
Feel touched, movement by John	3.99 (0.84)	6.2	12.2	81.6
<b>Factor 3 – Knowledge of rights</b>				
Should have the right to have sex	1.68 (0.74)	86.7	12.0	1.3
Should have the right to get married	1.63 (0.74)	88.6	9.8	5.1
Should have the right to vote	1.86 (0.93)	77.2	16.2	6.5
Should gave the right to have children	1.95 (0.93)	74.4	19.5	6.2
<b>Factor 4 – Knowledge of capacity</b>				
To carry on a conversation	2.32 (0.89)	70.7	16.6	12.7
To make decisions	2.50 (0.875)	59.3	25.4	15.3
To handle money	2.79 (0.95)	44.0	31.5	5.6
To hold down a job	2.87 (1.03)	41.4	28.0	30.6
<b>Factor 5 – Interaction</b>				
Would agree to supervise Peter at work	2.14 (0.91)	76.0	13.1	10.8
Would agree to supervise John at work	2.78 (1.17)	45.7	21.1	34.3
Would accept Peter as son or daughter's friend	1.66 (0.70)	90.1	8.5	1.4
Would accept John as son or daughter's friend	1.88 (0.85)	81.1	14.4	4.6
Would accept being advised by Peter in clothing store	2.50 (0.98)	57.8	23.7	18.5
Would accept being advised by Peter in electronic store	3.03 (1.07)	34.1	27.0	39.0
Feel comfortable talking to John	3.63 (1.01)	15.6	23.0	61.5
<b>Factor 6 – Knowledge of causes</b>				
Malnutrition in mother	2.66 (1.14)	52.5	22.3	25.1
Serious head injury during childhood	1.94 (.89)	51.6	9.4	7.2
Lack of stimulation during childhood	2.83 (1.20)	46.6	18.6	34.8

Chemicals in the environment	2.21 (0.94)	69.1	20.4	10.5
Consumption of drugs and alcohol	1.82 (0.86)	84.0	11.4	4.6
Problems during birth	1.97 (.92)	78.6	14.0	7.4

**IDLS – Supernatural causal beliefs**

Possession by spirits	4.35 (1.15)	9.8	17.5	72.6
Punishments for past wrongdoings	4.37 (1.03)	8.3	12.2	79.4
A test from God or Allah	4.29 (1.11)	9.2	18.8	72

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#### **4.4 Reliability**

Cronbach's alpha coefficients for all the factors are presented in Table 6.

The overall internal reliability of the ATTID-SF was 0.83 and the subscale reliabilities ranged from 0.56 to 0.88 compared to Morin et al.'s (2013) original ATTID ranged from 0.59 to 0.89. Since factor 4 has a small number of items ( $n = 4$ ), its coefficient of 0.56 can be considered acceptable (Cortina 1993; Martinex Arias, 1995). No single item deletion improved the internal reliability of the subscale.

Table 6. Reliability of all 6 ATTID-SF factors

<b>Item</b>	<b>Factor loading (<math>\alpha</math>)</b>
Factor 1: Discomfort	0.88
Factor 2: Sensitivity or tenderness	0.82
Factor 3: Knowledge of rights	0.88
Factor 4: Knowledge of capacity	0.56
Factor 5: Interaction	0.85
Factor 6: Knowledge of causes	0.71

#### **4.5 Research Question 1**

##### *Baseline attitudes*

Hypothesis one predicted that at baseline attitudinal scores towards people with ID would not be favourable and that the control group would remain the same over time. At baseline, the results suggested that on average the intervention and control groups had positive attitudes, that is, less discomfort,

willingness to interact and believed that people with ID had equal rights and had capacity contrary to hypothesis one predictions. However, in both groups, lower sensitivity and higher beliefs in supernatural causes were found (see Table 7).

Table 7. Pre-post follow up scores for ATTID-SF and IDLS factors

	Time point	Control	Intervention
		<i>M (SD)</i>	<i>M (SD)</i>
Discomfort	Pre	2.39 (0.82)	2.39 (0.79)
	Post	2.29 (0.78)	1.95 (0.79)
	Follow-up	2.14 (0.65)	2.08 (1.01)
Sensitivity/tenderness	Pre	3.54 (0.81)	3.57 (0.74)
	Post	3.35 (0.85)	3.05 (0.90)
	Follow-up	3.32 (0.77)	3.05 (1.02)
Knowledge of rights	Pre	1.81 (0.71)	1.75 (0.74)
	Post	1.91 (0.76)	1.69 (0.68)
	Follow-up	1.91 (0.76)	1.95 (0.69)
Interaction	Pre	2.48 (0.52)	2.54 (0.51)
	Post	2.40 (0.49)	2.29 (0.51)
	Follow-up	2.51 (0.61)	2.43 (0.51)
Knowledge of capacity	Pre	2.61 (0.79)	1.88 (0.66)
	Post	2.33 (0.84)	2.63 (0.75)
	Follow-up	2.71 (0.79)	2.33 (0.73)
Knowledge of causes	Pre	2.24 (0.68)	2.24 (0.59)
	Post	2.32 (0.79)	2.16 (0.76)
	Follow-up	2.23 (0.62)	2.33 (0.82)
IDLS supernatural causes	Pre	4.28 (0.88)	4.41 (0.91)
	Post	4.42 (0.89)	4.68 (0.67)
	Follow-up	4.36 (0.92)	4.75 (0.62)

## **4.6 Research Question 2**

*Differences in attitudes by participant socio-demographics and level of functioning*

Analyses revealed that attitudes towards people with ID differed by participants' socio-demographic characteristics (age, sex, education level, religious affiliation) and level of functioning variables of the person with ID depicted. The *t*-test and ANOVA and effect sizes results are presented in Table 8. For very small sample sizes standard deviations are not reported.

*Factor 1 – Discomfort* was significantly associated with frequency of contact with persons and with ID. Hypothesis two predicted that participants with prior contact with people with ID would have more favourable attitudes. In line with this prediction, those participants who had contact with persons with ID on a weekly basis ( $M = 2.09, SD = .76$ ) reported significantly less discomfort than those who had contact with this group less than once a year ( $M = 2.50, SD = .81$ ).

Hypothesis three predicted that there would be a relationship between religion, education, age and sex. *For the discomfort factor*, postgraduate holders ( $M = 2.24, SD = .84$ ) and those with vocational qualifications ( $M = 2.14, SD = .60$ ) reported significantly less discomfort than those who completed secondary school ( $M = 2.67, SD = .56$ ). *For factor 2 – Sensitivity and tenderness* significantly differed with religious affiliation. Traditional religion reported attitudes ( $M = 4.08, SD = .22$ ) that were less positively polarised than Buddhist ( $M = 4.00$ ), Christian ( $M = 3.61, SD = .74$ ), Muslim ( $M = 3.48$ ), Non-religious ( $M = 3.23, SD = .87$ ) and Hindu ( $M = 2.88, SD = .34$ ). *Factor 4 – Interaction* was significantly associated with level of education. There was a significant difference observed between the mean attitude scores for postgraduate ( $M = 2.39, SD = .51$ ) and university degree ( $M = 2.56, SD = .48$ ) degree holders, with the postgraduate degree holders having more positive evaluations towards persons with ID. For *factor 6 - Knowledge of causes*, there was a significant association between postgraduate degree holders ( $M = 2.09, SD = .64$ ) and those with vocational qualifications ( $M = 2.61, SD = .55$ ), with postgraduate holders

disagreeing strongly with the statements about causes of ID. These results were in line with predictions made in hypothesis 3.

*IDLS Supernatural causal beliefs* significantly differed with religious affiliation and quality of relationship. Non-religious individuals ( $M = 4.90$ ,  $SD = .53$ ), Hindus ( $M = 4.42$ ,  $SD = .79$ ) and Christians ( $M = 4.32$ ,  $SD = .88$ ) were more likely to endorse supernatural causes of ID than the Muslim ( $M = 3.80$ ,  $SD = 1.02$ ) and traditional religion ( $M = 3.17$ ,  $SD = .129$ ) groups. There was a significant difference in the attitudes towards spiritual causes and quality of relationships. Family members ( $M = 4.13$ ,  $SD = 1.07$ ) were less likely to endorse supernatural causes than other groups ( $M = 4.50$ ,  $SD = .75$ ).

#### **4.7 Level of functioning**

A paired-samples t-test was conducted to compare participants' baseline scores by level of functioning of the person with ID depicted in the ATTID-SF. There was a significant difference in the attitude scores on vignettes towards Peter (high functioning) ( $M = 2.61$ ,  $SD = .57$ ) and John (low functioning) ( $M = 2.93$ ,  $SD = .54$ );  $t(417) = -14.85$ ,  $p < 0.001$ ,  $d = 0.58$ . These results suggest that level of functioning does have an effect on attitudes. Specifically, participants tended to have a more negative attitude towards the lower functioning individual.

Table 8 *T*-tests and ANOVA and effect sizes ( $\eta^2$ ) results for the factors by participant sociodemographic variables

	<b>Factor 1 Discomfort</b>	<b>Factor 2 Sensitivity and tenderness</b>	<b>Factor 3 Knowledge of rights</b>	<b>Factor 4 Interaction</b>	<b>Factor 5 Knowledge of Capacity</b>	<b>Factor 6 Knowledge of causes</b>	<b>IDLS</b>
Age	F(5, 318) = .51	F(5, 318) = .92	F(5, 318) = 1.48	F(5, 318) = .77	F(5, 318) = .51	F(5, 318) = 1.18	F(5, 318) = .09
Sex	<i>t</i> (316) = -.92	<i>t</i> (316) = -.02	<i>t</i> (316) = -.29	<i>t</i> (316) = -.14	<i>t</i> (316) = -.34	<i>t</i> (316) = -.81	<i>t</i> (316) = -1.22
Education level	F(3, 318) = .275*	F(3, 318) = 1.00	F(3, 318) = .47	F(3, 318) = 3.23*	F(3, 318) = .50	F(3, 318) = 4.36**	F(3, 318) = .14
Effect size( $\eta^2$ )	0.05			0.03		0.04	
Religious affiliation	F(4,318) = 1.29	F(4, 318) = 2.76*	F(4, 318) = .62	F(4, 318) = .39	F(4, 318) = .44	F(4, 318) = 6.13	F(4, 318) = 6.13**
Effect size ( $\eta^2$ )		0.04				0.08	
Frequency of contact	F(3, 252) = 2.73*	F(3,252) = .27	F(3, 252) = .38	F(3, 252) = .48	F(3, 252) = 1.05	F(3, 252) = 1.25	F(3, 252) = .48
Effect size( $\eta^2$ )	0.03						
Nature of relationships	F(2, 253) = .69	F(2, 253) = .68	F(2, 253) = .86	F(3, 252) = .54	F(2, 253) = .92	F(2, 253) = 1.71	F(2, 253) = 4.86**
Effect size( $\eta^2$ )						0.04	

\* $P < 0.05$ , \*\* $P < 0.01$ .

