# Combatting Intellectual Disability Stigma: Testing an E-Intervention with Nigerian Internet Users.

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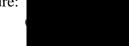
University College London

## UCL Doctorate in Clinical Psychology

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.

Signature:



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#### Overview

Volume 1 of this thesis focuses on interventions used to combat public stigma towards people with intellectual disabilities (ID) in African countries. It is presented in three parts.

Part one presents a systematic review of the types of interventions conducted in African countries to combat public stigma towards people with ID. It also critically appraises the quality of evidence reported by these initiatives. The paper concludes by identifying which interventions are likely to thrive in African settings and discussing the factors that contribute to their successful implementation. However, it points out that there remains insufficient evidence to adequately judge the efficacies of such interventions and calls for more rigorous evaluations in African settings.

Part two is a joint empirical study that investigates the efficacy of a brief digital intervention as a tool to combat public stigma towards people with ID in two countries: Nigeria and Kenya. The empirical paper within this volume looks at the Nigerian intervention. The intervention focuses on an integrated approach combining education and indirect contact through film. The paper outlines the impact of the integrated approach used, the study limitations and the implications for further research.

Part three is a critical appraisal of the work undergone in the empirical paper. Focus is given to the need for more global research within the programme and the significant relevance of this type of work.

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## **Part 1: Literature Review**

Anti-Stigma initiatives towards people with intellectual disabilities carried out in

African Countries: A systematic review

#### Abstract

**Aims:** Little is known about initiatives undertaken to combat stigma associated with intellectual disability (ID) in Africa. This review aims to identify and critically appraise such initiatives implemented in African countries.

**Methods:** Relevant studies were identified by searching electronic databases, content platforms and references of included articles, examining key journals, and consulting the publications of both experts in the field and non-profit international organisations.

**Results:** In total, 17 studies published between 1978 and 2016 were found to meet the inclusion criteria. They reported a diverse range of interventions promoting stigma reduction at multiple levels. Eleven of these studies assessed the effects of their intervention on stigma. In the case of the other six, there was either no evidence of or a lack of reporting on the evaluation process undertaken.

**Conclusion:** Resources for initiatives that aim to reduce stigma associated with ID appear to be limited, as are evaluations of the impact of respective efforts. The success of initiatives in African countries seems to be largely derived from the partnerships formed with non-government organisations (NGOs), and in some cases government bodies. Nonetheless, initiatives that target multiple levels of a community, despite limited resources, appear to be the most effective within an African context.

#### Introduction

There are large disparities between regions of the world that harbour the highest levels of stigma towards people with intellectual disabilities (ID) and regions that produce the most research/initiatives to target such stigma (McKenzie, McConkey, & Adnams, 2013; Scior et al., 2015; Townsend, 2011). Although statistics show that about 80% of people with ID live in low and middle-income countries (LMICs), most research and initiatives to combat stigma have been conducted in high-income countries (HICs, Durkin, 2002). It is therefore unsurprising that, despite increasing evidence from HICs supporting a reduction of stigma around ID, it is reported that prejudice and discrimination are alarmingly high in many LMICs (Scior et al. 2015; Scior & Werner, 2015; 2016). This holds true amongst African countries, where IDs are reported to be one of the largest impairment groupings on the continent (McKenzie et al., 2013). Despite this, the visibility within their communities of those with ID is minimal, as they remain low priority in government policies and programmes (Scior et al., 2015).

The impact of stigma on the wellbeing of people with ID has been examined in numerous studies. Compared to their disabled and non-disabled counterparts, people with ID are reported to be more likely to have their fundamental rights and freedoms denied (Scior et al. 2015). They experience higher levels of health, social and financial inequality (McKenzie et al., 2013). For example, many children with ID in African countries are reported to have high mortality rates and are known to have low school attendance (Salvador-Carulla & Garcia-Gutierrez, 2009). People with ID are also more susceptible to abuse and still widely viewed as incapable and unable to live independently or contribute to society (McKenzie et al., 2013; Scior et al. 2016).

Little is known about what is being done to narrow these gaps and improve the quality of life for people with ID living in African countries. To date, only a few studies have attempted to provide information on how the needs of people with ID are being met. Two to note are the WHO Atlas: Global Resources for Persons with Intellectual Disabilities, published in 2007 and Scior et al. Intellectual Disabilities: Raising Awareness and Combatting Stigma: A Global Review, published in 2015. The WHO Atlas sought to gather information on the presence of resources and services available to people with ID by collecting data from key informants in 147 countries, capturing 95% of the world's population. Findings from this study revealed that there are few adequate policies and legislative responses in African countries, and a scarcity of services available to care for people with ID. In general, African countries were amongst those that provided the least amount of resources (WHO, 2007). Although informative, the WHO Atlas presented limited information on efforts being taken to address such an imbalance of resources. The authors also acknowledged that in the case where efforts were identified, most of them consisted of general disability awareness campaigns and did not specifically target ID.

The global review by Scior et al. (2015) aimed to provide an overview of the range of initiatives being implemented to reduce ID stigma globally. The review collected data from key informants in 88 countries and found that, alongside other developing countries, initiatives in African countries were few and 'entirely dependent on the efforts of parent-run organisations and NGOs (Scior et al., 2015, p. 10). Most of these initiatives targeted children within educational settings and the wider community. The review provided a preliminary picture of anti-stigma efforts being implemented in Africa and those undertaking them. However, only 19 African countries, constituting just 35% of the continent, contributed data to the review.

#### Aims and Objectives

The objective of this review was to identify and critically appraise initiatives to reduce ID stigma in African countries. While the global review collected data from key informants, this review examined the relevant literature to gain an understanding of the efforts being carried out in African countries. By taking this approach, it was hoped that reviewing relevant literature would facilitate an evaluation of the quality of evidence reported by these initiatives. This was imperative given that initiatives from African countries are often considered to lack both theoretical rigour and empirical evaluation (Scior at al., 2015).

The aim of this review was twofold:

- Initiation: To identify what interventions have been initiated in African countries to raise awareness, challenge prejudice and discrimination and to ensure equal rights for people with intellectual disabilities.
- Outcome: Where available, to evaluate the quality of evidence reported for such initiatives.

#### Methods

#### Overview

A scoping search was carried out in several electronic databases (i.e. PsycINFO, Scopus, Web of Science, Eric, and CINHAL) from the 25<sup>th</sup> of July to the 5<sup>th</sup> of August 2016. This was done to identify the quantity and quality of relevant literature available. The preliminary search revealed a general scarcity of studies in line with the aims of this review. In the case where relevant publications were identified, some studies were out-dated (published over 20 years ago) and presented methodologies that were of low standards. Others were descriptive research with no mention of an evaluation process. Given these initial results, two UCL postgraduate librarians were consulted because it was unclear if these findings were a depiction of the overall quality of work coming out of Africa, due to publication bias, or both. From these consultations, the author was advised on search strategies to use in order to maximise the retrieval of relevant data (more details below). However, it was also pointed out that despite the increase of African articles in Westernised databases, the majority of these studies continue to be indexed in local or regional journals (Schemm, 2014). As such, the author was encouraged to search grey literature, in addition to main psychology databases.

Also, keeping in mind that a number of researchers (McKenzie et al., 2013; Scior et al., 2015) have questioned the quality of evidence coming out of Africa, it seemed both restrictive and counterintuitive to limit the current review to studies of high methodological standards (e.g. randomised control trials [RCTs]). It was thought that such a restriction could undermine the intended objectives of this study (i.e. to present an accurate depiction of the efforts being undertaken in African countries). As a result, studies relevant to this review were included irrespective of their methodological quality. Robertson, Emerson, Hatton and Yasamy (2012) took a similar approach when conducting a review on the efficacy of community-based rehabilitation programmes in LMICs.

In line with Hawker, Payne, Kerr, Hardey, and Powell (2002), an iterative approach was adopted to ensure a systematic way of identifying and drawing from a range of methodologies and disciplines. This process involved using early findings to guide how new sources of evidence were discovered.

#### Search Strategy

Relevant studies were identified by searching electronic databases, content platforms, key journals, and references of included articles. Publications by experts

in the field and non-profit international organisations were also examined. The search was conducted from August 20<sup>th</sup> to November 30<sup>th</sup> 2016. Details of all the places searched are provided below.

Electronic Databases: PsycINFO, Scopus, Eric and Web of Science. These databases were selected as they contained a substantial amount of African-based articles related to the aims of this review.

Content Platforms: African Online Journal and Taylor and Francis Online. These content platforms were searched because they contained journals that had been referenced within relevant articles but were not indexed in the electronic databases searched.

Journals Hand Searched: African Journal of Disability (AJOD), Journal of Intellectual Disability Research (JIDR) and Journal of Policy and Practice in Intellectual Disabilities (JPPID). Except for AJOD, both hand-searched journals are recommended (and one published) by the International Association for the Scientific Study of Intellectual and Developmental Disabilities; the only global group dedicated to the scientific study of ID. AJOD was searched because it is a journal that is often cited by experts in the field but not indexed in the electronic databases examined for this review.

Authors Searched: R. McConkey, J. Ronning, D. Nabuzoka and J. A. McKenzie. All experts researched had done substantial work in Africa regarding ID and had published key publications that informed and shaped the focus of this review.

Publications by Organisations searched: Special Olympics, Save the Children, and World Health Organisation (via African index Medicus [AIM]). These three organisations were identified in key publications as either having funded and/or partnered with locals, university bodies, or researchers to carry out initiatives in

Africa. It is important to note that despite the existence of other organisations carrying out work in Africa (e.g. Inclusion International), the search strategy used (i.e. iterative method) limited retrieval only to organisations that had been identified in relevant articles.

Reference Search: The references of all included articles were searched.

#### **Search Terms**

The author initially used the following combination of keywords to guide the search:

Table 1

Search Terms

Keyword	Synonyms		
Intellectual Disability	developmental disability, mental retardation*,		
	down syndrome		
	*Although this term is strongly frowned upon, it is		
	still a terminology used in some African countries		
Negative Attitude	social stigma, stigma, prejudice, discrimination,		
	stereotype		
Change Intervention	raise awareness, intervention, positive framing,		
	change strategies, contact, social interaction,		
	social acceptance, inclusion, anti-stigma, attitude		
	change,		
Africa	All 54 African countries listed individually		

Although some relevant studies were found with these search terms (n=28), consultation with an expert in the field (R. McConkey, personal communication, October 31, 2016) revealed that relevant initiatives in African countries may be indexed differently in Westernised databases because they use different keywords to their international counterparts, such as *community-based rehabilitation* and *parental advocacy*. As such, in order to carry out a more comprehensive search and account for the multiple ways studies might be indexed, the author then used broader search terms: (1) intellectual disability and its listed synonyms above; and (2) the names of all listed African countries. Search terms were combined using Boolean logic.

Although community-based rehabilitation and parental advocacy were not used as direct search terms, their presence in titles and abstracts were viewed as relevant key words during the extraction process. Overall, this change in search terms led to a decrease in the specificity of the search results. However, there was an increase in the number of relevant publications found. See Table 2 for the number of articles identified through each database, bibliography and grey literature search.

Table 2

Database	Number of Papers
PsycINFO	230
Scopus	342
Eric	91
Web of Science	83
African Online Journal	3
Taylor and Francis Online	7
AJOD	0
JIDR	4
JPPID	1
R. McConkey	8
J. Ronning	1
D. Nabuzoka	1
J. A. McKenzie	0
Special Olympics	0
Save the Children	5
World Health Organisation (AIM)	0
Total	775

Number of Articles Retrieved from Searched Sources

#### **Criteria of Inclusion and Exclusion**

The following criteria were used to select the relevant studies for this review:

#### Inclusion Criteria:

1. Any study or description of an initiative with a primary or secondary aim:

- a. To combat prejudice and/or raise awareness towards intellectual disabilities, including:
  - i. To reduce negative attitudes
  - ii. To promote positive perceptions
  - iii. To promote recognition of the skills and abilities of persons with intellectual disabilities as detailed in the Convention on the Rights of People with Disabilities (CRPD, 2006).
- b. To reduce discrimination, including:
  - To nurture receptiveness to the equal rights of persons with intellectual disabilities, including their rights to education and in the workplace.
  - ii. To promote full inclusion and participation of people with intellectual disabilities in their communities either by improving community participation and/or creating avenues for community integration.
  - iii. To reduce harmful practices towards people with intellectual disabilities

These initiatives must exclusively target intellectual disability or clearly include it in efforts targeting an array of other disabilities, e.g. developmental disabilities.

- 1. Target population: Any studies that meet inclusion criteria 1 and
  - a. Primarily target "stigmatisers" (that is, members of the general public or any of its constituent groups), or
  - b. Target the "stigmatised" (people with intellectual disability and their family members), with a clear secondary aim to tackle stigma (i.e. raise awareness, reduce prejudice and discrimination) among stigmatisers, which is reflected in the findings.