## **4.8 Research Question 3**

*Comparison of attitudes from baseline to one month follow up*

A series of generalised linear mixed models for repeated measures were used to test for intervention effects. These are reported below by the three dimensions in turn.

*Affective Dimension (discomfort and sensitivity/tenderness factors)*

The analyses revealed a main effect of Time  $F(2, 455.50) = 29.8, p < .001$  and a Time\*Group interaction  $F(2, 455.50) = 11.65, p < .05$  was observed for the discomfort factor. Further post hoc analyses of least significant differences (LSD) comparisons showed that within the intervention group there was a significant increase in positive attitude, that is, less discomfort post-intervention and follow up compared to baseline  $t(456.98) = 2.32, p < .05$ . However, the positive attitudes at T3 indicated less positive attitudes than T2 but were more positive compared to baseline supporting the (hypothesis five) predictions that favourable attitudes would be maintained at follow-up. In the control group, there was significant increase in positive attitude scores at T2 compared to baseline. No other significant changes were observed in the control group. The interaction effects indicated that the intervention group reacted differently to the control group with more positive attitude changes over time in the intervention group. That is, less discomfort towards people with ID over time (see figure 1 and table 7).

For the sensitivity/tenderness factor a main effect of Time  $F(2, 462.53) = 49.42, p < .001$ , Group  $F(1, 589.46) = 5.21, p < .05$  and Time\*Group interaction  $F(2, 462.53) = 10.82, p < .001$  was identified. Further analyses revealed that

there were significant differences between groups with a significant increase in positive attitudes at T2 in the intervention group  $t(790.43) = 2.03, p < .05$  compared to baseline that was maintained at follow up compared to the control group  $t(477.58) = -2.39, p < .05$ . In the control group, no significant changes over time were observed. The interaction effects indicated the different ways both groups reacted over time compared to each other, with the intervention having more positive attitudinal changes over time. The results from both these factors were in line with hypothesis four that predicted more favourable attitudes in regard to affective dimensions.

*Cognitive Dimension (knowledge of rights, knowledge of capacity, knowledge of causes factors)*

Significant main effect of Time  $F(2, 509.96) = 3.40, p < .05$  and Group\*Time interaction  $F(2, 509.96) = 3.22, p < .05$  was observed for the knowledge of rights factor. Further LSD comparisons indicated that in the intervention group there was an increase in positive attitudes, that is, participants strongly agreed that people with ID should have equal rights at T2 compared to the control group  $t(516.52) = -2.94, p < .05$ . However, the intervention group showed a decrease in positive attitudes at T3 compared to baseline and post intervention but it is important to note that these attitudes were still positively polarised. Interestingly, the control group showed a significant increase in negative attitudes at T2 and a decrease at follow-up  $t(515.82) = 2.08, p < .05$ . See Figure 2. The interaction effects reflected the differences in reactions for both groups over time with the intervention group having more positive attitude changes post intervention (see Figure 2).

For the knowledge of capacity factor, significant main effects of Group  $F(1, 598.61) = 14.53, p < .001$ , Time  $F(2, 514.83) = 73.37, p < .001$  and a Time\*Group

interaction were observed. LSD comparisons showed that the intervention group had significantly more positive attitudes over time  $t(790.85) = 2.79$ ,  $p < .05$  compared to control group. Positive attitudes were maintained at T3 compared to baseline  $t(529.25) = -4.36$ ,  $p < .001$  despite reduced magnitudes. Therefore, participants in the intervention group had more positive attitudes regarding the capacities people with ID held at T2 and T3 compared to the control group. These results were in line with predictions of hypothesis four and five (see Figure 3).

A significant Time\*Group interaction was observed for the knowledge of causes factor  $F(2, 495.11) = 4.68$ ,  $p < .05$ . The interaction reflected the different ways both groups reacted over time (see Figure 4). The intervention group had more positive attitudes post intervention compared to control group, however at T3 these attitudes were less favourable compared to baseline. Overall, the cognitive dimension had more favourable attitudes in the intervention group post intervention and were maintained over time and were in line with the predictions from hypothesis four and five.

#### *Behavioural dimension (Interaction)*

There was a significant main effect for Time  $F(2, 421.501) = 26.79$ ,  $p < .001$  and a Group\*Time interaction  $F(2, 421.50) = 6.68$ ,  $p < .001$  was observed for this factor. No significant main effect for group was observed. Further analysis revealed that over time participants in the intervention group positively evaluated interaction with persons with intellectual disability post intervention  $t(422.93) = -2.54$ ,  $p < .05$  but at follow up the results were less positive compared to baseline. In the control group, no significant differences were observed over time. Overall, the interaction effect revealed that participants in the intervention group had more

positive attitudes at T2 and T3 compared to control group (see Figure 5). These results were in line with the predictions from hypothesis 5.

#### *IDLS Supernatural causal beliefs*

Significant main effects for Time  $F(2, 485.71) = 12.44, p < .001$  and Group  $F(1, 584.25) = 10.42, p < .001$  were observed for the IDLS supernatural causal beliefs. In the intervention group, there were large and significant pre-post changes compared to the control group  $t(784.88) = -2.72, p < .05$ . There was a significant main effect of Time with the baseline scores showing significant differences compared to T2 and T3  $t(501.87) = -3.34, p < .001$ . Overall, both groups showed a gradual increase in negative attitudes over time indicating agreements with the statements about supernatural causes of ID. However, the intervention group had greater differences post-intervention group and maintained these changes at one month follow up. These results were not in line with the predictions made in hypothesis four and five.

#### **4.9 Research Question 4**

##### *Reach of the study and appropriateness of methodology*

The inclusion of several process evaluation questions (see Table 9) provided insight into means of accessing the study, survey completion times and nature of difficulties with completing the study and how this affected their participation. Overall, the participants (86.1%) thought that the length of the questions, length of the video (81.8%) were “just right”. The content of the video was rated as excellent (49.4%) and the questions asked in the survey were thought to be good (52.9%). Participants were asked several questions about the process of the study - 74.8% accessed the study via personal devices (e.g. mobile phones and

laptops) and 13.6% accessed it from their place of work. Most participants (60.3%) completed the study in less than twenty minutes and 92.7% did not experience any difficulties with internet connectivity. However, of those who did experience difficulties, 45% reported that these were due to slow internet connection speeds. The majority of the participants (63.6%) reported that difficulties with internet connectivity did not affect their ability to access the study (45.5%), answer the questions (63.6%); watch the films (40.9%) or complete the study (45.0%).

Table 9. Reach of the study

	N	%
<b>Means of accessing study</b>		
Personal device (e.g. mobile phone, laptop, ipad)	237	74.8
Internet cafe	6	1.9
Educational centre	8	2.5
Place of work	43	13.6
Other	23	7.3
<b>Time taken to complete study</b>		
Less than 20 minutes	191	60.3
20-40 minutes	111	35.0
1 Hour	2	.6
I didn't complete it in one sitting	12	3.8
Other	1	.3
<b>Difficulties with internet connectivity while completing study</b>		
Yes	23	7.3
No	294	92.7
<b>Nature of difficulties</b>		
Slow speed connection	10	45.5
No wifi signal	1	4.5

Insufficient data	6	27.3
Other	5	22.7

Note: Out of 457participants, only 317 completed the process questions.

## 5. Discussion

The aims of this study were to investigate (1) prevalent attitudes towards people with intellectual disabilities with regard to the affective, cognitive and behavioural dimensions; (2) the effect an e-intervention would have on intellectual disability stigma ; (3) whether attitudes would vary according to socio-demographic factors and frequency of contact with persons with intellectual disabilities; and (4) the validity and reliability of the methodological choice of this study by examining the reach of the study and the appropriateness of the chosen method in this Kenyan sample.

In contrast to previous studies which indicated negative attitudes towards persons with ID in African countries (e.g. Bayat, 2014, Mckenzie & Swartz, 2011, Muchiri & Robertson, 2000), the results of this study suggest that attitudes in this relatively young and highly educated sample were generally positive at baseline across the three attitudinal dimensions for six of the ATTID factors; *Discomfort, Knowledge of Rights, Interaction, Knowledge of Capacity* and *Causes and Sensitivity/tenderness*. These results were not in line with the predictions of hypothesis one that predicted attitudes towards people with ID would not be favourable and would remain so in the control group at all three time points.

Possible reasons for this concerns sampling differences and recent technological advancements. Selection bias may have been confounding as nearly 80% of the sample reported prior contact with an individual with ID which may have positively skewed the findings given the established link between contact and attitudes (Allport, 1954; Cameron & Rutland, 2006; Eller & Abrams, 2003). Gjeslstand (1996) suggested that online survey administration is limited in that not everyone has access to the internet. Therefore, coverage bias may have been influenced by the differences between people with and without internet access and the possibility of participants being particularly

interested in the study for reasons that may have or have not been related to the content of the study, again possibly skewing the results generated and unrepresentative of the wider Kenyan population. Additionally, even though frequency of contact was predominantly occasional during the year, this suggests that occasional contact may be useful in improving attitudes toward people with ID and reducing discomfort among the general public. These results support findings from the systematic review by Scior (2011) which reported prior contact is likely to be associated with more positive attitudes and a reduction in anxiety.

The internet has shown a huge potential for promoting health and well-being (Reis and Frankel, 2013). One way in which the internet has been used in connection with health is through the distribution of information through both high and low income countries (Siegel et al, 2009; Higgins et al., 2009). Over recent years, Kenya has become a global technology leader for innovation in mobile and internet technology that has opened doors for the general public to have access to what is happening around the world. Consequently, technology has advanced the dissemination of information that has allowed the global village to produce and exchange information. For example, global events such as the Paralympic games increase visibility of people with disabilities around the world and continue to provide opportunities to challenge attitudes (Hodges et al., 2014). Although, future research needs to consider study designs that would be useful for older, less well educated people in rural environments.

However, the data also highlighted areas to target. The results for the *Sensitivity and Tenderness* factor of the ATTID and IDLS supernatural causal beliefs, revealed less positive attitudes or areas where participants had reservations. The *Sensitivity and Tenderness* factor asked about emotions such as sadness, being touched and moved by people with ID. Studies have also reported pity towards people with ID (Findler et al., 2007) and that these emotions do not encourage social participation or autonomy. Results of the IDLS supernatural beliefs were more negatively polarised suggesting that causes of ID are misunderstood by a large part of the population. This is in accordance with other studies that show beliefs that ID has supernatural causes, e.g. curses or punishment of past sin (Baffoe, 2013), suggesting that

misconceptions about the causes of ID are still very much alive. This highlights an important aspect that needs to be addressed in public awareness raising programmes (Hunt & Hunt, 2004; Findler et al., 2007).

In this study, the association between participants' socio-demographic characteristics (such as age, sex, education, religious affiliation) and their attitudes towards persons with intellectual disability was examined. The results reveal that age and gender did not have any association with attitudes across all three attitudinal dimensions. This is contradictory to other studies (Findler et al., 2007) whose results have indicated that on the *discomfort factor* men had more negative attitudes compared to women on the affective and cognitive dimensions. Moreover, Morin et al (2013) found that adults over the age of 60 had more negative attitudes across all factors. However, these findings support Hengst (2003) and Choi and Lum (2001), Scior (2011) who did not find significant difference as a function of gender regarding attitudes toward people with ID. Overall, there has been a lack of consistency across studies that have investigated the impact of age on attitudes (Lau & Cheung, 1999). However, this was in line with hypothesis three that predicted there would be no positive association between gender and attitudes.

The results reveal that participants with postgraduate education had more positive attitudes than those with vocational education on the *interaction* and *knowledge of causes factors* indicating that education does impact upon attitudes as found in previous studies (Fiske, 1997; Oullette-Kuntz et al., 2010). Religious affiliation also had an impact on attitudes (Haj-Yahia 1999). In this study, religion had an impact on *sensitivity and tenderness* and the *IDLS factors*. Individuals who were Christian, Hindu or non-religious reported more negative attitudes on the supernatural causal beliefs subscale than those who were Muslim or believed in traditional religions. This is in line with hypothesis three and previous research that beliefs about causes of disability may be divine retribution or witchcraft lead families to hide these individuals (Mung'omba, 2008) and also as 'gifts from God' sent to challenge their family members strength which may affect the person with disability's acceptance within their family and community negatively (Rohlder & Swartz, 20009). Therefore, it is important to consider that these causal beliefs may be more deeply rooted and

harder to challenge despite the lay public having more general positive attitudes towards people with ID, e.g. with recognising their rights and capacity. It may be useful to explore an alternative approach to challenging stigma and promoting inclusion and human rights for persons with ID by being mindful of cultural roots and beliefs about such groups, their rights and roles in society. Furthermore, participants who had less contact with persons with disability reported more negative attitudes for the *discomfort factor*, suggesting that contact does have a positive impact on attitudes (Scior, 2011) which was in line with hypothesis two that predicted that attitudes would be more favourable among participants with prior contact with individuals with ID.

The current study also tested the effects of the intervention at one month follow-up. Positive changes in the intervention group for the affective dimensions (*Discomfort, Sensitivity/tenderness*) and cognitive dimensions (*Knowledge of rights, Knowledge of causes, Knowledge of capacity*) were maintained at follow up despite reduced magnitude in line with hypothesis four and five. However, negative attitudes persisted for the supernatural causal beliefs. This emphasises the persistence of traditional values despite changes in economic, political and social changes (DiMaggio, 1994) highlighting that different societies may follow different trajectories despite experiencing the same forces of development (Inglehart and Baker, 2000). Weber (2002) argued that traditional religious values have an enduring influence on individuals and institutions, therefore it may be possible to have knowledge about ID but still hold negative attitudes and or engage in stigmatizing behaviours towards this group. Thus knowledge and attitudes may be considered distinct from one another.

In contrast to Morin (2013), the results of this study found knowledge of capacity and knowledge of rights to load on two separate factors. This finding illustrates a difference in conceptualisation associated with these constructs in this culture. This suggests that the participants may agree with equal rights in principle but deem people with ID as incapable which can have serious implications for equality and self-determination. However, this measure has been found to have good psychometrics in other countries such as Canada and the internal consistency of the scale in this study was good (Morin, 2013).

This highlights how different cultures vary to the degree to which they observe and construct experiences and the methodological confounds that occur in cross-cultural research. For example, translation errors can produce measures conveying different meanings across cultures (Brislin, 1970). Members of westernised cultures may be more familiar with completing questionnaires than non-westernised cultures (Greenfield, 1997), such as the Kenyan culture, which led the researchers to develop the shortened version of the ATTID in this study. It is also important to consider that members of some collectivist cultures may be more likely to respond to questionnaires more modestly than others (Heine et al., 2000). These are all significant concerns and the use of different methodologies have been used to correct many of these confounds (e.g. standardisation of data and observations of the samples).

Overall, the findings suggest that web surveys are generally accepted in this Kenyan sample. Majority of the participants completed the survey via personal devices (74.7%) or at their places of work (13.6%) and over 90% did not experience any difficulties with their internet connection and 60.3% completed the study in less than 20 minutes. This reflects the high penetration and accessibility of mobile phone handsets and electronic devices available in the Kenyan market and the availability of affordable, reliable bandwidth through mobile phones and fibre optic infrastructure amongst this educated urban population. These results indicate high user acceptability given their accessible and anonymous format as well as great strength and opportunities for the use of web based surveys in Kenya.

However, it is important to note that there was a high attrition rate in this study. Research studies note attrition as one of the major methodological problems in longitudinal studies that can reduce generalisability of findings (Schaffer, 1996). It would have been interesting to get the perspectives of the participants who not only completed the study as to the appropriateness of the intervention content and material (e.g. what was important content for them) but those who did not complete the study. Paxton (2013) noted that anonymous online platforms can be met with user dropout because of reduced face-to-face engagement and accountability. Retention strategies recommended in the literature (e.g. Maxwell et al., 2014) were used to maintain the sample, including

(1) community engagement through the support of local experts, religious leaders and organisations who promoted, encouraged participation and raised the credibility of the study; (2) convenient communication with the sample using posters and promotional videos via social media and webpages to keep the study in the public eye; (3) at the follow up stage, non-responders received reminder emails to complete the survey; and (4) incentives were used to promote retention (Laurie & Lynne, 2009; Booker et al., 2011). As noted above, missing data techniques (GLMM) were used to account for attrition and retain numbers of the sample and reduce the negative effects it may have on the findings.

Furthermore, online based platforms require continuing attention and substantial partnerships to ensure successful implementation. Therefore, future research may need to consider shorter web surveys or direct contact approaches for topics that are not easily spoken about in this population to encourage higher rates of participation and impact on changing attitudes, stigma and social inclusion.

### **5.1. Limitations**

This study has several limitations that should be noted. One that affects many self-report survey studies is sample bias. Younger, more educated individuals with access to the internet and social media applications were over-represented in this convenience sample despite Kenya having a young population. Research has found that many web studies are self-selection surveys (Eysenbach & Wyatt, 2002) that are not based on probability sampling. The participants visit the websites, find the study information, and decide to complete the survey. In the case of self-selection, the researchers know very little about the website or app members (e.g. Facebook, snapchat) and have no control on the selection process (Eysenbach & Wyatt, 2002). Thus, online self-selection surveys are particularly subject to coverage and selection bias, which undermines the external validity of the studies and interpretation of the studies. Furthermore, exposures to the study advertisements might have been influenced by the time users spent on social media and frequent internet users may have been more likely to share the study details with others compared to those who

use social media less (Ferner et al., 2012). Furthermore, the sample consisted of a high proportion of female participants however, no gender effects on attitudes were found. However, an advantage of the sample in this study is that it consisted of different Kenyan religious and ethnic groups. Thus, this study should be repeated with a more representative sample.

The attrition rates in this study meant that there may have been reduced power and significant differences may not have been observed (Dumville et al., 2006). The findings were based on self-report measures and whether the responses reflect the participants' true attitudes is subject to question. Response biases including socially desirable answers may have influenced the responses given and other methods of data collection should be used in future (Randall & Fernandes, 1991). A further key limitation concerns the relationship between self-reported attitudes and what they mean in the real change. Participants may have equally endorsed the general philosophy of people with ID having equal rights and the capacity to make their own decisions but this does not mean communities are necessarily willing to make adaptations and implement policies set by local governments and international agreements.

## **5.2 Implications and future research**

This study and the literature review emphasise the dearth of data concerning attitudes to ID from low income countries. To avoid paradigms being narrowly limited to western realities, there is an increasing need for cross-cultural studies that carefully examine their fit for different cultural contexts. This would help researchers; (1) identify what factors are culture-dependent and culture independent in attitude and stigma formation and in turn inform what areas interventions should focus on in specific cultures and globally, and (2) provide comparisons across cultures and increase the understanding of environmental variables and experiences that shape the constructs in question. Therefore, cross-cultural research would be an effective gate-keeper in preventing ideas from easily being accepted into some cultures before withstanding replication tests in societies with different values and social structures.

In Kenya and other African countries where beliefs and culture have been largely preserved, taught and passed down through proverbs, folktales and oral

traditions, future research should consider what additional research methods may be useful. This would give researchers the chance to investigate and understand deeply rooted beliefs and perspectives and account for any methodological biases in cross cultural studies. Survey studies have recommended the application of additional methods (e.g. observations, qualitative methods) to collect information about the same constructs such as triangulation (Lipson & Meleis, 1989). Triangulation in addition to web surveys may reduce missing data and increase compliance with responses to questions and potentially lead to effective retention of participants and a more representative sample of the study (Heine et al., 2000). Furthermore, collaborations and partnerships with local citizens, professionals and organisations who understand the native rich cultures and its dialogues have proved to be necessary for such studies.

The use of the internet offers great potential for research and useful for production, data collection, dissemination and exchange of information around the world, human interaction and contact can be extremely powerful. Therefore, in cultures where beliefs are deeply rooted and embedded in social discourses, direct contact interventions as suggested by Allport (1954) should be conducted alongside web-based interventions to challenge negative attitudes and stigma, inform social, health services and inform and implement policies while increasing accessibility and reach of this information and achieve long standing positive changes.