- 2. Document type: Peer reviewed journal articles, unpublished dissertations and reports published by NGOs.
- 3. Methodology: where available, both quantitative and qualitative studies
- 4. All initiatives must be carried out within Africa and not with the African diaspora.

Exclusion Criteria:

- 1. Studies not directly related to ID stigma were excluded:
  - a. Prevalence studies
  - b. Health conditions and public health issues
  - c. Studies related to service needs and infrastructure.
- 2. Studies with no clear definition of intellectual disability, those that focus on stigmatised individuals with an IQ above the diagnostic criteria (according to the DSM and ICD-10) for intellectual disability.

#### **Selection Process**

Of the 775 articles identified from the initial search, titles and abstracts were individually examined and articles that were not relevant to the review or duplicates were removed. The full text of the remaining 76 articles was reviewed against the aforementioned inclusion/exclusion criteria. In two cases, two or more articles described the same initiative. The articles with less comprehensive descriptions of their respective initiatives were removed. See Figure 1 for full details on the selection process.

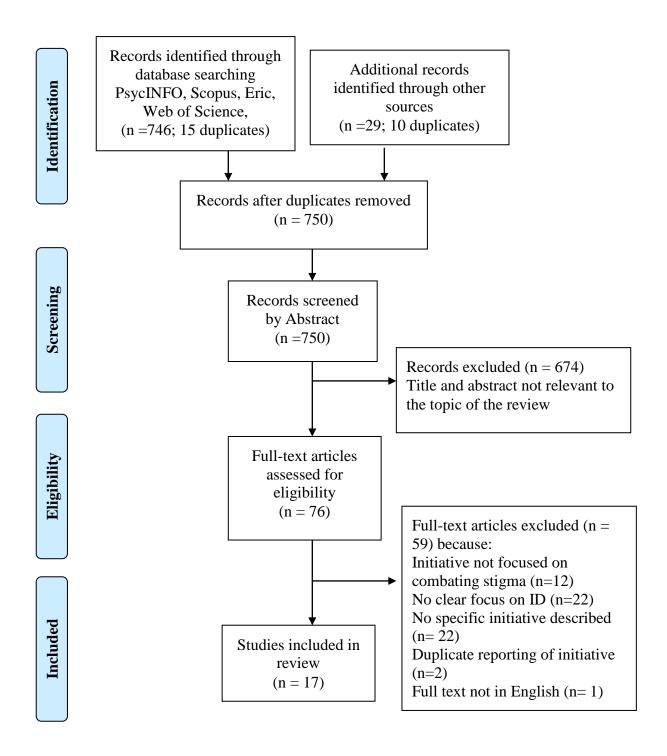


Figure 1: Flowchart of selected studies.

#### **Quality Appraisal**

In the book, *Supplementary Guidance for Inclusion of Qualitative Research in Cochrane Systematic Reviews of Interventions*, Hannes (2011) discussed the types of articles that could be sufficiently appraised by critical appraisal instruments. Using her recommendations, only 11 of the 17 articles included in the current review were suitable for quality appraisal. The other six articles (which were predominately NGO reports and descriptive studies) could not be appraised because they did not report on the types of methodologies used (e.g. sampling strategies, data collection procedures, and analyses conducted). The reporting of such information is necessary, as it 'facilitates the systematic use of critical appraisal and a more paradigmatic appraisal process' (Hannes, 2011, pp. 5). However, these articles could not be completely excluded from the current study due to their relevance in meeting the first aim of the review (i.e. initiation).

The appraisal tool designed by Hawker et al. (2002) was used to quality rate the 11 included articles. This tool was designed to appraise the reporting of studies with diverse methodologies. It includes nine items; abstract and title, introduction and aims, methods and data, sampling, data analysis, ethics and bias, results, transferability or generalisability and implications and usefulness, measured on a 4point Likert scale. Articles appraised got a total score between 10 (meaning very poor) and 40 (meaning good), see Appendix A.

The first five articles were independently double rated by the author and another research student. Where discrepancies were found, a discussion was conducted, and scores were re-evaluated accordingly. The first author then rated the other six studies independently. Subsequently, the author's supervisor, K. Scior (personal communication, March 11 2017) was consulted on how the rating process was undertaken. K. Scior then independently rated two of the 11 articles at random. Comparison showed that the two sets of ratings were similar. The overall scores were identical for both articles, however, for one article K. Scior rated one item higher and one item lower than the author, both by one point. Given that the total scores were identical and there was minimal variation between the individual items, it was agreed that the author's ratings were accurate.

#### Results

#### **Overview of Included Articles**

In total, 17 articles were included<sup>1</sup>. The articles were published between 1978 and 2016, with eight published since 2000 and, of those, six published within the last five years. The key findings of these articles are presented according to the aims of the review. The first part focuses on the characteristics of initiatives carried out in Africa to date and their reported outcomes. The second part reviews the quality of these documented outcomes. See Table 3 for an overview of all studies included.

#### **Characteristics of Interventions Initiated in African Countries**

Intervention location and initiators. The majority of the interventions were implemented in East Africa (n=11), two in North Africa, two in West Africa, one in South Africa, and one in North East Africa. Nine were initiated locally while eight were instigated by international organisations. Of the local initiators, four were academics, four were NGOs (of which two were parent-led organisations, one was volunteer driven and the other unknown), and one a church. Four of the locally driven initiatives were either fully or partially funded by international bodies (Mariga & McConkey, 1987; McConkey, Mariga, Braadland, & Mphole, 2000; Nabuzoka & Ronning, 1997; Ronning & Nabuzoka, 1993), another three were privately funded

<sup>&</sup>lt;sup>1</sup> For all included studies, only details relevant to this review were reported.

within the local community (Hassanein, 2015; Khandelwal & Workneh, 1987; MacDonald, 2012), one was government funded (Yaker, 1978), and one did not report on the source of funding (Redley, Maina, Keeling, & Pattni, 2012).

Of the eight international initiators, four were NGOs (i.e. Portage, Save the Children and UNESCO) and four were academic institutions. Six of these initiators partnered with local NGOs and/or universities to ensure the successful implementation of their initiatives (Favazza, Siperstein, Ghio, Wairimu, & Masila, 2016; Kelly, Ghalaieny & Devitt; 2012; McConkey & Templer 1987; Save the Children, 2013; UNESO, 2002; Walker, 1978). For example, one study (UNESCO, 2002), though initiated internationally, was executed by a local parent organisation. This parent organisation, with the backing of UNESCO, successfully sought the involvement of the government as well as several local and international NGOs in order to carry out the initiative.

Of the remaining two initiatives, one (McConkey, O'Toole, & Mariga, UNESCO, 1999) was conducted in partnership with the government.

# Table 3

# Overview of Studies Included in the Review

Author	Location/ Initiators	Study Focus/ Aim	Target Population	Intervention Type	Attitudinal Measurements	Outcome/findings (Relating to stigma)
Favazza, Siperstein, Ghio, Wairimu, & Masila (2016)	Kenya International Initiative, Local partnership	Create awareness of the abilities of children with ID in order to promote inclusion.	18 children with ID & other developmental disabilities and their families. 14 boys and 4 girls	Community based programme	Structured open-ended questions, focusing on participants' experience of initiative.	Increase in knowledge about disability. Encouraged enrolment of children to school "Perceived multilevel impact on inclusion of the children within their family and the wider community"
Hassanein (2015)	Egypt Local Initiative	Attitude change	18 school teachers: 9 males and 9 females	Education and Contact Workshop	Attitude Towards People with Disabilities (Alkoreity, 1992) 60 items likert type scale. Scale measured positive and negative statements about people with ID	Combination of education and contact found to be most effect in changing attitudes. Education alone found to increase knowledge but have no impact on other aspects of attitude.

Kelly, Ghalaieny & Devitt (2012)	Malawi International Initiative	Promote the rights of people with ID to community inclusion	<ul><li>10 children at risk of ID and their families.</li><li>4 community home visitors (CHVs)</li></ul>	Community based programme. Home based Pilot Study Train the trainer's model for CHVs	"Language structured questionnaires." Combination of tick box-type and Likert- scale questions. Used for participants, CHVs and their supervisors.	Increase in family and community awareness leading to more involvement from family members and neighbours. CHVs found to be crucial in the sustainability of the programme.
Khandelwal & Workneh (1987)	Ethiopia Local Initiative	Attitude change	100 medical students	Education and contact based workshop	Vignette based questionnaire. Adapted from Wig et al. (1980). 10 vignettes with a 3- point scale. Vignette focused on gravity, prognosis and its influence on marriage prospects, family life, and work.	Increase in negative attitudes. Higher perception of presence of illness and inability to get married.
MacDonald (2012)	Tanzania Local initiative	Promote the rights of people with ID to community inclusion	Children with intellectual disabilities and other comorbid disorders	Community based school	Constructivist grounded theory methodology	Greater community awareness of abilities of children with ID.

Mariga & McConkey (1987)	Zimbabwe Local initiative, International funding	Promote the rights of people with ID to community inclusion	297 children with ID and their families	Community based programme. Home based	"Simple written questionnaire" Items and content unknown.	Increase in knowledge (improving parents understanding). Created opportunities for community integration (inclusion of children in schools).
McConkey & Templer (1987)	Zimbabwe International Initiative, Local partnership	Promote awareness and recognition of skills	117 professionals: nurses, sisters, nursing aids, postgraduate trainee nurses and teachers	Education based workshop	Anonymous short questionnaire evaluating reaction to the workshop	Increase in knowledge, change in attitude.
McConkey, O'Toole, & Mariga (1999)	South Africa International Initiative	Promote inclusion of children with Intellectual disability	Teachers	Education based Workshop	N/A	Change in teacher's attitudes towards inclusive education. Increase in number of children with ID enrolled in mainstream schools.
McConkey, Mariga, Braadland, Mphole (2000)	South Africa Local initiative, International support	Change attitude towards inclusive education	21 relatives and volunteers.	Education based Workshop (Train the trainers model)	Interviews and verbal feedback Content focused on reaction to workshop.	Increase in awareness raising campaigns carried out, increase in social integration, increase in number of children enrolled in mainstream schools

Nabuzoka & Ronning (1997)	Zambia Local Initiative	Promote social acceptance	75 school children: 15 with an intellectual disability and 60 without an intellectual disability.	Contact based intervention	Original attitudes questionnaire I5 items questionnaire, 4-point scale. Scale measures acceptance of children with intellectual disability.	More positive attitude amongst exposed boys compared to their non- exposed counterparts. Less positive attitudes amongst exposed girls compared to non-exposed girls.
Redley, Maina, Keeling, & Pattni (2012)	Kenya Local initiative	Promote rights of people with ID to vote and support them in voting.	Government, local community, people with ID and their families	Court Order, Education based awareness raising campaigns through media and events	N/A	Led to the ratification in the Kenyan constitution, allowing people with ID to vote. Resulted in over 600 people with ID voting in the 2007 election and a further 1.5million registered to vote in future elections.
Ronning & Nabuzoka (1993)	Zambia Local Initiative	Promote social interaction between children with ID and their non-disabled peers.	17 school children: 8 with an ID and 9 without ID.	Contact based Intervention (Social skills, play skills and special friends training)	Measure of Social interaction: Modified observational system developed by Strain, Shores & Kerr (1976) Sociometric Measure: Combination of the peer-nomination and peer-rating procedures Connolly, 1983)	Increase in social interaction of children with ID in both the experimental and natural situations. Positive interaction was highest in special friend condition. Non-disabled children gave their disabled counterpart higher ratings during the special friend condition

Save the Children (2012)	Ethiopia International initiative, Local partnership	Increase awareness of ID in the community	People with ID, their families, the community and the government.	Community support programme	N/A	Increase in knowledge, rights to education recognised and acted upon, increase interactions with peers
UNESCO (1998)	Burkina Faso International initiative but Locally driven	To inform national policy of inclusive education and equip teacher and schools to promote and implement inclusion	100 children with disabilities (ID explicitly included)	Community support programme	N/A	'Created wider awareness throughout the basic education system, as well as the civic community.' Increased acceptance of educational inclusion.
UNESCO (2002)	Mauritius International Initiative, Local partnership	Increase awareness and promote equal rights to education for children with ID	Children with ID and their families, teachers, education authorities and the general community	Community support programme (Use of media outlets)	N/A	Created favourable perception of inclusion, promoted the rights of children to education. Increased knowledge of the principles of inclusion.