In Kenya where a significant proportion of the population are internet users, there is a great need for improving the translation of e-health research into clinical practice to achieve a large public health impact. A useful example is a Kenyan project using mobile phones to help manage depression by accessing the WHO's Mental Health Gap Action Programme. It does this by training non-mental health workers to deliver a mobile-based and evidence-based intervention through a mobile app. The technology helps overcome the barriers of distance and travel, increasing and speeding up patients' access to care.

As discussed, the literature proposes that disability is socially constructed therefore to achieve this significant impact in this society, raising awareness should not only be directed at the general public but also at clinicians, legal

professionals, policy makers, educators as well as families, communities and those with intellectual disabilities. Increasing the accessibility of evidence, efficacy and dissemination of information, services and computerised mental health interventions to these different groups and into treatment guidelines would helpful.

Lastly, ethical guidelines application for research in developing countries can raise some issues (Morris, 2015). While researchers desire to adhere to ethical and cultural norms and promote collaborate work and accountability, very little advice is available to undertake research in these countries (Resnik, 2011). Therefore, future studies should consider developing collaborative relationships with local researchers and raise awareness of the potential benefits of ethical review while appreciating the need to work flexibly with a higher degree of reflexivity (Morris, 2015).

## References

- Adnams C,M. (2008). Poverty and intellectual disabilities: A view from Africa [abstract]. *Journal of Intellectual Disability Research*; 52(8):639.
- African Union. (2005). *African Decade of Disabled Persons (199-2009)*. International Partners Meeting Addis Ababa, Ethiopia – 21<sup>st</sup> and 22<sup>nd</sup> September 2005.
- Allport, G. (1954). *The nature of prejudice*. Reading, MA: Addison-Wesley.
- Akrami, N., Ekehammar, B., Claesson, M., & Sonnander, K. (2006). Classical and modern prejudice: Attitudes toward people with intellectual disabilities. *Research in developmental disabilities*, 27(6), 605-617.
- Antonak, R. F., Mulick, J. A., Kobe, F. H., & Fiedler, C. R. (1995). Influence of mental retardation severity and respondent characteristics on self-reported attitudes toward mental retardation and eugenics. *Journal of Intellectual Disability Research*, 39(4), 316-325.
- Barry, M. M., Domegan, C., Higgins, O., & Sixsmith, J. (2011). A literature review on health information seeking behaviour on the web: a health consumer and health professional perspective.
- Booker, C. L., Harding, S., & Benzeval, M. (2011). A systematic review of the effect of retention methods in population-based cohort studies. *BMC Public Health*, 11(1), 249.
- Brislin, R. W. (1970). Back-translation for cross-cultural research. *Journal of cross-cultural psychology*, 1(3), 185-216.
- Carsrud, A. L., Ahlgren, R. D., & Dood, B. G. (1986). Evaluating the effects of a community awareness programme on attitudes toward sheltered work and living projects. *British Journal of Mental Subnormality*, 32, 12–41.
- American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*. Arlington, VA: American Psychiatric Publishing.

- Asongu, J. J., & Marr, M. (2007). *Doing business abroad: A handbook for expatriates*. Lawrenceville, GA: Greenview Publishing Co.
- Baffoe, M. (2013). Stigma, discrimination & marginalization: Gateways to oppression of persons with disabilities in Ghana, West Africa. *Journal of Educational and Social Research*, 3(1), 187-198.
- Bayat, M. (2014). Understanding views of disability in the Cote d'Ivoire. *Disability and Society*, 29(1), 30-43.
- Blanchard, F. A., Weigel, R. H., & Cook, S. W. (1975). The effect of relative competence of group members upon interpersonal attraction in cooperating interracial groups. *Journal of Personality and Social Psychology*, 32(3), 519.
- Brislin, R. W. (1970). Back-translation for cross-cultural research. *Journal of Cross-Cultural Psychology*, 1, 185–216.
- British Psychological Society. (2010). *Code of human research ethics*. Leicester: BPS
- Burge, P., Ouellette-Kuntz, H., & Lysaght, R. (2007). Public views on employment of people with intellectual disabilities. *Journal of Vocational Rehabilitation*, 26(1), 29-37.
- Byron, M., & Dieppe, P. (2000). Educating health professionals about disability:'attitudes, attitudes, attitudes'. *Journal of the Royal Society of Medicine*, 93(8), 397.
- Cameron, L., Rutland, A., Brown, R., & Douch, R. (2006). Changing children's intergroup attitudes toward refugees: Testing different models of extended contact. *Child development*, 77(5), 1208-1219.
- Carsrud, A. L., Ahlgren, R. D., & Dodd, B. G. (1986). Evaluating the effects of a community awareness programme on attitudes toward sheltered work and living projects. *British Journal of Mental Subnormality*, 32(62), 37-41.
- Carter, J. M., & Markham, N. (2001). Disability discrimination. *British Medical Journal (Clinical Research Ed.)* 323, 178-179.
- Central Intelligence Agency (2012). "Kenya". *The World Factbook*. Retrieved 28 May 2013.

- Choi, G, & Lam, C.S. (2001). Korean students' differential attitudes toward people with disabilities: an acculturation perspective. *International Journal of Rehabilitation Research*, 24(1), 79-81.
- Corrigan, P. W., & Penn, D. L. (1999). Lessons from social psychology on discrediting psychiatric stigma. *American Psychologist*, 54(9), 765.
- Corrigan, P. W., & Lundin, R. K. (2001). *Don't Call Me Nuts!: Coping with the stigma of mental illness*. Recovery Press.
- Corrigan, P. W., Morris, S. B., Michaels, P. J., Rafacz, J. D., & Rüsch, N. (2012). Challenging the public stigma of mental illness: a meta-analysis of outcome studies. *Psychiatric services*, 63(10), 963-973.
- Corsini, R. J. (1999). *The dictionary of psychology*. Ann Arbor, MI: Braun-Brumfield.
- Crocker, J., Major, B., & Steel, C. (1998). Social Stigma in New York. *The Handbook of Social Psychology*. ed, 2, 4th.
- Culham, A., & Nind, M. (2003). Deconstructing normalisation: clearing the way for inclusion. *Journal of Intellectual and Developmental Disability*, 28(1), 65-78.
- Cummins, R. A., & Lau, A. L. D. (2003). Community integration or community exposure? A review and discussion in relation to people with intellectual disabilities. *Journal Applied Research in Intellectual Disabilities*, 16, 145–157.
- Ditchman, N., Werner, S., Kosyluk, K., Jones, N., Elg, B., & Corrigan, P. W. (2013). Stigma and intellectual disability: potential application of mental illness research. *Rehabilitation Psychology*, 58(2), 206.
- DiMaggio, P. (1994). Culture and economy. *The handbook of economic sociology*, 27.
- Dumville, J. C., Torgerson, D. J., & Hewitt, C. E. (2006). Research methods: reporting attrition in randomised controlled trials. *BMJ: British Medical Journal*, 332(7547), 969.
- Eagly, A. H., & Chaiken, S. (1993). *The psychology of attitudes*. Harcourt Brace Jovanovich College Publishers.

- Eller, A., & Abrams, D. (2004). Come together: longitudinal comparisons of Pettigrew's reformulated intergroup contact model and the common ingroup identity model in Anglo-French and Mexican-American contexts. *European Journal of Social Psychology*, 34(3), 229-256.
- Elobeid, M. A., Padilla, M. A., McVie, T., Thomas, O., Brock, D. W., Musser, B., & Gadde, K. M. (2009). Missing data in randomized clinical trials for weight loss: scope of the problem, state of the field, and performance of statistical methods. *PloS ONE*, 4(8), e6624.
- Eide, A., & Ingstad, B. (2011). *Disability and poverty: A global challenge*. Bristol: The Policy Press.
- Emerson, E., & Baines, S. (2011). Health inequalities and people with learning disabilities in the UK. *Tizard Learning Disability Review*, 16(1), 42-48.
- Eysenbach, G., & Wyatt, J. (2002). Using the Internet for surveys and health research. *Journal of Medical Internet Research*, 4(2).
- Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). G\* Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior research methods*, 39(2), 175-191.
- Findler, L., Vilchinsky, N., & Werner, S. (2007). The Multidimensional Attitudes Scale Toward Persons With Disabilities (MAS) Construction and Validation. *Rehabilitation Counseling Bulletin*, 50(3), 166-176.
- Finkelstein, J., Lapshin, O., & Wasserman, E. (2008). Randomized study of different anti-stigma media. *Patient Education and Counseling*, 71(2), 204-214.
- Fujiura, G. T., Park, H. J., & Rutkowski-Kmita, V. (2005). Disability statistics in the developing world: A reflection on the meanings in our numbers. *Journal of Applied Research in Intellectual Disabilities*, 18(4), 295-304.
- Fyson, R., & Kitson, D. (2010). Human rights and social wrongs: Issues in safeguarding adults with learning disabilities. *Practice*, 22(5), 309-320.
- Krantz, J. H., & Dalal, R. (2000). Validity of Web-based psychological research.

Gara N. (2011). Effects of caring on mothers of intellectually disabled children in Alice, Eastern Cape, South Africa M Phil dissertation. University of Cape Town, Cape Town.

Gardner, B. (2009). Incentivised snowballing. *The Psychologist*, 22, 768-769.

Gardner, K. (2007). Conducting your PhD via the internet. *The Psychologist*, 20, 232-233.

Gjestland, L. (1996). Net? Not yet. *Mark. Res.: Mag. Manage. Appl.* 8: 26–29.

Great Britain. Department of Health (2005). Adults with learning difficulties in England 2003/4. Retrieved from:

[http://webarchive.nationalarchives.gov.uk/20110504140405/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH\\_4120033](http://webarchive.nationalarchives.gov.uk/20110504140405/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_4120033)

Greenfield, P. M. (1997). You can't take it with you: Why ability assessments don't cross cultures. *American Psychologist*, 52, 1115-1124.

Goffman, E. (1963). Stigma: Notes on the management of spoiled identity. London: Prentice-Hall.

Greenfield, P. M. (1997). Culture as process: Empirical methods for cultural psychology. In J. W. Berry, Y. H. Poortinga, & J. Pandey (Eds.), *Handbook of cross-cultural psychology* (Vol. 1, pp. 301–346). Boston: Allyn & Bacon.

Haj-Yahia, M. M. (1999). Attitudes towards mentally ill people and willingness to employ them in Arab society. *International Sociology*, 14(2), 173-193.

Hastings, R. P., Sjöström, K. E., & Stevenage, S. V. (1998). Swedish and English adolescents' attitudes toward the community presence of people with disabilities. *Journal of Intellectual Disability Research*, 42(3), 246-253.

Heine, S. J., Takata, T., & Lehman, D. R. (2000). Beyond self-presentation: Evidence for self-criticism among Japanese. *Personality and Social Psychology Bulletin*, 26, 71–78.

Henry, D. B., Duvdevany, I., Keys, C. B., & Balcazar, F. (2004). Attitudes of American and Israeli staff toward people with intellectual disabilities. *Mental Retardation*, 42, 26–36.

- Herek, G. M., & Capitanio, J. P. (1996). "Some of My Best Friends" Intergroup Contact, Concealable Stigma, and Heterosexuals' Attitudes Toward Gay Men and Lesbians. *Personality and Social Psychology Bulletin*, 22(4), 412-424.
- Hilton, J. L., & Von Hippel, W. (1996). Stereotypes. *Annual review of psychology*, 47(1), 237-271.
- Hodges, C. E., Jackson, D., Scullion, R., Thompson, S., & Molesworth, M. (2014). Tracking changes in everyday experiences of disability and disability sport within the context of the 2012 London Paralympics.
- Hosking, D. L. (2008, September). Critical disability theory. In *A paper presented at the 4th Biennial Disability Studies Conference at Lancaster University, UK*.
- Inglehart, R., & Baker, W. E. (2000). Modernization, cultural change, and the persistence of traditional values. *American sociological review*, 19-51.
- Kagendo Mutua, N., & Dimitrov, D. M. (2001). Parents' expectations about future outcomes of children with MR in Kenya: Differential effects of gender and severity of MR. *Journal of Special Education*, 35(3), 172-180.
- Kiarie, M. W. (2006). Plans for inclusive education in Kenya. A comparative overview. *Journal of International Special Needs Education*, 9, 27- 33.
- Kisanji, J. (1995). Attitudes and beliefs about disability in Tanzania. *Innovations in developing countries for people with disabilities*, 51-70.
- Kromberg, J., Zwane, E., Manga, P., Venter, A., Rosen, E., & Christianson, A. (2008). Intellectual disability in the context of a South African population. *Journal of Policy and Practice in Intellectual Disabilities*, 5(2), 89-95.
- Lau, J. T. F., & Cheung, C. K. (1999). Discriminatory attitudes to people with intellectual disability or mental health difficulty. *International Social Work*, 42(4), 431-444.
- Laurie, H., & Lynn, P. (2009). The use of respondent incentives on longitudinal surveys. *Methodology of longitudinal surveys*, 205-233.

- Levin, S., Van Laar, C., & Sidanius, J. (2003). The effects of ingroup and outgroup friendships on ethnic attitudes in college: A longitudinal study. *Group Processes & Intergroup Relations*, 6(1), 76-92.
- Lipson, J. G., & Meleis, A. I. (1989). Methodological issues in research with immigrants. *Medical Anthropology*, 12(1), 103-115.
- Llewellyn, A., & Hogan, K. (2000). The use and abuse of models of disability. *Disability & Society*, 15(1), 157-165.
- Marsh, H. W., & Byrne, B. M. (1993). Confirmatory factor analysis of multitrait-multimethod self-concept data: Between-group and within-group invariance constraints. *Multivariate Behavioral Research*, 28(3), 313-449.
- Maxwell, K., Maynard, M., & Harding, S. Retention and attrition in longitudinal cohort studies. Report on culturally-appropriate retention strategies in an ethnically diverse cohort: lessons from the DASH Study.
- McCaughey, T. J., & Strohmer, D. C. (2005). Prototypes as an indirect measure of attitudes toward disability groups. *Rehabilitation Counseling Bulletin*, 48(2), 89-99.
- McConkey, R., Walsh, P. N., & Conneally, S. (1993). Neighbours' reactions to community services: contrasts before and after services open in their locality. *Journal of Applied Research in Intellectual Disabilities*, 6(2), 131-141.
- Mckenzie, J. A., & Swartz, L. (2011). The shaping of sexuality in children with disabilities: AQ methodological study. *Sexuality and Disability*, 29(4), 363-376.
- Mckenzie, J., McConkey, R., Adnams, C. (2013). Intellectual disability in Africa: implications for research and service development. *Disabil Rehabil*; 35(20): 1750-1755.
- MacDonald, J. D. & MacIntyre, P. D. (1999). A rose is a rose: Effects of label change, education, and sex on attitudes toward mental disabilities. *Journal of Developmental Disabilities*, 6, 15-31.
- Morin, D., Rivard, M., Crocker, A. G., Boursier, C. P., & Caron, J. (2013). Public attitudes towards intellectual disability: A multidimensional perspective. *Journal of Intellectual Disability Research*, 57(3), 279-292.

- Morin, D., Crocker, A. G., Beaulieu-Bergeron, R., & Caron, J. (2013). Validation of the attitudes toward intellectual disability—ATTID questionnaire. *Journal of Intellectual Disability Research*, 57(3), 268-278.
- Morris, N. (2015). Providing ethical guidance for collaborative research in developing countries. *Research ethics*, 11(4), 211-235.
- Mukuria, G., & Korir, J. (2006). Education for children with emotional and behavioral disorders in Kenya: Problems and prospects. *Preventing School Failure: Alternative Education for Children and Youth*, 50(2), 49-54.
- Muchiri, N., & Robertson, L. (2000). Including the excluded: an inclusive education project in Meru, North District-Kenya. In *International Special Education Conference, University of Manchester*.
- Mutua, N., & Dimitrov, D. M. (2001). Parents' expectations about future outcomes of children with MR in Kenya: Differential effects of gender and severity of MR. *The Journal of Special Education*, 35(3), 172-180.
- Myers, F., Ager, A., Kerr, P., & Myles, S. (1998). Outside looking in? Studies of the community integration of people with learning disabilities. *Disability & Society*, 13(3), 389-413.
- Nagata, K. K. (2007). The measurement of the Hong Kong-based 'Baseline Survey of Students' Attitudes toward People with a Disability': cross-cultural validation in Lebanon. *International Journal of Rehabilitation Research*, 30(3), 239-241.
- Njenga, F. (2009). Perspectives of intellectual disability in Africa: epidemiology and policy services for children and adults. *Current Opinion in Psychiatry*, 22(5), 457-461.
- Oriredo, T. (2003). The state of persons with disabilities in Kenya. *Council for Exceptional Children: Division of Internal Special education and Services*.
- Ouellette-Kuntz, H., Burge, P., Brown, H. K., & Arsenault, E. (2010). Public attitudes towards individuals with intellectual disabilities as measured by the concept of social distance. *Journal of Applied Research in Intellectual Disabilities*, 23(2), 132-142.

- Oulette-Kuntz, H., Burge, P., & Henry, D. B. (2003). Attitudes of senior psychiatry residents toward people with intellectual disability. *Journal of Intellectual Disability Research*, 48, 538-545.
- Patel, M., & Rose, J. (2014). Students' attitudes towards individuals with an intellectual disability. *Journal of Intellectual Disabilities*, 18(1), 90-103.
- Paxton, S. J. (2013). Dissemination in the internet age: taming a wild thing. *International Journal of Eating Disorders*, 46(5), 525e528. <http://dx.doi.org/10.1002/eat.22116>.
- Pooh, K. (2016). An examination of the relationship between implicit and explicit attitudes towards people with intellectual disabilities in Singapore. *Journal of Intellectual Disability Research* 60(7), 720. Retrieved from: <https://insights.ovid.com/intellectual-disability-research/jidr/2016/07/000/examination-relationship-implicit-explicit/487/00002547>
- Prestwich, A., Kenworthy, J. B., Wilson, M., & Kwan-Tat, N. (2008). Differential relations between two types of contact and implicit and explicit racial attitudes. *British Journal of Social Psychology*, 47(4), 575-588.
- Rao, S. (2004). Faculty attitudes and students with disabilities in higher education: A literature review. *College Student Journal*, 38(2), 191.
- Randall, D. M., & Fernandes, M. F. (1991). The social desirability response bias in ethics research. *Journal of business ethics*, 10(11), 805-817.
- Reinke, R. R., Corrigan, P. W., Leonhard, C., Lundin, R. K., & Kubiak, M. A. (2004). Examining two aspects of contact on the stigma of mental illness. *Journal of social and clinical psychology*, 23(3), 377-389.
- Reis, S., Visser, A., & Frankel, R. (2013). Health information and communication technology in healthcare communication: the good, the bad, and the transformative. *Patient education and counseling*, 93(3), 359-362.
- Resnik DB. (2011) What is ethics in research and why is it important? National Institute of Environmental Health Sciences. Available at: <http://www.niehs.nih.gov/research/resources/bioethics/whatis/> (accessed 19 July 2014).

- Rillotta, F., & Nettelbeck, T. (2007). Effects of an awareness program on attitudes of students without an intellectual disability towards persons with an intellectual disability. *Journal of Intellectual & Developmental Disability*, 32, 19–27.
- Rohleder, P., & Swartz, L. (2009). Providing sex education to persons with learning disabilities in the era of HIV/AIDS: Tensions between discourses of human rights and restriction. *Journal of Health Psychology*, 14(4), 601-610.
- Schaffer, H. R. (1996). *Social development*. Blackwell Publishing.
- Schulz, D. N., Candel, M. J., Kremers, S. P., Reinwand, D. A., Jander, A., & de Vries, H. (2013). Effects of a Web-Based Tailored Intervention to Reduce Alcohol Consumption in Adults: Randomized Controlled Trial. *Journal of Medical Internet Research*, 15(9), e206. <http://doi.org/10.2196/jmir.2568>.
- Schwartz, C., & Rabinovitz, S. (2001). Residential facilities in the community for people with intellectual disabilities: How neighbours' perceptions are affected by the interaction of facility and neighbour variables. *Journal of Applied Research in Intellectual Disabilities*, 14(2), 100-109.
- Scior, K. (2011). Public awareness, attitudes and beliefs regarding intellectual disability: a systematic review. *Research in developmental disabilities*, 32(6), 2164-2182.
- Scior, K. & Werner, S. (2015). Changing attitudes to learning disability: A review of the evidence. Mencap, University College London & the Hebrew University of Jerusalem.
- Seccombe, J. A. (2007). Attitudes towards disability in an undergraduate nursing curriculum: The effects of a curriculum change. *Nurse Education Today*, 27(5), 445-451.
- Seewooruttun, L., & Scior, K. (2014). Interventions aimed at increasing knowledge and improving attitudes towards people with intellectual disabilities among lay people. *Research in developmental disabilities*, 35(12), 3482-3495.
- Sheikh, S., Pralat, R., Reed, C., & Sin, C. H. (2010). Don't stand by: Hate Crime research report. *Mencap, London*.