Walker (1978)	Ghana International initiative,	Attitude change	<ul><li>59 Students,</li><li>education</li><li>major.</li><li>30 students in</li><li>experimental;</li><li>29 students in</li><li>control group</li></ul>	Education based curriculum	Two Adapted questionnaires from Siller, Ferguson, Vann, Holland (1969). Each scale contained 68 items employing a Thruston type format (Kerlinger, 1973). Scale measured statements about intellectual disability as well as other disabilities.	More favourable attitudes towards people with ID in the experimental group. However, no overall change in attitudes towards people with disability as a whole.
Yaker (1978)	Algeria Local initiative	Community integration	Children with ID	Community support programme	Qualitative Study Descriptive case study	N/A

Note: For studies with a secondary aim to combat stigma, only the sections relevant to this review were reported for each respective study.

Aims, target population and types of initiative. The different initiatives identified in this review were categorised using the multilevel model by Cook, Purdie-Vaughns, Meyer, and Busch (2014), as recommended by Scior and Werner (2015) as a structured way to design and evaluate anti-stigma interventions. It categorises interventions into three main levels based on the "what" and "who" of the study. The three levels are intrapersonal (interventions focusing on the stigmatised and aiming to help them cope with the consequences of stigma), interpersonal (interventions focusing on the interaction between those who are stigmatised and the stigmatisers) and structural (interventions that address systemic influences that give rise to stigma) (Scior & Werner, 2015).

*Intrapersonal level.* Several interventions (n=5) targeted stigma at an intrapersonal level, focusing initiatives on children with ID and their families. The majority of children targeted were between the ages of 1 to 13 years old. However, two interventions (MacDonald, 2012; Mariga & McConkey, 1987) also included adolescents and young adults (maximum age 25). All initiatives at this level had a secondary aim to increase the potential for community integration and social inclusion of people with ID. This was done by facilitating an increase in their levels of development in an attempt to dispel community misconceptions around the abilities of people with ID. Initiatives carried out at this level were all community rehabilitation programmes/schools. Some were pilot studies (Favazza et al., 2016; Kelly et al., 2012; Mariga & McConkey, 1987) while others had been established in the community for a number of years (MacDonald, 2012; Yaker, 1978).

The model of delivery for the community-based programmes differed. For example, two were home-based and staff-developed programmes implementing

developmental goals<sup>2</sup> for children with ID in their communities with the expectation of facilitating family and community acceptance and support (Kelly et al., 2012; Mariga & McConkey 1987). Another programme constituted of several neighbourhood centres that each enrolled up to 40 children with ID at a time and provided 'apprenticeships' in daily living, education about the environment, and activities that developed mental and physical coordination (e.g. handicrafts) (Yaker, 1978).

*Interpersonal level.* Most of the initiatives (n=8) combatted stigma at an interpersonal level. Initiatives at this level targeted different groups in the community based on their academic pursuits, professional roles and/or likely contact with people with ID. Some interventions focused primarily on potential stigmatisers. Two intervention (Khandelwal & Workneh, 1987; Walker, 1987) targeted students in the field of medicine and education, two were directed towards schoolteachers (Hassanein, 2015; McConkey et al., 1999), and two (McConkey et al., 1987; 2000) focused on a range of professionals (nurses, social workers, teachers, nursing aides) most likely to come in contact with children with ID and their relatives. Another two focused on the interaction between the stigmatised and the stigmatisers: children with and without ID ranging in age from 8 to 12 years (Nabuzoka & Ronning, 1997; Ronning & Nabuzoka 1993).

The aims of initiatives at this level varied. Three interventions (McConkey et al., 1987; 1999; 2000) set out to nurture and promote equal rights for people with ID; two aimed to promote social integration (Nabuzoka & Ronning, 1997; Ronning & Nabuzoka 1993); and three focused explicitly on changing attitudes (Hassanein, 2015; Khandelwal & Workneh, 1987; Walker, 1978).

 $<sup>^2\,</sup>$  Developmental goals were in the areas of motor, cognition, language, socialisation, nutrition, health and self-help

In terms of the strategies used to meet these aims, the majority of interventions (n= 6) carried out education-based and/or contact-based workshops or modules and a few (n=2) carried out purely contact based interventions. The content of workshops included screening for ID, offering information on the causes and effects of ID, emphasising abilities and methods by which to nurture strengths, dispelling misconceptions and highlighting discrimination.

*Structural level.* There were four initiatives carried out on the structural level. All four took a multi-level approach, targeting people with ID, relatives, the community and the government (Redley et al., 2012; Save the Children, 2012; UNESCO, 1999; 2002). The aims of these initiatives were to reduce discrimination at a macro level as well as to increase awareness.

In terms of the approaches used to meet these aims, one initiative, which was conducted by a local NGO, sought a court order against the government regarding the rights of people with ID to vote (Redley et al., 2012). Upon receiving the court ruling in their favour, this NGO took additional actions to ensure the ruling was actualised by training over 600 "human readers" to assist people with ID to vote, and ran an 18-day campaign to create awareness of people with ID's right to vote.

The other three initiatives were community-based programmes focused on raising awareness through one or more of the following goals: (1) initiating community meetings and running media campaigns; (2) facilitating informationbased training for professionals; (3) carrying out needs assessments with parents; (4) providing support to children with ID through skills development; and (5) negotiating with government and schools to increase the number of children with ID in mainstream schools (Save the Children, 2012; UNESCO, 1999; 2002).

**Duration of interventions.** The duration of the initiatives varied based on the model of delivery used. Education-based and integrative (i.e. education and contact) workshops/modules (n=7) were conducted for a minimum of two days up to a maximum of five months, with curriculum-based workshops at the higher end of that time scale. Purely contact interventions (n=2) ranged from a period of six months to a year. Pilot studies for community-based programme (n=2) operated for a minimum of eight months to a year. However, for fully running initiatives at the time of evaluation (n=5), all had been operating for a minimum of four years. The initiative that sought a court case, took five years to obtain a ruling (Redley et al., 2012). The duration of one initiative on the structural level (Save the Children, 2012) was not reported.

#### **Outcome of Interventions**

*Intrapersonal level.* Except for one, interventions at the intrapersonal level reported an increase in knowledge/awareness amongst relatives, professionals and the community with respect to the abilities and capabilities of people with ID (Favazza et al., 2016; MacDonald, 2012), and factual knowledge on their condition (Kelly et al., 2012; Mariga & McConkey, 1987). There was also a general increase across studies in caregivers' abilities to support and care for children with ID.

Studies also reported a link between the increase in knowledge/awareness and behavioural change. Three studies reported an increase in community inclusion and acceptance. Amongst several changes, two reported enrolment in schools for children with ID who had previously not attended (Kelly et al., 2012; Favazza et al., 2016) and one reported a change in status, with people with ID being seen as contributing members of society (MacDonald, 2012). One study (Yaker, 1978) did not report any specific outcomes.

*Interpersonal level.* The majority of interventions (n=6) at this level reported a shift in attitudes amongst different members of the community. However, one study (Khandelwal & Workneh, 1987) found that following an integrated approach of education and contact strategies, there was an increase in negative attitudes towards people with ID, with students holding higher perceptions of the presence of illness and an inability to get married. Another study (Walker, 1978) reported that there was no significant change in attitudes following an initiative towards people with disabilities as a whole. However, looking specifically at people with ID, the author found that people in the experimental condition held more favourable attitudes.

As for the other six studies, attitude was operationalised differently. Two studies focused on the change in social acceptance and integration (Nabuzoka & Ronning, 1997; Ronning & Nabuzoka 1993), two on reception and willingness to include in the community (McConkey et al., 2000; McConkey et al., 1999); one on increasing awareness (McConkey et al., 1987) and one on changes in beliefs concerning social interaction, education and training, characteristics and values (Hassanein, 2015).

*Structural level.* Initiatives at this level led to an acknowledgement and implementation of equal rights for people with ID. Three of these initiatives created a greater emphasis on the right to equal education, resulting in an increase in favourable perceptions of inclusion, school enrolment, and/or attitudinal change amongst teachers and peers (Save the Children, 2012; UNESCO, 1999; UNESCO, 2002). The other initiative (Redley et al., 2012) led to ratification of the Kenyan constitution allowing people with ID to vote and resulting in over 600 adults with ID voting in the 2007 election.

**Impact of intervention.** Only 11 studies reported on the impact of their initiatives. However, impact was quantified differently by these studies and, in some cases, was dependent on the intervention level targeted. Some of the studies reported on how their initiatives permitted dialogues and created partnerships with government units, health centres, and universities which the authors viewed as an important prerequisite for more work to be done (UNESCO, 1999; UNESCO, 2002; Save the Children, 2012). Others discussed how their initiatives had encouraged ongoing training that they were willing to provide or other educational bodies were willing to incorporate into their training (Favazza et al., 2016; McConkey & Templer, 1987; McConkey et al., 1999; 2000).

Two studies mentioned an expansion of their initiatives to other parts of the country due to the outcomes received from their initiatives (Mariga & McConkey, 1987; Yaker, 1978). One had a direct impact on government policies, leading to a change in Kenya's constitution (Redley et al., 2012). MacDonald (2012) reported that, as a result of the initiative, two students with ID became recognisable adults able to earn money and contribute to their families. However, there was no mention about how this impact was measured or verified.

#### **Quality of Findings**

Using the Hawker et al. (2002) appraisal rating, the quality of the 11 articles appraised varied from poor to good. The overall rating for four articles fell within 20 to 25 (borderline to poor quality), one was rated between 25-28 (fair quality) and six scored 30 or above (good quality). Except for one, all articles provided clear details on the implications and usefulness of their findings. In addition, the generalisability of the majority of the articles appraised was of fair to good quality. A majority (n=7) scored poorly on ethics and bias, either not mentioning these issues or briefly touching on them. One major weakness of both the fair and poor quality articles was in the reporting of the data analysis used, which lacked sufficient rigour. The strength of the good quality articles was in the appropriateness of the methodology used and the clarity in which the studies' processes and findings were reported. See Table 4 for details of studies' quality appraisal.

# Table 4

# Quality Appraisal of Relevant Articles

Authors	Methodological Items (0-4)									Overall score
	Abstract & title	Intro& aim	Method & data	Sampling	Data Analysis	Ethics & Bias	Findings & Results	Transferability /generalisability	Implication & usefulness	(Total=36)
Favazza et al., (2016)	4	3	3	3	2	3	3	3	4	28
Hassanein (2015)	4	4	3	3	3	2	4	3	4	30
Kelly et al., (2012)	4	4	3	3	3	4	4	3	4	32
(2012) Khandelwal & Workneh (1987)	3	2	3	2	2	1	3	2	2	20
MacDonald (2012)	4	4	4	4	4	3	3	3	3	32
Mariga & McConkey (1987)	3	3	2	4	2	2	2	3	3	24
McConkey et al., (1987)	1	2	3	2	2	1	2	2	3	18
McConkey et al.	. 3	2	3	3	1	1	3	3	4	22
Nabuzoka & Ronning (1997)	4	3	3	3	4	2	4	3	4	30
Ronning & Nabuzoka (1993)	4	4	4	3	4	2	4	3	4	32
Walker (1978)	4	4	4	4	4	3	4	4	4	35

The following section expands on three of the nine items appraised to further review the quality of outcomes reported by these articles. It specifically focuses on the logical structure of these articles by evaluating their respective descriptions of the following sections: methods, sampling and data analysis. Given that quantitative and qualitative studies present empirical data differently, studies were divided based on the methods undertaken. Of the 11 articles, two were qualitative while nine were quantitative studies.

**Quality of qualitative outcomes reported.** The concepts of validity and reliability require adapting when assessing qualitative studies. As such, the two qualitative studies were appraised in terms of the following dimensions suggested by Elliott, Fischer and Rennie (1999):

*Disclosure of perspective.* Of the two articles, only MacDonald (2012) provided a detailed account of any personal characteristics of the researcher that may have influenced how the data was collected and analysed. McConkey et al. (2000), on the other hand, used multiple methods of verbal interviewing to evaluate their findings, each time with a different set of evaluators. The authors briefly mentioned a few characteristics of some of the evaluators (i.e. professional/personal role) on one occasion.

*Grounding interpretation in data.* The amount of data presented to demonstrate the conclusions reached differed between both articles. For McConkey et al. (2000), the data provided to ascertain the effects reported was limited, thus creating doubts regarding their conclusions. Sources of potential weakness included limited direct quotation from participants, and a lack of rigour in analysing the data (e.g. the absence of a multiple reading process). However, the authors did acknowledge alterative explanations for changes observed, stating that external factors outside the programme (e.g. the presence of local branches) could have accounted for some of the changes observed, although, the 'how' of these external factors was not discussed.

On the other hand, MacDonald (2012) provided a clear process of how and what data were collected, made direct links between data and conclusions, acknowledged uncertainties (differentiating facts from interpretation) and presented direct quotations from participants in support of any findings. The authors thoroughly demonstrated the use of the multiple reading processes, however, the quotations included in the results were not fully representative of all those interviewed.

*Coherence of interpretative framework.* Both articles presented results in a logically coherent structure. MacDonald (2012) presented results based on the themes developed and McConkey et al. (2000) reported findings based on the different sources used to collect data. However, as mentioned above, only the former presented the data in an integrative manner.

*Credibility Check.* Only MacDonald (2012) carried out thorough procedures to assure its credibility. The author used the following techniques: (1) in-depth interviews and triangulation of interviews; (2) observation and documents; and (3) member checks and peer debriefing. McConkey et al. (2000) made no mention of credibility.

*Sampling Strategies.* Both articles reported sufficient information regarding the sampling strategies used. They both provided details on the demographics of participants, how they were recruited, and why they were targeted.

**Quality of quantitative studies.** There were nine quantitative studies assessed. Four of these studies used a post-test only design (Favazza et al., 2016;

Kelly et al., 2012; Mariga et al., 1987; McConkey et al., 1987) to evaluate the impact of their interventions on stigma change. Of these four, three evaluated their interventions by collecting data from participants post intervention (Favazza et al., 2016; Mariga et al., 1987; McConkey et al., 1987). However, one study (Kelly et al, 2012) also collected data from staff administering the intervention and their supervisors. Given that all four studies were pilot studies, the researchers' chosen method of evaluation appeared appropriate for the generation of hypotheses concerning causation (Booth, Papaioannou, & Sutton, 2012).

One major limitation of this design is that it is insufficient for making causal inferences (Booth et al., 2012). As such, this increases the risk that the outcomes reported by these interventions may have been due to other factors outside the intervention itself. However, Kelly et al. (2012) controlled for this risk by collecting data from multiple sources. Doing so, created an avenue to compare effects to potential causes (Booth et al., 2012).

Khandelwal & Workneh, (1987) used a one-group pretest-posttest design. The main aim of the study was to measure the effectiveness of an initiative in changing attitudes. Although this design allowed for a direct estimate of change over time, causation could not be inferred, which is in contrast with what the study aimed to do. It should be noted that the authors mentioned that a baseline measure of the participants' attitudes was collected in another study. However, these findings were not presented. There were several threats to validity identified from the study design, including maturation trends, interfering events and confounding variables. For example, participants were exposed only to people with ID presenting at an outpatient service. This could have potentially skewed the representation of the latter group, who may have had a higher presence of illnesses. As such, this served as a

possible confounding variable and may explain why the article reported less favourable attitudes towards people with ID following the initiative.

Walker (1987) used a non-equivalent control group pretest-posttest design. The presence of a control group helped to rule out the aforementioned threats to internal validity, thus strengthening the likelihood that the effects reported by this study were attributable to the initiatives carried out (Booth et al., 2012). Another study (Nabuzoka & Ronning, 1997) used a non-equivalent control group posttestonly design. The presence of a control group constituted a strength of the study. However, no direct pre-post change could be estimated given that no baseline measures were taken. In addition, both studies employed a non-randomised sample, meaning that the groups may have systematically differed in ways other than the manipulation of the independent variables (i.e. initiatives) (Booth et al., 2012). The issue of an uncontrolled selection of participants presents threats to both the internal and external validity of these studies. Only one study (Nabuzoka & Ronning, 1997) addressed this by examining the interaction of exposure to the intervention and gender effects but not other participant characteristics.

Another study (Ronning & Nabuzoka,1993) used an interrupted time-series multiple baseline design. The authors used a single case design in which participants served as their own control. The strength of this evaluative method is that it allows for both intra-participant and inter-participant analysis, which helps to identify causal influences in a valid and reliable way. Two main threats to this study were multiple intervention interference (i.e. carryover effects between treatments), and reactive effects of the experimental arrangement (i.e. Hawthorne effect). The authors accounted for these threats by spreading the interventions over a period of almost a

year and studying the impact of each intervention in two situations to examine generalisation effects.

The last study (Hassanein, 2015) utilised a randomised experimental design. This evaluative method has all the strengths of the previously mentioned research designs while addressing their flaws. Indeed, randomised control trials (RCTs) reduce the likelihood of selection bias (Booth et al., 2012). However, the low sample size of this study (n=18) prompts concerns regarding its external validity and appropriateness for detecting meaningful effects. The authors acknowledged this limitation and called for efforts directed towards replication.

Overall, there were one or more potential threats to all the studies assessed. Although some authors acknowledged these flaws, only a few accounted for them and for the most part not in a satisfactory manner. These flaws raise questions concerning the validity and reliability of the initiatives used and weakens the possibility that changes observed were mainly due to the initiatives provided.

**Practicalities of designs.** Of the 11 assessed, three articles reported that the practicalities of implementing a more rigorous study were restricted by a lack of resources and time. Two studies (Favazza et al., 2016; Walker, 1978) intended to carry out randomised sampling, however, obtaining the required sample size proved difficult, resulting in both studies settling for non-probability samples. Regarding the other study (Ronning & Nabuzoka 1993), although they were aware of the potential flaws of their research design, the authors reported that resources and time constraints prevented them from selecting a counterbalanced design.

## Discussion

This systematic review identified 17 articles with reports of initiatives being undertaken in Africa to combat stigma. The interventions included were carried out

at multiple levels, ranging from the intrapersonal (i.e. focusing on those with ID) to the structural level (i.e. targeting social forces and institutions), though the bulk of interventions were conducted on the interpersonal level. For interventions that targeted stigmatisers, participants differed in age, gender, profession, nature of relationship and prior contact with people with ID. However, the majority of these interventions aimed at improving the quality of life for children with ID while the stigma facing their adult counterparts received very little attention. This is an area for future initiatives and research.

About 47% of initiatives used community-based interventions as a way to combat stigma, while 52% utilised education based and/or contact based approaches. The outcomes from these initiatives reported changes on one or more of the three levels of stigma. For example, some interventions led to the actualisation of the rights of people with ID, as it pertained to getting an education and voting while others led to an increase in awareness of the capabilities of people with ID. However, the magnitude of change being attributed to the reported initiatives are questionable given: (1) the presence of methodological flaws identified in the majority of studies appraised and (2) the absence of a clear methodological process for another six studies that could not be appraised. The quality of their outcomes thus remains unknown.

Furthermore, despite an overarching theme within all included articles of combating stigma, there were notable variations in how this construct was defined and measured within each study. While some studies reported an increase in knowledge as evidence of attitude change, others presented knowledge and attitudes as two distinct components of change. However, according to Corrigan and Watson (2002), having the knowledge of a set of stereotypes does not necessarily imply

endorsements of these stereotypes. People who are prejudiced (i.e., hold negative attitudes) hold these stereotypical beliefs along with a negative evaluative component that results in an emotional response such as anger or fear (Corrigan & Watson, 2002). These negative attitudes then lead to discrimination. The term "stigma" consists of three components (lack of knowledge, prejudice/attitude, discrimination) that need to be individually targeted to affect an overarching stigma change (Scior et al., 2015; Scior & Werner, 2015). Targeting one component does not necessarily imply change in the other two components. As such, despite attempts to combat stigma, some of the studies included in this review were only able to increase knowledge at best, failing to shift attitudes or change behaviours.

### Anti-stigma Interventions Conducted in African Countries

Similar to other studies (McConkey, Kahonde, & McKenzie, 2016; McKenzie et al., 2013; Scior et al., 2015), this review found that families, local organisations and NGOs remain the main providers of anti-stigma initiatives in Africa. Having said that, the success of the majority of initiatives reviewed was in the multiple partnerships formed between local-to-local and local-to-international organisations. Although governments did not develop any of these initiatives, their involvement was vital to the successful implementation of some of the work undertaken (UNESCO 1999; 2002). These findings were also identified by Scior et al. (2015) who went on to recommend the need for more collaboration between governments and NGOs for the successful implementation of anti-stigma interventions. Indeed, this may present a viable avenue for more anti-stigma work, i.e. partnerships between governments and dedicated local organisations that are invested in the success of these initiatives. On the interpersonal level, contact and/or educational-based approaches were most commonly used to combat stigma, which is consistent with findings from the wider ID literature (Scior & Werner, 2016). However, despite evidence showing that educational and contact approaches are most effective when combined (Corrigan, Morris, Michaels, Rafacz, and Rüsch, 2012; Scior & Werner, 2015), standalone educational approaches were the most used strategy in this review in comparison to both contact based and integrated approaches. One explanation for this preference in African settings may be due to the implementation efficiency of educational strategies in terms of time and resources. In some studies (McConkey, 1987; 1999; 2000), using an educational approach meant that printed materials and films could be used to compensate for the lack of manpower/resources required in developing and maintaining their initiatives.

Alternatively, given that the majority of studies that used this approach were undertaken on or before the year 2000, another explanation could be that the evidence of a combined approach was less established at the time. Although, one could argue that the knowledge of contact approaches (i.e. contact hypothesis by Allport; 1954) precedes all publications reviewed in this study, and as such, should have been the preferred choice against educational approaches. This is because contact based approaches have been shown to demonstrate more significant and sustainable change when compared to the latter approach (Corrigan et al., 2012).

However, within an African context, committing resources and evaluation to contact approaches may be perceived as less efficient due to the difficulties of providing and ensuring the quality of direct contact. Indeed, of the five studies that attempted to incorporate interpersonal contact in their anti-stigma initiatives, two

studies reported less positive attitudes from participants following their contact with people with ID (Khandelwal & Workneh, 1987; Nabuzoka & Ronning, 1997).

Alternatively, indirect contact via film has been identified as a viable way to control for some of the disadvantages of direct contact (Stern, 1994). However, none of the interventions reviewed made mention of or attempted this approach. Furthermore, combining education and indirect contact approaches has been found to be most useful, given that it combines the benefits of both approaches (Scior & Werner, 2016; Walker & Scior, 2013). This integrated approach may therefore compensate for some of the resource limitations identified by researchers undertaking initiatives in African settings, thus highlights a promising area for future research.

Community based rehabilitation programmes (CBRs), were found to be another effective method of reducing public stigma. Amongst the interventions reviewed, these programmes had a broader reach and in some cases, were more likely to report change in all three dimensions of stigma (e.g. Save the Children, 2012; UNESCO 1999; 2002). Indeed, the benefits of giving people with ID access to rehabilitation in their own communities have been highlighted by a number of researchers. For example, in their review, McConkey et al. (2016) discussed how initiatives that encourage the presence and participation of people with ID, create an opportunity for more visibility and contact in their community. Furthermore, acceptance and status in African countries has been linked to one's ability to contribute to the society (McDonald, 2012). As such, CBRs can be said to help facilitate an increase in the levels of development for people with ID, which in turn increases their likelihood to be better integrated within African society.

However, it is important to note that in this review, CBRs were identified as

interventions undertaken at both the intrapersonal and structural levels. Interestingly, this review found that the level in which the interventions were carried out influenced the extent of their reported impact. While CBR interventions at the intrapersonal level predominately reported change on an individual level (i.e. enrolment of children with ID in schools) and the surrounding community (e.g. increase in acceptance of people with ID within their neighbourhoods), CBRs on the structural level reported more extensive impact on social institutions and polices in addition to the outcomes found at the intrapersonal level. One explanation for this is that CBRs on the structural level were more likely to use multiple delivery methods; i.e. using media campaigns, running multiple events in the community, and identifying and targeting drivers of attitude change within the community.

All in all, these findings are in line with other publications that have discussed the multifaceted nature of CBRs (International Labour Office, 2004; World Health Organization 2003). According to Robertson et al. (2012), CBRs are now recognised as a "strategy for (re)habilitation, equalisation of opportunity, poverty reduction and the social inclusion of people with disabilities" (p. 143). CBRs have also been recommended in other studies as a way to advance the welfare of people with ID in LMIC (Einfeld et al., 2012). As such, they present as a viable tool to combat stigma in an African setting. More research on this approach should be encouraged.

# **Quality of Evidence Reported**

The search strategy used revealed that anti-stigma initiatives in African settings are presented in a diverse manner within the body of literature. This not only influenced how and what was reported about the initiatives included in this review but also limited the evidence available to ascertain the quality of their effects. Indeed, a number of the initiatives included were presented in organisational reports, case studies or descriptive articles, as opposed to the standard efficacy/effectiveness studies that are specifically designed to evaluate interventions. Robertson et al. (2012) reported similar findings in his review of CBR interventions in LMICs. The authors found that for the majority of studies reviewed, their evaluations tended to describe practice (i.e. process evaluations) rather than the effectiveness of practice (i.e. impact evaluations). However, rather than excluding these non-efficacy studies from the current review, they were viewed as containing viable sources of knowledge that could broaden our understanding of a relatively scarce area of research. Indeed, these articles provided a more comprehensive picture of the kinds of structural level interventions that have taken place in Africa, which would have been missed if excluded (e.g. Redley et al., 2012; UNESCO, 1998; 2002). Nevertheless, the need for more methodologically sound research in African studies warrants more attention in future research.