- Siegel, E. R., Wood, F. B., Scott, J. C., & Royall, J. (2009). Web-based public health information dissemination and evaluation. *Oxford textbook of public health, Volume 2: the methods of public health*, (Ed. 5), 427-443.
- Smedema, S. M., Ebener, D., & Grist-Gordon, V. (2012). The impact of humorous media on attitudes toward persons with disabilities. *Disability and Rehabilitation*.
- Soussou, M. A., & Yogoiba, J. A. 2009. "Abuse of Children in West Africa: Implications for Social Work Education and Practice." *British Journal of Social Work Advanced*, Access (April, 10), 1–17.
- Stevens, J. P. (2012). *Applied multivariate statistics for the social sciences*. Routledge.
- Tervo, R. C., & Palmer, G. (2004). Health professional student attitudes towards people with disability. *Clinical rehabilitation*, 18(8), 908-915.
- United Nations Educational Scientific and Cultural Organization (1995). World conference on special needs education access and quality. Paris: UNESCO
- United Disabled Persons of Kenya (UDPK). (2003). United Disabled Persons of Kenya: The organization (UDPK).
- UN. Convention on the Rights of Persons with Disabilities. New York: United Nations; 2006.
- Van de Vijver, F., & Hambleton, R. K. (1996). Translating tests. *European psychologist*, 1(2), 89-99.
- Verma, J. P. (2015). *Repeated Measures Design for Empirical Researchers*. New Jersey: John Wiley & Sons.
- Verdonschot, M. M., De Witte, L. P., Reichrath, E., Buntinx, W. H. E., & Curfs, L. M. G. (2009). Impact of environmental factors on community participation of persons with an intellectual disability: a systematic review. *Journal of Intellectual Disability Research*, 53(1), 54-64.
- Walker, J., & Scior, K. (2013). Tackling stigma associated with intellectual disability among the general public: A study of two indirect contact interventions. *Research in developmental disabilities*, 34(7), 2200-2210.

Weber, M. (2002). *The Protestant ethic and the "spirit" of capitalism and other writings*. Penguin.

Weiner, B. (1995). *Judgments of responsibility: A foundation for a theory of social conduct*. Guilford Press.

World Health Organisation. (1992). *ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva: World Health Organisation.

World Health Organisation. (2001). *International classification of functioning disability and health*. Geneva: World Health Organisation.

Yazbeck, M., McVilly, K., & Parmenter, T. R. (2004). Attitudes toward people with intellectual disabilities: an Australian perspective. *Journal of Disability Policy Studies*, 15(2), 97-111.

## **Part 3**

### **Critical Appraisal**

## **Overview**

This appraisal sets out insights I have gained throughout the process of conducting the current research study and literature review. Firstly, given that the study was conducted on a Kenyan sample in partnership with local professionals, I will reflect on the collaboration process. Secondly, the methodological issues, including recruitment, retention and dissemination will be discussed. Lastly, I will share my personal experience of conducting this research.

## **Collaboration**

Research findings from higher-income countries may convey potential limitations for remaining within their own perspectives. Some of the findings from Western countries have been difficult to implement in lower-income countries because they are costly, not culturally appropriate and tend to focus on issues prevalent in high-income countries (National Research Council, 2007). Therefore, there can be a propensity to neglect specific local needs of lower-income countries. Over the years, the interest and potential to develop international partnerships for research purposes has grown exponentially, particularly with technological advancements and increased cultural awareness of common global issues (Chetwood et al, 2015).

It was of personal importance that I made strong networks and collaborated with local professionals and organisations to ensure local ownership and active support throughout the study. As a Kenyan, I felt more connected with the

people involved and the audience who participated. I was cautious that the findings of this study would not just be written for western audiences but most importantly for non-western audiences (Kisanji, 1995). Therefore, my supervisor and I contacted several organizations and local professionals to develop true partnerships and allow access to more diverse groups and ethnicities. At first, I found this process quite frustrating as I received very few responses. However, travelling home and visiting various professionals and organisations seemed to be more productive and was well received. This highlighted that meeting with people directly is more effective at building relationships with key professionals than more passive, indirect methods such as emails.

The people with intellectual disabilities from the Jacaranda Workshop – Nairobi who were featured in the film were happy to be involved as they felt they could finally be heard and seen. Building ways of working collaboratively with different professionals around the world to produce high standard research and generate an impact is not easy. I found that because I had limited time, building trust and creating relationships did not come easily. However, with detailed planning, good communication and transparency, adherence to internationally-accepted ethical standards, different guidelines and clear intended outcomes, common problems can be avoided and ultimately enhance the standards and implementation of research globally.

## **Methodological issues**

With the increasing interest in cross-cultural research, the need for standard and validated psychological instruments that are suitable for different cultural contexts is growing. Throughout the study, I exercised caution from reviewing the literature, composing the storyboard and vignettes as well as analysing and interpreting the data collected. Gajar (1983) noted some of the difficulties in attitudinal research include language, attitudinal measures and attitudinal biases. Many African languages do not include words that allow ‘disabled’ to be directly translated from English (Ogechi & Ruto, 2002). Each disability is named as it related to the body part that is affected, preventing disabilities such as intellectual disabilities to be classified together. In Kenya for example, the Abagusii and Nandi ethnic groups, the children are given names that describe their disability along with other clan names (Ogechi & Ruto, 2002). These names may reflect the extent to which the families and communities accept the child’s disability. Therefore, it was of paramount importance to provide a definition for all the participants in the study, however, the conceptions and understanding of this western definition may have differed among the Kenyan ethnic groups. Due to my own cultural influences, I have experienced difficulties in conceptualising diagnoses and the use of labels in my clinical practice and often consider the ramifications these may have for the clients from non-western cultures. Therefore, this has presented opportunities for me not to rely on diagnoses and labels and I have been able to unpack the client’s difficulties in a more meaningful way.

Cross-cultural research generates questions that challenge the translatability of survey questions, constructs and concepts being examined (National Research Council, 2007). This allowed me to really consider construct and item bias and whether the measures were culturally appropriate for the samples and what could be done to assess and report genuine community attitudes. This was an important process as it gave us the space and the ownership to share our thoughts about the questions and vocabulary used to avoid ethnocentric tendencies. The international partnerships did not just take into account the Kenyan sample but also the researchers (Morin and colleagues and ourselves) in the hopes of developing a good cross-cultural measure of attitudes and help contribute to the little existing research of public attitudes in Kenya and other African countries.

Furthermore, holding in mind the 2007 Kenyan post-election violence that brought ethnic animosity to the fore, I was careful not to use ethnic specific names in the vignettes. Therefore, popular Christian names were used instead to avoid influencing the participants' responses in order to get the most genuine answers. However, it is hard to ascertain if the participants' responses would have been different if the vignettes were slightly more culturally specific. Despite this, questions that were most appropriate for the sample were kept and reliability of the measure conducted.

### **Recruitment and retention**

Carrying out a longitudinal study via an online survey needed more attention than I initially thought at the beginning planning stages of the study. I assumed

that because the sample comprised of young, regular internet users, recruitment and data collection would be simple. However, to keep the study in the public's eye, promotional videos and flyers had to be uploaded frequently and gaining popular Kenyan bloggers or personalities to promote this was a challenge. This was particularly difficult during the Christmas holidays when fewer people would be accessing the survey web page, sharing the flyers or links and completing the study. Consequently, this may have been a contributing factor to incomplete data that is commonly reported in studies (Ibrahim & Molenberghs, 2009). In hindsight, I believe recruitment and retention would have been more successful if we had more local professionals, researchers and organisations promoting the study. This may have reduced the perceived distance between the researchers and the sample.

## **Dissemination**

Freemantle and Watt (1994) defined dissemination as the 'process by which target groups become aware of, receive and utilise information'. Research and evidence with effective implementation can have an impact on policy and practice, resulting in positive outcomes. However, translating findings into practical recommendations has proven to be difficult in low and middle-income countries as a direct result of ineffective dissemination (Bradley & McSherry) despite it being a key process in evidence-based practice. For example, at present, only a small proportion of published research from or about low and middle-income countries is accessible in mental health and psychiatric journals yet over 85% of the world's population live in low and middle-income countries

(Low, 2004). Therefore, the countries in which this research may be of most help and have the largest impact may not have access to these journals (Aronson, 2004) or they may not be available in their native language despite the rise in open journal access, free online networks (Aronson, 2004) and international journal partnerships.

Taking into consideration the barriers to dissemination, improving the visibility of this study's findings is important. Therefore by; (1) aiming for journal publications of the study not just in Kenya or African journals but also international databases would improve accessibility and wide distribution at little or no cost; (2) continue to share the feature film through social media and different organisations online and contact different educational institutions to share it among students. Additionally, the Kenyan and other low and middle-income governments need to make use of the recent opportunities by technology advancements for the dissemination and application of research knowledge. This would help with gathering and verifying more information, aggregating and visualising data to aid communication and decision-making and allow the public to gain and provide feedback e.g. for clinicians and health services to improve accountability and quality. Therefore, the use of these innovative digital approaches can be used to facilitate good governance and promote transparency, accountability and public participation. Finally, international collaborations may consider peer-sponsoring initiatives.

## **Personal Experiences**

I decided to carry out a project in an area in which I had limited knowledge and experience. This decision was driven by the stigma I observed growing up towards people with disabilities and mental health problems in Kenya. This project was an invaluable experience for me as an international student on the doctoral course at the University College London. It provided me with the opportunity to gain a better understanding of the condition in a Kenyan context, its implications and possible effective anti-stigma programmes.

It was a true honour and privilege to film the intervention video at the Jacaranda Workshop in Nairobi. The opportunity to witness firsthand how the lives of people with ID were affected by stigma and what they hoped would change e.g. negative societal attitudes and better opportunities was insightful. This highlighted the potential research has in making a real difference to the lives of these individuals and communities they live in. People at the Jacaranda Workshop were excited to show the public what they are capable of and what they would like others to help them with in their daily lives. I was surprised at how eager and brave they were to share their experiences and dreams despite all the neglect and abuse they may have experienced. Moreover, my close work with this group allowed me to witness the beautiful engagement of two individuals with ID, an experience that would usually be hidden from the public.