Given the diversity of studies included in this review, it was no surprise that the quality of the studies appraised varied. For one, the time frame in which these initiatives were carried out was spread across 29 years. Within this time, the body of literature has not only progressed but the expected standard of studies has also changed. Indeed, the majority of the studies that scored higher on the quality appraisal tool were published from 2012 onwards. Having said that, the study with the highest quality rating was published in 1978. It was a dissertation from a wellknown academic institution, which may have required a high standard of methodological rigour (Walker, 1978).

Nevertheless, this is not to say that high-quality research cannot come out of Africa. Scior et al. (2015) stated, at the time of their review, that there was no

evidence of an RCT being conducted in less developed countries such as those in Africa. However, this review identified one recent RCT conducted from Egypt (Hassanein, 2015). Although promising, other researchers (Sharma, 2007) have suggested that striving for high standards of methodological rigour in developing countries may be impractical for reasons such as 'a lack of baseline data, the undesirability of having controls in community settings and a lack of personnel with training in quantitative methods and statistics" (Robertson et al., 2012, p. 151). Speaking specifically about CBRs, Sharma (2004) went on to recommend that an integration of qualitative and quantitative methods may offer the best form of evaluation in LMICs.

Overall, this review found that in African settings, the use of community based programmes initiated through multiple delivery methods and partnerships can be an effective way to combat stigma. However, the quality of outcomes reported for the majority of these CBRs (especially on the structural level) remains unknown. Across all initiatives, methodological rigour continues to be an issue in how interventions are evaluated, but the presence of an RCT may suggest a promising change in how future studies are conducted. Also, the combination of indirect contact and educational approaches is an anti-stigma approach that has not received much attention in Africa but could potentially account for some of the limitations that arise when trying to run an intervention that is both time and resource-efficient, sustainable and has a wide reach.

# Limitations

Despite attempts to carry out a systematic review of the literature, there were several potential sources of bias in this review that should be acknowledged. First, only one researcher carried out the selection process. Although studies were rated

against the inclusion/exclusion criteria, the absence of multiple raters threatens the credibility of the process. Also, given that there was only one RCT article included in this review, the studies reviewed may be misleading and may not contribute greatly to evidence based practice.

# Implications

The success of initiatives in African countries appears to be based on the practicality of their designs and the partnerships to which they have led. Initiatives that can be carried out with limited resources yet target multiple levels of the community appear to be the most effective. Also, a need to focus on the impact of stigma on adults with ID warrants more attention in African settings. These factors should be considered when developing initiatives in African countries.

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# **Paper 2: Empirical Paper**

Combatting Intellectual Disability Stigma: Testing an E-Intervention with Nigerian Internet Users.

#### Abstract

**Aims:** This study aimed to test the impact of an e-intervention focused on an integrative approach of education and indirect contact through film as a tool to combat stigma towards people with intellectual disabilities in Nigeria. It also aimed to assess baseline attitudes towards ID among a subset of Nigerian Internet users and explore the impact of demographic variables and contact on attitudes.

**Methods:** A total of 571 participants were randomly allocated to watch either the intervention or control film. Data were collected at three time points: baseline, immediately post intervention and at one-month follow-up. All three dimensions of stigma: knowledge, prejudice and discrimination were targeted and assessed. Socio-demographic information and process variables (appropriateness, acceptability of the intervention and barriers to implementation of the study) were also collected.

**Results:** The findings indicate that baseline attitudes within a subset of Nigerian internet users are generally positive. The use of an integrated approach was found to have a small to medium size positive effect on all dimensions of attitudes except on Knowledge of Causes. Effects were maintained at follow-up.

**Conclusion:** The findings from this study support the evidence of an integrated approach to combat intellectual disability stigma and the use of the internet as an appropriate platform to deliver these interventions in Nigeria. However, the generalisability of this study needs to be tested with other sections of the population.

## Introduction

Stigma is an overarching term that contains the following three elements: problems of knowledge (ignorance), problems of attitude (prejudice), and problems of behaviour (discrimination) (Thornicroft, Brohan, Rose, Sartorius & Leese, 2009). A lack of knowledge provokes inferences of undesirable stereotypes about a person or group. When others endorse these stereotypes, this elicits prejudice, i.e., negative thoughts and emotions such as anger, anxiety, and hostility (Scior & Werner, 2015; Thornicroft et al., 2009). It also elicits a negative behavioural response, discrimination. Discrimination has been linked to acts of rejection and avoidance and has often resulted in a range of detrimental consequences for those stigmatised including a diminished sense of self and self-efficacy on an individual level to reduced access to employment, healthcare, and social networks on a more communal level (Corrigan & Fong, 2014).

Over the years, the multi-level impact of stigma has raised both public and global health concerns resulting in the development of a number of evidence-based approaches to tackle stigma across disciplines (Corrigan, Morris, Michaels, Rafacz, & Rüsch, 2012; Department of International Development, 2015; Scior et al., 2016; Scior & Werner, 2015). However, as noted by the UK Department of International Development (2015), despite the progress made, many around the world are yet to benefit from these antistigma efforts. This statement rings true for people with intellectual disabilities (ID), a heavily stigmatised population, who tend to be underrepresented in the disability rights movement. They are often perceived as unattractive and inferior both by their disabled and non-disabled counterparts (Scior et al., 2016).

In the global review conducted by Scior et al. (2015), Africa was identified as one of the world regions where pejorative terminologies, stigmatising beliefs, and a desire to ostracise people with ID continue to exist. The authors concluded that there is an urgent need to tackle societal barriers that impede the quality of life of people with ID in Africa. Nigeria is the most populous country in Africa (CIA, 2017). It is home to over 25 million people with disabilities of whom 3.5 million have significant difficulties in social and physical functioning (Sango, 2017). Nigeria is also considered by many to be the biggest growing economy on the African continent (Grace, 2012). As such, it is an important country to target when trying to influence social change in Africa.

## Intellectual Disability in Nigeria

The literature on ID in Nigeria is limited. However, the little we know suggests that stigma towards people with ID prevails and is heavily influenced by embedded cultural beliefs and other socio-demographic characteristics, e.g. gender, religion, and education amongst others (Ajuwon & Brown, 2012; Sango, 2017).

**Superstitious Beliefs.** Superstitious beliefs about the causes of ID have been cited in multiple studies as one of the major causes of ID stigma in African contexts (Hartley, Ojwang, Baguwemu, Ddamulira, & Chavuta, 2005; Kisanji, 1995; Kromberg et al., 2008; McKenzie, McConkey, & Adnams, 2013; Mulatu, 1999; Mung'omba, 2008). Looking specifically at Nigeria, Abasiubong, Obembe, and Ekpo (2008) studied the opinions and attitudes<sup>3</sup> of Nigerian mothers and found that many saw their children's

<sup>&</sup>lt;sup>3</sup> The terms *stigma* and *attitude* are used interchangeably in this paper. Although, the definition of stigma adequately captures the experiences of those with ID, it is less commonly used in the ID field. The construct attitude is the preferred term. However, despite being a construct that is made up of three parts; cognitive, affective and behavioural components, only the cognitive component of attitude is often referenced. As such, this paper will use the term attitude when referencing works within the ID field. The term stigma will be used

ID as being caused by spiritual forces, malicious tactics from estranged family members, or personal negligence. Similarly, Ajuwon and Brown (2012) reported that some Nigerian parents attributed their children's ID to evil spirits, initiation into cults or family curses. Such beliefs have been linked to the maltreatment of people with ID in the country and, in some cases, results in neglect or abandonment (Atilola, Omigbodun, Bella-Awusah, Lagunhu, & Igbeneghu, 2014; McKenzie et al., 2013).

Socio-Cultural Factors. Other researchers (such as Abah, 2009; Aguoji, 2007; Mbubaaegbu, 1985; Uzoigwe, 2007) have also highlighted how socio-cultural factors influence attitudes. In his dissertation, Uzoigwe (2007) found that beliefs and attitudes towards people with disabilities differed among the three main ethnic groups in Nigeria (i.e. Yoruba, Igbo and Hausa). Looking at ID specifically, Aguoji (2007) assessed the correlation between place of residency and attitudes held towards people with ID by comparing Nigerian parents living in America to those living in Nigeria. She found that parents living in Nigeria were more likely to exclude people with ID from human rights entitlements than their US counterparts. In another study, Nigerians who identified as Christian were more likely to associate with people with ID when compared to those that identified as African traditionalist. However, both religious groups did not believe in the rights to self-determination for people with ID (Abah, 2009). These findings differ somewhat from the study by Akindenor (2007), which looked at the relationship between six demographic variables (gender, religion, ethnicity, age, years of residence in the USA and level of education) and attitudes held by Nigerians in Sacramento. Akindenor (2007) found that only years of residency and age influenced attitudes

when discussing the theory-evidence link of known interventions as reported in other fields, and the lived experiences of those with ID (Scior & Werner, 2015).

towards people with ID.

Putting all this together, these findings suggest that acceptance of people with ID within the Nigerian context is influenced by individual characteristics including ethnicity, age and religion (Ajuwon & Brown, 2012). Indeed, within the wider ID literature, numerous studies have reported on the association between socio-demographic factors and attitudes (Morin, Rivard, Crocker, Boursier, & Caron, 2013; Scior, 2011). However, as identified above, results have been said to be contradictory within different cultural groups in regards to the direction and strength of the association (Lee, 2016).

In addition, contact factors (i.e. quality, duration and frequency of contact with people with ID) and levels of perceived severity of ID (i.e. mild to profound) have also been found to affect attitudes. For example, several studies have shown that people with more frequent contact tend to hold more positive attitudes towards people with ID (Antonak & Harth, 1994; Krajewski & Flaherty, 2000; Lau & Cheng, 1999; Morin et al., 2013). Also, people with severe ID are less likely to experience favourable attitudes within their communities, as they are often viewed as a burden (McKenzie, et al., 2013; Morin et al., 2013). However, there is very little research on the association between these factors and attitudes held in Nigeria. As a whole, gaining more information on the association of socio-demographic factors with stigma is paramount in advancing antistigma efforts in Nigeria.

Nevertheless, Mbubaegbu (1985) concluded that the general perception of people with ID in Nigeria, despite the influences of socio-cultural factors, is highly stigmatised. This view was also echoed in the multinational study by Siperstein, Norins, Corbin, and

Shriver (2013) that presented data showing that Nigeria, as a whole, was amongst the countries that failed to recognise the range of capabilities individuals with ID possess, with expectations about what they could and could not achieve being generally low. Indeed, stigma within the Nigerian context has been linked to the general public and the systemic lack of awareness and misconceptions about ID (Abang, 1988; Sango, 2017).

This brief review of the literature highlights the impact of systemic ideas and beliefs on the maintenance of stigma. This is in line with Article 8 of the United Nations Convention on the Rights of Persons with Disabilities, which notes the importance of tackling stigma on a public level as a way to break down social barriers that hinder the rights and dignity of person with disabilities (United Nations Foundation, 2006).

#### **Combating Public Stigma towards Intellectual Disability**

In their meta-analysis examining the effects of anti-stigma initiatives in the mental health field, Corrigan et al. (2012) highlighted the following three major approaches to stigma change: protest, education and contact. These approaches have been tested across different fields (e.g., mental health, HIV, and ID) and cultures and have resulted in definite perspectives regarding which strategies might promote stigma change and which might generate unintended consequences (Corrigan & Fong, 2014).

Of these three approaches, both contact and education-based approaches have been found to significantly reduce stigma overall and its major three components (Corrigan et al., 2012; Scior & Werner, 2015). Indeed, these two approaches have been tested across different research conditions (e.g. against a control group or other intervention strategies) and have shown significant short-term effects that are maintained over time (Chan, Mak, & Law, 2009; Walker & Scior, 2013).

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). The educational approach tackles the first component of stigma (i.e., lack of knowledge), as a driving force for 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., 2012). Indeed, interventions in the ID field that have used an education-based approach to tackle stigma found that this approach leads to an increase in knowledge and a positive shift in attitudes (e.g., Campbell, 2003; Macdonald & MacIntyre, 1999). However, for brief interventions, the effects produced by educational strategies have been shown to vary in magnitude based on the demographic characteristics and experience of the target population (Corrigan et al., 2012). For example, Corrigan et al. (2012) noted that with adolescents, educational strategies yielded greater effects of stigma change than with adults. Other studies have shown that prior knowledge positively influenced the likelihood of adopting educational strategies within the general population (Corrigan & Fong, 2014).

Contact approaches emerged from contact hypothesis by Allport (1954). This proposes that positive interactions between in-group members (i.e., those doing the stigmatising) and out-group members (i.e., those being stigmatised) are capable of reducing prejudice when certain conditions are met. This hypothesis has received robust empirical support and has led to the identification of several important dimensions required to moderate the contact effect (Swart, Christ, Hewston, & Voci, 2011). These dimensions include one-to-one interactions (direct contact) with an out-group member that moderately disconfirms prevailing stereotypes, demonstrates similar interests with

the in-group, and highlights the pursuit of a common goal (Corrigan & Fong, 2014; Scior & Werner, 2015). Studies have also shown that there is an affective mechanism that underlines the contact–prejudice relationship (Brown & Hewstone, 2005; Swart et al., 2011). 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 affective reactions to the observed experiences of out-group members) (Stephan & Stephan, 1985; Swart et al., 2011).

Contact-based interventions for combating ID stigma have mostly shown positive effects on attitudes and behavioural intentions (a measure of likely discrimination) (Scior & Werner, 2015). However, securing direct contact on a large scale can prove difficult and can limit the researcher's control over the quality of the contact. On the other hand, indirect contact via film footage as an anti-stigma intervention or as a component of a multi-faceted anti-stigma programme, is potentially more promising for reaching larger audiences (Walker & Scior, 2013). Indirect contact through film has been found to promote persuasion in three major ways: 1) by creating an experiential learning situation; 2) eliciting empathy; and 3) encouraging inferential processes in the viewer (Stern, 1994). As such, despite the loss of the one-to-one interaction, indirect contact still contains the majority of the underlining dimensions that facilitate change (e.g., affective mechanisms and demonstrating similar interest).

In parallel, psychologists have begun to look at the integration of education and indirect contact to yield a fuller approach to tackling stigma (Corrigan & Fong, 2014; Walker & Scior, 2013). The few studies to date that have conducted e-interventions to

tackle stigma associated with ID report that an integrated approach of education and indirect contact strategies is potentially more promising in reaching larger audiences (e.g. Lindau, Amin, Zambon, & Scior, 2017; Walker & Scior, 2013).

# Anti-stigma Interventions in Nigeria

In 2007, the World Health Organisation (WHO, 2007) reported based on expert interviews that very little attention had been given to ID in Nigeria and this was reflected in the lack of efforts targeting this group. However, Scior et al. (2015) at the time of their review identified two local non-for-profit organisations carrying out multiple initiatives to combat public stigma in Nigeria, albeit very much on a small scale due to limited resources.

Of the two reported, one NGO, Down Syndrome Foundation Nigeria, carried out two initiatives on a local/regional level: (1) targeting children in educational settings by running awareness raising workshops for teachers, social workers and administrators; and (2) collaborating with media organisations to create an annual national awareness day which consisted of a charity walk as well as advocacy, training and support for people with ID and their families. The other NGO, Children's Developmental Centre, targeted multiple groups within society (i.e. professionals, the general public, and families) by running awareness raising road shows as well as training and cycling events as a way to raise awareness, highlight the capabilities of and fight for the rights of people with ID (K. Scior, personal communication, April 16<sup>th</sup>, 2015). Also, Sango (2017) highlighted several non-for-profit organisations trying to combat stigma on a small scale within the country.

However, one criticism highlighted by Scior et al. (2015) was that these

initiatives lacked formal evaluation to assess the effectiveness of their efforts. As such, although their efforts are promising, the effectiveness of these initiatives in combatting stigma and promoting social inclusion remains unknown. Furthermore, the majority of these initiatives require a large amount of resources to ensure a wide reach, which is limited due to lack of funding, government involvement and little partnerships in the country (Scior et al., 2015; Sango, 2017). On the contrary, e-interventions provide an opportunity for more robust research and a wider reach with limited resources needed (Scior &Werner, 2015; Walker & Scior, 2013).

#### Use of e-Interventions to Combat Stigma in Nigeria

There is growing evidence that Nigeria is establishing a strong ICT infrastructure for health initiatives. According to United Nations Foundation (2014), the Nigerian government has formally recognised the importance of ICT to 'improve access to health services, patient empowerment, health system performance and equality' (p. 1).

In terms of the potential reach of e-interventions, internet users in Nigeria are young and educated, with most users being 35 years or younger and holding a postsecondary degree (Adesugba, 2015; Pew Research Centre, 2016). This demographic is an important target group because not only are they at an age where they may still be receptive to messages aimed at changing their attitudes, but also as the future generation they have the power to either sustain stigma or support change (Campos, 2013; Schulze, Richter-Werling, Matschinger, & Angermeyer, 2003).

However, intermittent connectivity problems in the country may serve as a possible barrier in the deployment and uptake of e-health/digital initiatives (Ericsson,

2015). As such, the effectiveness and appropriateness of a digital integrated approach has to be explored within a Nigerian population.

## **Measuring Stigma**

According to Link, Yang, Phelan, and Collins (2004), a clear definition of the theoretical concept of stigma is pivotal to our capacity to observe and measure it appropriately. In this paper, stigma is defined as a tri-partite model, i.e. stereotype, prejudice and discrimination. Within the mental health field, the tri-partite model has allowed for clear intervention targets and units of measurement (Thornicroft, 2006). This in turn has set the foundation for the development of an array of stigma related measures that have made it easier to examine and consolidate findings pertaining to stigma in empirical research (Werner, Corrigan, Ditchman, & Sokol, 2012).

However, despite the usefulness of the tri-partite model in empirical research, several methodological limitations continue to exist when measuring stigma within the ID field (Werner, 2016). This is because until much recently, the term attitude had been used in preference to the term stigma, resulting in the majority of ID measures being based on the attitude framework (Werner et al., 2012). Although the terms *stigma* and *attitude* are used interchangeably within the ID field, the attitude construct (which is comprised of cognitive, affective and behavioural components) does not sufficiently capture the expressions of stigma (Werner, 2016). Therefore resulting in a gap in the area of ID when it comes to measuring stigma.

Notwithstanding these limitations, the Attitudes towards Intellectual Disabilities (ATTID) scale is considered one of the most comprehensive measures in the ID field (Scior & Werner, 2015). It is a multi-dimensional measure that has been reported to

adequately distinguish and measure all three components of attitude and is recommended to assess attitude change (Scior & Werner, 2015). Therefore, this study will measure attitude change using the ATTID.

# Aims and Objectives

This study aimed to test the effectiveness of an e-intervention focused on an integrative approach of education and indirect contact through film as a tool to raise awareness about ID and challenge public stigma in Nigeria. Given the limited evidence available regarding perceptions of ID in Nigeria, a secondary objective of this study was to add to the body of research by: (1) collecting baseline attitudes towards ID amongst a subset of Nigerian internet users, and (2) exploring the impact of demographic variables and contact on attitudes. Lastly, a process evaluation was incorporated to assess the acceptability and quality of implementation of this intervention via the internet.

### **Research Questions**

The study posed the following research questions and hypotheses:

- 1. Baseline Attitudes
  - 1.1. Within a subset of Nigerian internet users, what general attitudes are held towards people with ID?
    - a. What is the relationship between demographic characteristics (gender, age, religion, place of residence and socioeconomic status) and attitudes held towards people with ID?
    - b. What is the relationship between previous contact with people with ID (type, frequency and quality of previous contact) and attitudes held towards people with ID?

- c. What is the relationship between perceived level of functioning of people with ID (i.e. symptom severity) and attitudes held towards people with ID?
- 2. Intervention
  - 2.1. Will a brief film-based intervention focused on education and indirect contact positively shift attitudes towards people with ID in Nigeria?

Hypotheses:

- a. There will be a significant difference between the mean scores attained by the experimental group before and after the film intervention on all three attitude components (i.e. cognition, affect and behaviour). Attitudes will be more positive.
- b. There will be no significant difference in the mean scores attained by the control group before and after the film on all three-attitude components.
- c. Post intervention, there will be significantly more favourably attitudes towards people with ID in the experimental group compared to the control group on all three attitude components.
- Gamma A contract of the experimental group towards people with ID will remain at one-month follow-up, as reflected in the scores on all three attitude components.
- e. There will be no significant difference in the means scores attained by the control group post intervention and at one- month follow-up on all three attitude components.

# 3. Process

- 3.1. What impact would the chosen methodology have on the quality and acceptability of the intervention?
  - i. What is the reach of the study?
  - ii. How appropriate are the chosen methods of delivery and data collection?
  - iii. What is the acceptability of the intervention?

## Methods

## Overview

This study was a randomised control trial with repeated measures targeted at Nigerian internet users. It was informed by research conducted in Western countries (e.g. Walker & Scior, 2013) and supported by discussions with collaborators in Nigeria. Data was collected at three time points: baseline, immediately post film, and again at one-month follow-up to allow estimation of the size of any effects and assessment of any lasting positive effects. Qualtrics, a web survey platform was used to randomly assign participants to either the experimental group or the control group as well as to collect data. The film intervention was made in collaboration with two NGOs in Lagos, Nigeria. Ethical approval was granted by the UCL Ethics Committee (Reference: Project ID: 8807/001; See Appendix C).

## Joint Study

This study was a joint research study undertaken with Winnie Chege, Trainee Clinical Psychologist at University College London. Winnie Chege ran the same study simultaneously in Kenya while this study was run in Nigeria (Chege, 2017). See Appendix B for more details on our independent contributions to the study.

# **Procedure and Participants**

All participants were recruited through social media advertising (i.e. Instagram and Facebook) and by partnership with influential online figures and university platforms in Nigeria. All partners had over 10K followers respectively. Partners were fashion bloggers, student organisations, religious leaders and life coaches. Deciding on whom to approach was based on the level of interaction on their respective social media pages and how accessible they were to the researcher.

Advertisements were via electronic flyers. The flyers contained brief details of the study and potential incentives to be won (See Appendix D). Participants were offered two incentives: a one-month free subscription to an African online TV web platform for completing the first part of the study (i.e. pre and post-test), and a chance to be entered in to a prize draw to win two mobile phone air time vouchers for completing the one-month follow-up survey. Local experts in the field were consulted regarding what incentives would be most attractive in the local context.

An electronic link from the advert directed participants to the data collection website where they were given more information about the study and could choose to proceed to the actual survey. Participants were informed that starting the survey would be taken as informed consent. Before the baseline measures, participants were also given a brief description of ID to ensure that they had an adequate understanding of the condition as basis for completing measures on their attitudes to ID. The description was as follows:

For the purpose of this study, *intellectual disability* is a term used when a person has certain delays in their cognitive development. These delays must be present before the person reaches adulthood and can lead to difficulties understanding, learning and remembering new things. It may also affect the person's communication, social and self-care skills. A person with an intellectual disability may therefore develop and learn more slowly or differently than others. In the past, the term 'mental retardation' was used to describe intellectual disability. In Nigeria, terms like 'were' or 'imbecile' are also used. Some specific syndromes and conditions like 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.

An a priori power analyses was completed using G\*Power 3.1.8 (Faul, Erdfelder,

Lang & Buchner, 2007). By setting alpha at 0.05, a total of 398 participants (199 per group) were required in order to ensure an 80% chance of detecting a 'small' effect of d=0.25 (a value obtained from Walker & Scior, 2013) when comparing two independent means.

A total of 917 participants clicked on the survey link. There were two inclusion criteria: being above 18 and being a Nigerian citizen. Nigerian citizens living outside of the country were considered eligible to take part. Three participants were excluded from the study, as they did not meet the inclusion criteria. Of the remaining 914, 215 (23.5%) dropped out after reading the information sheet and before beginning the study.

Of the 699 that started the study, 571 (81.6%) completed the survey assessing baseline attitudes and were subsequently randomised, 508 (72.8%) completed the full pre-post of the survey including watching the intervention or control film, 428 (61.2%) expressed interest in taking part in the follow-up but only a total of 209 (29.8%) accessed the survey one month later. 198 (28.3%) of those who started the follow-up completed it. Figure 1 shows a flow chart of participants through the study.