Throughout my training, I was always aware of the risk of over familiarising myself with the developed world healthcare systems that may or may not lead to inappropriate experience for practice in my home country. However, conducting

a research study that was inclusive of Kenyans gave me the opportunity to preserve links with professionals and organisations that honed different skill sets such as leadership and effective communication that are appropriate for clinical practice in Kenya and around the world. Instead of limiting employment opportunities, I believe my clinical training at the University College London has expanded my employment opportunities. For future research, more supervisors should encourage and support international trainees to carry out their research projects and placements in their home countries.

In conclusion, through the process of carrying out this research I was struck by the complexities between and within cultures and the dilemmas that present in cross cultural longitudinal studies.

## References

- Aronson, B. (2004). Improving online access to medical information for low-income countries. *New England Journal of Medicine*, 350(10), 966-968.
- Bradley, E., & McSherry, W. The Opportunities and Challenges of Disseminating Healthcare Research.
- Chetwood, J. D., Ladep, N. G., & Taylor-Robinson, S. D. (2015). Research partnerships between high and low-income countries: are international partnerships always a good thing?. *BMC medical ethics*, 16(1), 36.
- Freemantle, N., & Watt, I. (1994). Dissemination: Implementing the findings of research. *Health Information & Libraries Journal*, 11(2), 133-137.
- Gajar, A. H. (1983). The relevance of problems encountered in attitudinal research: a personal perspective. *Journal of Learning Disabilities*, 16(10), 586-587.
- Ibrahim, J. G., & Molenberghs, G. (2009). Missing data methods in longitudinal studies: a review. *Test (Madrid, Spain)*, 18(1), 1-43.
- Kisanji, J. (1995). Attitudes and beliefs about disability in Tanzania. *Innovations in developing countries for people with disabilities*, 51-70.
- Low, R. F. (2004). Galvanizing Mental Health research in low-and middle-income countries: the role of scientific journals.
- National Research Council. (2007). *International collaborations in behavioral and social sciences research: Report of a workshop*. National Academies Press.
- Ogechi, N. O., & Ruto, S. J. (2002). Portrayal of disability through personal names and proverbs in Kenya: Evidence from Ekegusii and Nandi. *Vienna Journal of African Studies*, 3, 63-82.

## **APPENDICES**

**APPENDIX 1**  
**QUALITY APPRAISAL TOOL**

## **APPENDIX 3**

### **INTELLECTUAL DISABILITY LITERACY SCALE(IDLS); Supernatural Beliefs Causal Subscale**

2. Many people experience problems such as James'. Please indicate the extent to which you agree that the following are a likely reason for problems such as James' in *anyone*, using the same scale.

1. possession by spirits	1	2	3	4	5	6	7
2. punishment for own past wrongdoings	1	2	3	4	5	6	7
3. a test from God / Allah	1	2	3	4	5	6	7

## **APPENDIX 4**

### **PROCESS QUESTIONS**

**How did you access the study?**

- Personal device (e.g. mobile phone, laptop, ipad)
- Internet café
- Education center
- Place of work
- Other

**Approximately how long did it take you to access the study?**

- Less than twenty minutes
- 20-40 minutes
- 1 hour
- I didn't complete it in one sitting

**Did you experience difficulties with the internet connectivity while completing the study?****What were the nature of these difficulties?**

- Slow connection speed
- No wifi signal
- Insufficient data package
- Other

**How did these difficulties affect your ability to: (a lot, somewhat, a little, not at all)**

- Access the study?
- Answer the questions?
- Watch the video?
- Complete the study?

**Overall what did you think about: (too long, too short, just right)**

- The length of the questions?
- The length of the video?

Overall what did you think about: (excellent, good, average, poor)

- The content of the video?
- The questions asked?

## APPENDIX 5: INTERVENTION FILM STORY BOARD

1

### Story Board

**Title of Project:** Combating Stigma: Testing an e-intervention in Kenya.

**Deadline for Video:** September 2016

**Required length of video:** 5 minutes

**Budget:**

**Shoot date/s if known:** Late July or Early September

**Shoot location/s if known:** Nairobi

**Who is your target audience:** Kenyan Internet User

**Style of Video:**

*Links to examples of video that showcase the style for this video*

# #FundamentalSDG

**Special  
Olympics**



### **Key Messages**

Aim of Video: To combat stigma and change negative attitudes by dispelling common misconceptions of Intellectual disability and promoting contact.

Message 1: Show that stigma exists in Kenya and what maintains it

Message 2: Challenge misconceptions

Message 3: Showcase abilities and dispel stereotypes

### **Theories underpinning Intervention**

Education-based approaches challenge some of the stereotypic myths about a condition and replace them with factual information (Corrigan et al., 2012; Corrigan & Fong, 2014). Within the social cognitive model, the educational approach, also known as the “demythologizing approach”, tackles the first component of stigma, i.e., ignorance (lack of knowledge), as a mechanism of change. As such, an increase in knowledge around a certain condition is believed to have an indirect effect on negative attitudes and discrimination (Corrigan et al., 2001).

Contact approaches emerged from Allport's (1956) contact hypothesis, which proposes that positive interactions between “in-group members” (i.e., those doing the stigmatizing) and “out-group members” (i.e., those being stigmatized) are capable of reducing prejudice. Intergroup contact is believed to promote prejudice reduction by simultaneously reducing intergroup anxiety (the anticipation of negative consequences for oneself due to contact with the “out-group”) and increasing empathy (the capacity to experience affect reactions to the observed experiences of “out-group members”) (Stephan & Stephan, 1985; Swart, Hewston, Christ, & Voci, 2011). Indirect contact through film promotes persuasion by creating an experiential learning situation, engendering an empathic emotional response, and encouraging inferential processes in the viewer (Stern, 1994). Indirect contact possesses the majority of the underlining dimensions that facilitate change (e.g., affective mechanisms and demonstrating similar interest).

Leventhal's (1985) common sense model proposes that the different types of information we get from authority figures, interactions with others as well as our own personal experiences, influence our perceptions, attitudes and actions towards different illnesses. He proposed 5 components that make up our representation of illnesses. These include identity (the label or name given to the condition), cause (individualist ideas of what causes the condition), Time-line (the predictive belief about how long the condition might last), consequence (the individual's belief about the impact of the condition) and curability/controllability (beliefs about where the condition can be cured or managed) Rheumatology (2007). This model will inform the structure used for the intervention.

Structure of Board

Top part of table:  Visual Illustration (Examples of what will appear on the screen)
Bottom part of table:  Script of Video (This will be said by a voiceover or a person)

**1. Identity. The label or name given to the condition and the symptoms that ‘appear’ to go with. Theory used: Educational and Contact Strategies**

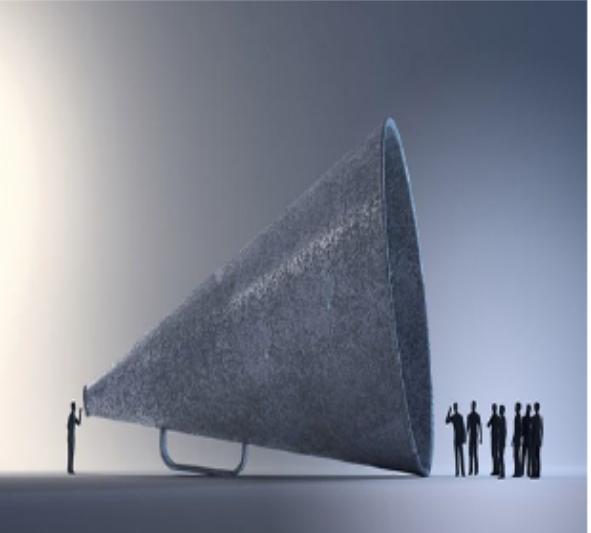
Scene 1	Scene 2 Intellectual Disability	Scene 3 Intellectual Disability
<p>During this video, the term intellectual disability (ID) will be used.</p> <p>.</p>		<p>KENYA</p> 
<p>Script: "Text shown on screen, No voice over"</p> <p>"Intellectual Disability (or ID) is a term used when a person has certain delays in their cognitive development.</p> <p>These delays can lead to difficulties understanding, learning and remembering new things. It may also affect their communication, social and self-care skills.</p> <p>A person with ID may therefore develop and learn more slowly or differently than a typically developing person.</p>	<p>Voice over: Background music begins; graphics used here if possible</p> <p>It is estimated that around 2 out of every 100 people have an intellectual disability.</p>	<p>Voice over: graphics used here if possible</p> <p>In Kenya, people with Intellectual Disabilities are sometimes called:</p> <ul style="list-style-type: none"> <li>• Mentally Retarded</li> <li>• Handicapped</li> <li>• Mjinga</li> <li>• wazimu</li> </ul> <p>Although these terms are commonly used in our society, people with Intellectual Disabilities and their families strongly reject such terms, because they allow discrimination to continue to exist.</p>

Scene 4  QUOTE	Intellectual Disability  Scene 5	Intellectual Disability  Scene 6
"Text shown on screen, No voice over"  "Language not only reflects values and beliefs held within a culture, but also powerfully shapes attitudes." - Scior	<p>Voice over: Pictures used here</p> <p>It is common for People with Intellectual disability to be seen as a symbol of shame or disgrace. A people to be hidden away.</p> <p>"In Kenya, people with Intellectual disability have been rejected and locked away by their family and community. They get less education, less stimulation and less medical care. (Bjorn, 1990)</p>	<p>Voice over: Pictures used here</p> <p>However, people with Intellectual disability have social and emotional needs similar to people in the general population- like you and me.</p> <p>"Text shown on screen, No voice over"</p> <p>Imagine a world where you are not given any opportunities to work, to be independent or have relationships because of how people see you?</p> <p>Seconds pass</p> <p>How would you feel?</p>

<p>Scene 7</p> <p style="text-align: right;">Intellectual Disability</p> 	<p>Scene 8</p> <p style="text-align: right;">Intellectual Disability</p> <div style="border: 2px solid red; padding: 10px; text-align: center;"> <h1>Causes</h1> <h1>Cure</h1> <h1>Consequences</h1> </div>
<p>Voice over:  <a href="#">Pictures used here</a></p> <p>people with Intellectual disability would love the opportunity to get a job but a large number of Kenyans think they have no place in the work environment.</p> <p>Also, they yearn to have good relationships and friendships but are often bullied and lonely.</p> <p>Like anyone else, they would love to be independent but we as a society constantly put limits on what they can or are allowed to do.</p>	<p>Voice over:</p> <p>Most negative attitudes towards people with ID are due to beliefs people hold on to about The Causes , the Cures and the Consequences.</p> <p>"Text shown on screen, No voice over"</p> <p>"Research shows that most people around the world are unsure what intellectual disability is."  - scior</p> <p>Does this stand true for people in Kenya?</p>