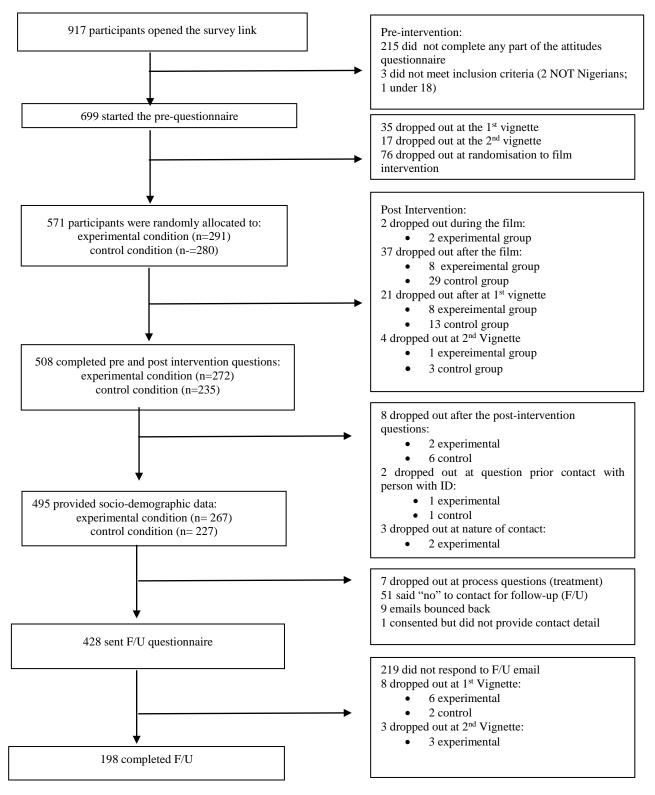


Figure 1: Participants flow through the study.

There were 0.7% (n=5) of intermittent missing data within the socio-

demographic questions. That is, for these participants, there were occasional missing data for one or two socio-demographic questions. As no other data were missing due to the survey setting, no participants were excluded due to missing data.

# Intervention

**Experimental group.** To minimise the impact of poor internet connectivity on the intervention and to avoid loss of interest among participants, the stigma change film was only six minutes long. It featured education about ID followed by indirect contact. This order in combined approaches has been shown to yield greater reduction in stigma (Chan et al., 2009). The structure of the educational segment of the film was informed by both theory and past research. The common sense model by Leventhal (1985) proposes that there are five main components that make up our representation of illnesses and influence our perceptions, attitudes and actions towards different illnesses. These components include identity, cause, time-line, consequence and curability/ controllability. Seewooruttun (2013) successfully used these components of illness representation to combat stigma within a South Asian community sample, where increased levels of ID stigma have also been reported (Scior, Potts & Furnham, 2013). As such, the selection of factual knowledge delivered was guided by identity (What is ID and what isn't?), causes (What causes ID and what doesn't), timeline/curability (Is there a 'cure'?), and consequence (How might having an ID impact on someone's abilities?). Experts in the field delivered this section in order to increase the credibility of the information.

The indirect contact section of the intervention included people with moderate ID

who varied in life roles and the challenges they faced, talking about their experiences, demonstrating their capabilities and wanting a common goal in terms of hopes and aspirations for themselves (Scior & Werner, 2014). It also highlighted the magnitude of stigma they face in the country. The author recorded the film in Lagos, Nigeria for the purpose of this study. See Appendix E for link to full video and storyboard.

**Control group.** In order to reduce ascertainment bias and ensure blinding, the control group watched a film of a similar length and structure to the experimental group. However, the film was unrelated to ID and focused on a different target group. It was a documentary on the current state of education in Nigeria. This film was chosen to control for the following variables that might influence observed change: reactivity to the outcome measures, study participation, length of film, and the social and demographic characteristics of people featured in the film.

## Measures

Participants completed two measures to assess attitude change. Both measures were completed at all time points (pre-, post-intervention and follow-up). Participants were also asked to provide demographic, contact and process information at the end of the study.

Primary Outcome:

Attitudes towards intellectual disabilities questionnaire Short Form (ATTID-SF) (Morin, Rivard, Crocker, Boursier, & Caron, 2012). The ATTID is a multidimensional measure that assesses the cognition, affect, and behavioural components of attitude. These three components were shown by Morin et al., (2012) to load on a five-factor structure: two factors in the affective dimension of *Discomfort* and *Sensitivity/tenderness*; two factors in the cognitive dimension of *Knowledge of Causes*  and *Knowledge of Capacity and rights;* and the remaining factor in the behavioural dimension, i.e., *interaction*. The affective and behavioural dimensions of the scale are measured across two vignettes. These vignettes present two people with ID who vary in their level of functioning: one with a higher level of functioning (named Jide) and the other with a lower level of functioning (named Uche). In this study, the vignettes were adjusted to make them more culturally appropriate. See appendix F for the adjusted vignettes used.

The original version of the scale is a 67-item measure that uses 5-point Likerttype response options (1 = agree completely to 5 = disagree completely; plus an option of 9 to indicate "I don't know"/"not applicable"). It has been tested for test–retest reliability, yielding correlations from 0.62 to 0.83 on the five factors. In addition, it has also been used across different cultures and has been found to yield reliable and valid results (Morin et al., 2012; Patel & Rose, 2013; Pooh, 2016).

However, the practicalities of administering a 67-item scale in a context known to have poor internet connectivity was not deemed feasible. As such, Diane Morin and her team (personal communication, 8 July 2016) were consulted on developing a shortened version that could be used with the intended target population. This resulted in the creation of the ATTID-SF (Morin, Valois & Crocker, 2017). This version consists of 36 items that load on the same five factors as the original measure. It was validated across the same large Canadian database (n= 1605) used for the original measure and showed Cronbach's alpha of .866, .811, .802, .755 and .671 for the five factors. The shortened version was used for this study and its psychometric properties were validated against the Nigerian data collected. See appendix F for details on ATTID-SF version

used in this study.

Intellectual Disabilities Literacy Scale (IDLS) (Scior & Furnham, 2011). The causal beliefs of the ATTID were supplemented with items from the IDLS. This was deemed important given that a major part of the stigma held towards people with ID in Nigeria is based on superstitious causal attributions, as discussed above. The IDLS has 22 items measuring causal beliefs about ID, of these, four items load on a fate/superstitious causes subscale. Following discussions with the first author of this measure, three of the four items were added to the ATTID. These included ID being seen as (1) a test from God/Allah, (2) possession by spirits and (3) punishment for past wrongdoing. The decision to add these three items was based on their high internal reliability.

In general, the IDLS has good psychometric properties. It has been tested in a range of cultural contexts, with high internal consistency ( $\alpha$ = 0.76) and acceptable test-retest reliability (>0.7) reported for the superstitious beliefs subscale (Scior & Furnham, 2011).

# Secondary Outcomes:

Acceptability of the Study. Participants were asked questions to assess their experience of the study. These questions were used to evaluate the quality of implementation (i.e. reach), acceptability of study (i.e. perception of length and content of survey and film intervention), and barriers (i.e. difficulties around accessing/completing the study). Questions were a combination of choice-based and open-ended questions. See Appendix G for questions.

**Demographics.** Socio-demographic data (age, gender, ethnicity, location, religious affiliation, educational attainment, and prior contact with someone with ID)

were also recorded.

## **Data Preparation**

The following sections highlight the major ways the data collected were cleaned before data analysis:

**ATTID-SF.** Upon collecting the data, items labelled 9 ("not applicable" or "don't know") were replaced with the item mean (i.e. a score of 3) to represent neutral attitudes. This decision was based on Graham and Hofer (2000) recommendation that recoding to the mean helps retain such responses within the final sample. Other researchers (i.e. Manisera & Zuccolotto, 2013) have recommended that "not applicable" or "don't know" responses should be seen as missing data and treated through listwise deletion. However, this method was not taken up by this study due to the risk that data deletion might lead to biased parameter estimates and loss of statistical power (Saunders et al., 2006). Also, the affective factors of the ATTID were reversed to be congruent with the other four factors, i.e. higher scores on all items and subscales indicating more negative attitudes.

**Superstitious beliefs Subscale of the IDLS.** Items were reversed so that the direction of attitudes was congruent to the ATTID measure, i.e. higher scores indicating stronger endorsement of the respective superstitious belief, shown to be associated with increased stigma.

**Socio-demographic questions.** Open-ended questions such as 'what is your occupation' 'place of residence' and 'nature of contact' were categorised. Categories were formed based on reoccurring responses. Also, skipped functions in the socio-demographic variables were recoded to differentiate these variables from other types of

missing data.

## Scoring

For both measures (i.e. ATTID-SF and Superstition Subscale of the IDLS), higher scores on the different items indicated more negative attitudes towards persons with ID (Morin, Rivard, Crocker, Bourseir & Caron, 2013). Also as suggested by Morin et al. (2013), scores above the neutral rating of 3 (i.e. factor mean) for individual items were seen as less positively polarised attitudes and as such, indicate negative attitudes.

#### **Data Analysis**

All analysis was completed using SPSS version 22. Before conducting any main analysis, the psychometric properties of the ATTID-SF were examined for the 699 Nigerian participants that took part at time one. Given that 7.4% of the data were missing at this point, Little's MCAR test was carried out to assess the pattern of missing data. Analysis showed that the data were missing at random, Little's MCAR test:  $\chi^2$  (45, N=699) = 45.87, *p*= 0.436. Expectation maximisation was used to replace missing data. This method has been proven to be particularly good for exploratory factor analysis with missing data (Graham, 2009). Similar to the ATTID-SF validation study (Morin et al., 2017), an exploratory factor analysis was carried out to confirm the structure of the instrument, using principal component factor analysis with Varimax rotation. Also, a Cronbach's alpha analysis was used to validate the internal consistency of the subscales.

To answer all research questions, an intent-to-treat analysis was conducted. As such, only the 571 participants randomised to the film intervention were included in all further analyses. However, for socio-demographic analyses (research question 1), only people who provided demographic information (i.e. list-wise deletion) were used. This was done to reduce the risk of bias that may arise from imputing such data; another method of handling categorical missing data as suggested by Allison (2002).

Assumptions of normality, linearity, multicollinearity and homoscedasticity were checked to ensure no violation. Despite the evidence of slight skewness and kurtosis in the data, the large sample size meant that normality could be assumed according to the central limit theorem (Fields, 2013). In cases were outliers were discovered, as recommended by Verma (2015), the nature of these outliers was explored and as long as scores were "genuine and could be obtained by the subjects easily" they were kept (p. 59). This recommendation was further backed up by comparing the group mean to the trimmed mean (Pallant, 2009). This comparison revealed that the outliers had no significant influence on the overall data. As such, untransformed data were used in this study.

Frequencies, mean scores and standard deviations were used to describe the baseline attitudes held by Nigerian internet users in this study. T-tests and Anovas were carried out to assess participants' attitudes against socio-demographic characteristics mentioned above (research question 1). Analysis of missing data across all three time points showed that data were missing at random, Little's MCAR test:  $\chi^2$  (273, N=571)= 291.80, *p*= 0.207. As such, intervention effects were analysed using a linear mixed model (research question 2). This model is a superior way to handling missing data in RCTs, outperforming other traditional methods; it uses all data presented at each time point and does not rely on complete cases to run analyses (Egan et al., 2014; Elobeid et al., 2009). For this study, a random intercepts model was used, with a variance

component structure assumed. Time and group were included in the model as fixed effects (Fields, 2013). For all analyses, p values of <0.05 were considered significant.

### Results

### **Psychometric Properties of ATTID-SF**

As stated above, a principal component factor analysis was conducted on the 36 items with varimax rotation. The Kaiser-Meyer-Olkin value verified the sampling as adequate for the analysis, KMO=0.83, which is considered meritorious by Hutcheson and Sofroniou (1990). All individual items also had KMO values equal to or greater than .71, which is well above the acceptable limit of .5 (Field, 2013). An analysis was run to obtain eigenvalues for each factor in the data. Eight factors had eigenvalues over Kaiser's criterion of 1 and in combination explained 62.3% of the variance. However, given that the sample size for this study exceeded 250 and had an average communality of less than 0.6, a scree plot was deemed to be a more reliable method to determine the number of factors (Stevens, 2002). The screen plot showed an inflection point after the sixth factor, which was one factor more than reported by Morin et al. (2017). As such, for the present Nigerian dataset, three factors loaded on the cognitive factor: Knowledge of Causes, Knowledge of Capacity, and Knowledge of Rights. Unlike Morin et al. (2017), Knowledge of Capacity and Knowledge of Rights loaded as two separate factors. This six-factor model explained 54.6% of the variance in the model: Factor 1 represents Discomfort; Factor 2: Sensitivity and Tenderness; Factor 3: Interaction; Factor 4: Knowledge of Rights; Factor 5: Knowledge of Capacity and Factor 6: Knowledge of Causes. The Cronbach's alphas for each factor were: 0.87, 0.82, 0.79, 0.89, 0.82, and 0.68 respectively, indicating acceptable to excellent internal reliability

for all six factors. See appendix F for the psychometric properties of the ATTID-SF comparing the Canadian population (Morin et al., 2017) and the Nigerian dataset.