		<p>conditions are Down syndrome, and Fragile X syndrome.</p> <p>And the other 30% of these cases are caused by environmental factors such as <b>Complications during pregnancy</b> that leads to the baby not developing properly inside the mother as well as <b>Problems during birth</b> such as a baby not getting enough oxygen, being exposed to toxic substances or poisons, or extreme malnutrition.</p> <p>However, in about 40% of cases, the causes of intellectual disabilities are not known.</p> <p>Regardless of the cause, it is widely agreed by doctors, psychologists and other helping professionals that intellectual disability is not contagious: you can't catch an intellectual disability from anyone else. It is not caused by juju or witchcraft. It is not a type of mental illness, like depression. We also know it is not a family curse or punishment from God because with the right support, people with intellectual disabilities can learn to do many things and lead a fulfilled life.</p>
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Scene 14  Intellectual Disability	Scene 15  Intellectual Disability	Scene 15  Intellectual Disability
	<p><b>How you see us</b></p> 	<p><b>How we see ourselves</b></p> 
<b>Voice over/ Influencer:</b>  What is the impact of having an ID?	<b>Voice over/ Influencer:</b>  A large percentage of Kenyans expressed in a recent study that people with intellectual disabilities have difficulties with self-care, making and keeping friends, playing sports understanding news events and holding down a job.  But does this stand true for people with Intellectual disabilities?	<b>People with ID speak into the camera:</b> Accompanying text and pictures for capabilities mentioned.  No it does not. We can learn to do a lot of things. We may just take more time or learn differently than other people.  We can -work (Pictures/videos)  -make friendships (Pictures/videos)  -Make important decisions e.g. vote (Pictures/videos)

<p><b>Scene 15</b></p> <p>Intellectual Disability</p> 	<p><b>Scene 16</b></p> <p>Intellectual Disability</p> <p><b>Video clips of people with ID talking</b></p>
<p><b>Voice over/ Influencer:</b></p> <p><b>Our message:</b></p> <p>Culture, gender, and religion, might make our beliefs different in little ways but being born with or without an intellectual disability does not make us different from one</p>	<p><b>People with ID speak into the camera:</b></p> <p><b>Accompanying text for capabilities mentioned.</b></p> <p>So don't write us off before you get to know us.</p> <p>When you see us, these are a few things you can do to help.</p>

<p>another. We all want similar things in life, which is to be <b>free to live the life we want.</b></p>	<ul style="list-style-type: none"><li>-Be sincere</li><li>-Listen</li><li>-Make eye contact</li><li>-Don't talk too much or too quickly</li><li>-Be patient</li><li>-Be sensitive.</li><li>-Say hello (influencer, Note the famous person will now say this part).</li></ul> <p>End with a hug!</p> <p>Thank you for watching!</p> <p>Many thanks to Jacaranda Workshop, Dr Frank Njenga, Bishop Njenga for their contribution and expertise in the making of this video.</p>
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## **APPENDIX 6**

### **INTERVENTION FILM**

Intervention stigma change video can be viewed at; Intellectual Disability: Stepping Out from the Margins in Kenya -  
[https://www.youtube.com/watch?v=ZSi\\_DJxGPrs&t=15s](https://www.youtube.com/watch?v=ZSi_DJxGPrs&t=15s)

## APPENDIX 7

### Ethical Approval

UCL RESEARCH ETHICS COMMITTEE  
ACADEMIC SERVICES



26 May 2016

Dr Katrina Scior  
Research Department of Clinical, Educational and Health Psychology  
UCL

Dear Dr Scior

**Notification of Ethical Approval**

**Re: Ethics Application 8807/001: Combating stigma, Testing an e-intervention on intellectual disability in Nigeria and Kenya**

I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the REC until 30<sup>th</sup> July 2021.

Approval is subject to the following conditions.

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form': <http://ethics.grad.ucl.ac.uk/responsibilities.php>
2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator ([ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.
3. For non-serious adverse events the Chair or Vice-Chair of the Ethics Committee should again be notified via the Ethics Committee Administrator ([ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)) within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

On completion of the research you must submit a brief report of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

Yours sincerely

A black rectangular redaction box covering a signature.

Professor John Foreman  
Chair of the UCL Research Ethics Committee

Cc: Deborah Odukoya & Winfred Chege, Applicants

Academic Services, 1-19 Torrington Place (9<sup>th</sup> Floor),  
University College London  
Tel: +44 (0)20 3108 8216  
Email: [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)  
<http://ethics.grad.ucl.ac.uk/>

## **APPENDIX 8**

### **Information Sheet**

**University College London  
Department of Clinical Psychology**

Thank you for your interest in our study. The aim of this study is to understand the general public perception of personal difficulties that people face.

#### **Who is this study for?**

This study is open to all internet users aged 18 or above 18, who are Kenyan nationals or residents.

#### **What does taking part involve?**

You will be invited to watch a brief film that we hope you find interesting. You will also be asked to answer questions before and after the film. It should take no more than about 15 to 20 minutes to complete the whole study.

#### **Do I have to take part?**

No, your participation in this study is voluntary. Choosing not to take part will not disadvantage you in any way. You are also free to withdraw from the study at any time - please simply close your web browser to do so. We regret that once you have submitted your complete response, you will no longer be able to withdraw from the study.

#### **Is everything confidential and anonymous?**

Yes, no-one will know of your participation or your responses in this study, unless you tell them. All data will be securely stored and accessed only by our research team. You will have the opportunity to enter a prize draw to thank you for taking part - for this purpose we will ask for your contact details at the end of the study. Your contact details will be stored separately from your responses to the questions to ensure your anonymity. We will not pass your details to any third party.

#### **What if my internet cuts off, would I have to start again?**

No - any incomplete responses will be saved for two weeks. During this time, you can continue from where you left off, as long as you access the study from the same device. After two weeks, any incomplete responses will be deleted.

#### **Are there any risks in participating?**

The study has received ethical approval from the University College London Research Ethics Committee (Project ID Number: 8807/001). There are no known risks associated with this study. In case you should wish to discuss any of the issues raised in the film, please contact the research team who will put you in touch with local organisations in Kenya.

#### **Are there any benefits in participating?**

To show our appreciation for taking part, all participants who complete the study will stand the chance to win vouchers from EatOut Kenya or eGiftAfrica. The vouchers will be redeemable at the best restaurants and leading shopping retailers in Kenya. Twenty participants will be picked in a prize draw after data collection has ended, in early 2017.

#### **What will be done with the results?**

The results from this study will be written up for publication in academic journals and may also be shared at conferences and other events. They will also be submitted as a thesis for the clinical psychology doctorate at University College London.

#### **We thank you very much in advance for your support.**

We would be happy to address any queries or comments you may have. Please contact:

Winnie Chege: [winfred.chege.14@ucl.ac.uk](mailto:winfred.chege.14@ucl.ac.uk)

Research Supervisor contact details:

Dr Katrina Scior

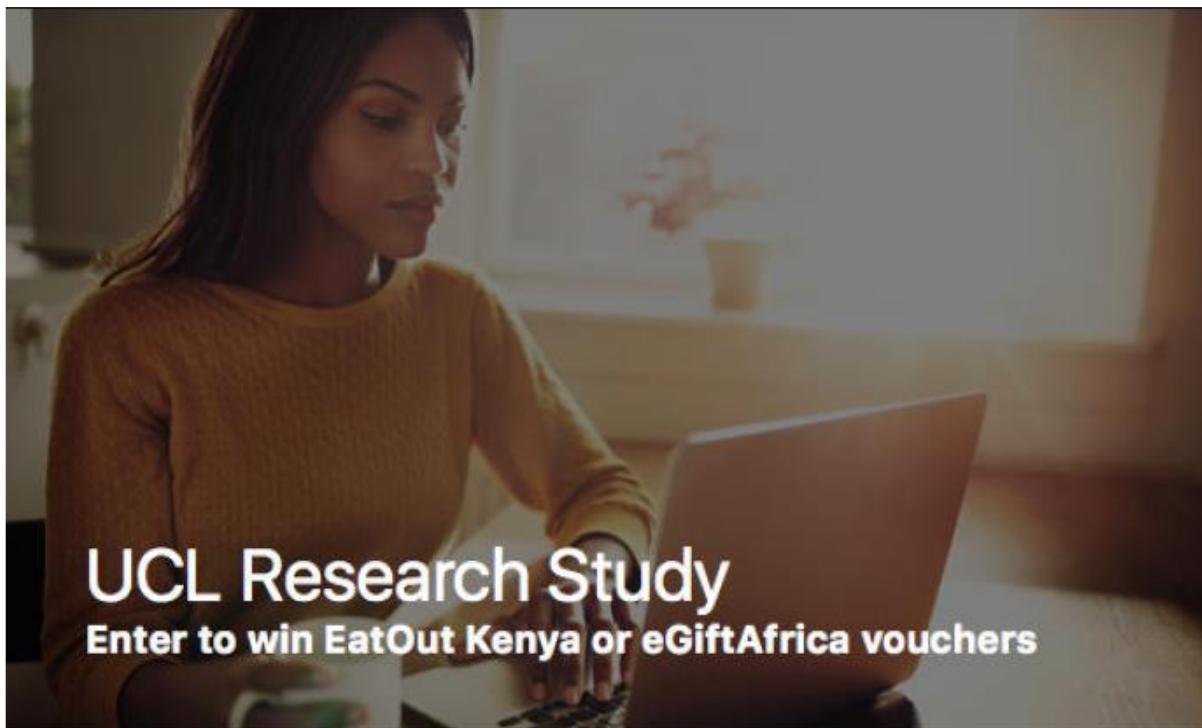
Senior Lecturer in Clinical Psychology

University College London

Email: [k.scior@ucl.ac.uk](mailto:k.scior@ucl.ac.uk)

For more information on who we are, please visit: <https://www.ucl.ac.uk/ciddr>

**APPENDIX 9**  
**STUDY FLYER**



**UCL Research Study**  
**Enter to win EatOut Kenya or eGiftAfrica vouchers**

## How to enter

Click the button below and tell us what you think about personal difficulties people face in Kenya

**ENTER TO WIN**