# Attrition

Participants who completed all three time points were compared to participants who dropped out at both time two and three. Analysis revealed significant differences between the means of these two groups on Knowledge of Rights (ATTID) and superstitious beliefs (IDLS). No other differences were found. Participants who dropped out (M=2.24, SD=0.87) had less favourable attitude in terms of endorsements of superstitious causes of ID, than those who completed the study (M=2.08, SD=0.85), t(569) =2.023, p=0.043. However, they had more favourable attitudes (M= 1.82, SD=0.71) on rights of people with ID than those who completed (M=2.00, SD=0.82), t(569) = -2.71, p=0.007. Despite these differences, both groups had means below 3 on these factors, indicating that their attitudes were generally positive.

### **Demographics of participants**

Due to attrition, the number of people who provided demographic information varied. As such percentages are not based on a cumulative total, see Table 1 for more detail. Participants who completed the study were predominately female (76.6%), aged 25 to 34 (56.4%), living in Nigeria (76.9%), with a university/postgraduate degree (95.4%), and identifying as Christian (97.2).

# Table` 1

# Participants' Demographic Information

Total	Ν	%
501		
	22	4.4.
	275	54.9
	204	40.7
501		
301	4	0.8
		97.2
		2.0
	10	2.0
500		
		23.5
	383	76.6
500		
	90	18.0
		56.6
		18.2
		7.2
500	50	1.2
500	50	11.0
		11.8
		54.2
		12.8
		4.6
	83	16.6
496		
	387	78.0
	102	20.6
	7	1.4
499		
777	342	68.5
		31.5
10.0	157	51.5
493		
		16.4
		17.6
		14.2
		15.4
		2.6
	9	1.8
	157	31.8
493		
	81	16.4
		8.5
		21.3
		8.7
		13.2
	157	31.8
	501 500 500	$\begin{array}{cccccccccccccccccccccccccccccccccccc$

Of participants, 68.5% reported prior contact with people with ID, of these 16.3% had a family member with ID followed by 14.1% who knew a person with ID professionally. The majority of those reporting prior contact (21.3%) only had contact with people with ID occasionally through the year. Table 1 presents the socio demographic characteristics of participants.

# **Baseline attitudes**

Attitudes are presented for each ATTID-SF factor and superstitious subscale of IDLS. Similar to Morin et al. (2013), in addition to presenting the means and standard deviations, attitudes were separated into three categories: more positive (scores of 1 and 2), neutral (scores of 3), and more negative (scores of 4 and 5). This was done to present a more comprehensive picture of attitudes held. For all factors and superstitious belief subscale, only items at or above the mean are presented below. See Table 2 for further details.

On the Discomfort subscale, participants scored an average of 2.56 (SD=0.81), with individual mean scores ranging from 1 to 4.88 (where 1 indicates little to no Discomfort and 5 meaning strong Discomfort). Four out of the eight items within this factor were above the factor mean (2.56), indicating less positive attitudes. These items were *experience anxiety* and *be wary* if encountering someone with both moderate and severe ID. All four items were within one standard deviation of the mean. In total, only 27.49% agreed or strongly agreed with all eight items in this factor, conveying more negative attitudes.

On the Sensitivity and Tenderness<sup>4</sup> subscale, factor 2, participants scored a mean of 3.68 (SD=0.74), with the majority of participants (71.8%) agreeing or strongly agreeing with all items in this factor. Of the six items that load on this factor, three were above the factor mean: *feel pity* (severe ID), and *feel touched or moved* (for both ID severities). None were above one standard deviation from the mean. *Feel touched or moved* for Uche (severe) received the highest percentage (88.4%) of participants who agreed or totally agreed with this statement, M= 4.11, SD=0.8. In addition, all six item means were above 3, indicating more negatively polarised attitudes on this factor.

For Interactions, factor 3, participants' mean score was 2.53 (*SD* = 0.61). Four out of the seven items were above the factor mean. None was more than one standard deviation from the mean. These items were: *advise in clothing store* and *advise in an electronics store* (for moderate ID) and *agree to supervise at work* and *feel comfortable talking to him* (for severe ID). *Advise in an electronics store* elicited the most negative attitudes, with 37.7% of people disagreeing or totally disagreeing with this statement. Overall, only 19.59% of participants disagreed or totally disagreed with all items analysed in this factor.

The mean score for Knowledge of Rights, factor 4, was 1.86 (*SD*=0.75). Two items were above the factor mean: *should have the right to vote,* and *should have the right to have children.* However, a very low percentage of the participants disagreed or strongly disagreed with these statements: 8.8% and 6.3% respectively. None of these items were above one standard deviation from the mean.

<sup>&</sup>lt;sup>4</sup> Although some may argue that the emotions under the Sensitivity subscale can be seen as favourable attitudes towards people with ID, Morin et al., (2013) explained that these emotions do not encourage personal autonomy, self-determination or social participation.

# Table 2

Descriptives for Participants' ATTID-SF and the IDLS superstitious beliefs Subscale Scores

Factor	Mean	Standard Deviation	Positive attitudes (1-2) %	Neutral attitudes (3)	Negative attitudes (4 and 5)
Discomfort	2.56	0.8	57.99	14.50	27.49
Experience anxiety	2.70	1.1	51.3	17.3	31.3
(Moderate)					
Feel insecure	2.15	1.0	75.1	12.4	12.5
(Moderate)					
Be wary (Moderate)	2.91	1.2	44.1	13.8	42.1
Feel afraid	2.11	1.0	76.7	10.3	13
(Moderate)					
Be wary (Severe)	2.99	1.2	39.1	15.6	45.3
Feel afraid (Severe)	2.41	1.1	65.0	15.4	19.6
Experience anxiety	2.88	1.3	44.8	15.4	39.7
(Severe)					
Feel insecure (Severe)	2.30	1.1	67.8	15.8	16.4
Sensitivity and	3.68	0.7	17.47	10.73	71.80
Tenderness	5.00	0.7	1/.4/	10.75	/1.00
Feel touched, moved	3.92	0.9	7.4	11.2	81.5
(Moderate)	5.72	0.7	7.4	11.2	01.5
Feel pity (Moderate)	3.33	1.2	28.7	13.0	58.3
Feel sad (Moderate)	3.21	1.2	32.2	14.5	53.2
Feel touched, moved?	5.21	1.2	32.2	1110	00.2
(Severe)	4.11	0.8	5.6	6.0	88.4
()		0.0	0.0	0.0	0011
Feel pity (Severe)	3.84	1.0	13.7	7.4	78.9
Feel Sad (Severe)	3.68	1.0	17.2	12.3	70.5
( , , , , , , , , , , , , , , , , , , ,					
Interaction	2.53	0.6	56.09	24.33	19.59
Would accept being	2.78	1.0	45.7	28.0	26.3
advised by (Moderate)					
in a clothing store					
Would accept being	3.06	1.0	32.0	30.3	37.7
advised by (Moderate)					
in an electronics store					
Would agree to	2.19	0.9	74.2	15.8	10.0
supervise (Moderate) at					
work					
Would accept	1.98	0.8	81.3	13.7	5.0
(Moderate) as son or					
daughter's friend					
Would agree to	2.77	1.1	45.2	27.3	27.5
supervise (Severe) at					
work					
Would accept (Severe)	2.31	0.9	64.8	24.2	11.0
1					

as son or daughter's friend Feel comfortable talking to him (Severe)	2.60	1.0	49.4	31.0	19.6
Knowledge of Rights	1.88	0.8	81.78	12.80	5.45
Should have the right to get married	1.77	0.8	87	10.0	3.0
Should have the right to have sex	1.81	0.8	84.9	11.4	3.7
Should have the right to vote	2.00	0.9	77	14.2	8.8
Should have to right to have children	1.95	0.9	78.2	15.6	6.3
Knowledge of Capacity	2.86	0.8	42.95	27.45	29.6
To hold down a job	3.17	1.1	30.8	24.7	44.5
To handle money	2.91	0.9	38.5	31.2	30.3
To carry on a	2.63	0.9	55	24.0	21.0
conversation	2.03	0.9	55	2110	21.0
To make decisions	2.74	0.9	47.5	29.9	22.6
Knowledge of Causes	2.38	0.6	63.78	18.12	18.10
Lack of stimulation	2.88	1.2	44.7	20.3	35.1
Malnutrition in	2.83	1.1	45.7	25.4	28.9
motherhood					
Chemicals in t	2.46	1.0	58.7	23.8	17.5
environment					
Serious head injury in childhood	2.19	1.0	73.4	14.4	12.2
Problems during birth	2.10	0.96	75.6	14.5	9.8
Consumptions of drugs	1.87	0.8	84.6	10.3	5.1
or alcohol by mother					
during pregnancy					
	2.18	0.9	63.23	22.63	14.10
Superstitious Beliefs					
(IDLS)	0.14	1 1	(2.4	247	11.0
Test from God/Allah	2.14	1.1	63.4 50.0	24.7	11.9
Possession by spirits	2.47	1.2	50.9	27.5	21.5
Punishment for past	1.94	1.0	75.4	15.7	8.9
wrongdoings					

The mean score for Factor 5, Knowledge of Capacity, was 2.86 (*SD*=0.77). Two items were one standard deviation from the factor mean: *hold down a job*, and *handle money*. Looking at participants' responses, 44.5% disagreed or totally disagreed with the

statement that people with ID can hold down jobs, while 30.3% held negative attitudes around their capacity to handle money. Overall, only 29.6% of participants disagreed or totally disagreed with all eight items under this factor.

Participants scored an average of 2.38 (*SD*=0.63) on factor 6, Knowledge of Causes. Three items in this factor were above the factor mean, all within one standard deviation. These items were: *lack of stimulation, malnutrition in motherhood,* and *chemicals in the environment*. Participants disagreed or totally disagree with these items 35.1%, 28.9% and 17.5% respectively.

Lastly, in regards to superstitious beliefs, the mean score was 2.18 (SD= 0.87). One item, *possession of sprits*, was above the group mean (2.47, SD=1.2), with 21.5% agreeing or totally agreeing with this statement.

Relationship of Socio-demographics to attitudes. Attitudes were analysed across six demographic variables (gender, age, occupation, place of residence, religion, and education,) and three contact variables (prior contact, nature of contact and frequency of contact). The analyses showed that attitudes held towards people with ID varied based on specific demographic characteristics and contact variables. No significant associations were found with occupation, religious affiliation, and frequency of contact.

Gender was associated with knowledge of rights (t (498) = -2.07, p=0.039; d= 0.24), Sensitivity (t (498) =-2.53, p=0.012; d=0.26) and Discomfort (t (498) =-2.68, p=0.008; d=0.29). Women were more likely to report Discomfort (M=2.60, SD=0.78), Sensitivity (M= 3.71, SD= 0.74), and to disagree with the rights of people with ID

(M=1.94, SD=0.79) than men  $(M_{\text{Discomfort}}=2.37, SD=0.82; M_{\text{Sensitivity}}=3.51, SD=0.71; M_{\text{rights}}=1.77, SD=0.62).$ 

Age was associated with feelings of Discomfort ( $F(3, 496) = 3.92, p=0.009, n^2=$ 0.02), Sensitivity ( $F(3, 123.9) = 6.53, p < 0.001, n^2 = 0.03$ ) and Knowledge of Capacity ( $F(3, 125.5) = 3.66, p=0.014, n^2 = 0.02$ ). Post hoc analyses using the Games-Howell correction was then conducted to identify what differences between age groups were significant. Participants between the ages of 18-24 were more likely to report Discomfort (M=2.73, SD=0.82) in the presence of a person with ID than participants aged 35-44 years of age (M = 2.37, SD = 0.74). The former were also more likely to report Sensitivity and Tenderness (M=3.90; SD=0.63) when encountering someone with ID compared to all other age groups: age 25-35 (M=3.67, SD=0.72); age 35-44 (Mean= 3.51 SD=0.84); and age 45-74 (M=3.42, SD=0.73). In terms of Knowledge of Capacity, participants between the ages of 35-44 (M=3.00, SD=0.87) expressed less favourable attitudes about the capabilities of people with ID when compared to participants age 45 and above (M=2.59, SD=0.62). There were no significant differences between the other age groups.

Participants' level of education was associated with feelings of Discomfort (F(2, 498)=5.47 p=0.004, n<sup>2</sup>= 0.02), Interaction (F(2, 498)=5.01 p=0.007, n<sup>2</sup>= 0.02), Knowledge of Causes (F(2, 498)=3.61 p=0.01), and Superstitious Beliefs (F(2, 498)=4.08 p=0.018, n<sup>2</sup>= 0.02). *Post hoc* analyses revealed that participants with university degrees reported less positive attitudes on Discomfort (M=2.63, SD=0.83), Interaction (M=2.61, SD=0.65), Causes of ID (M=2.43, SD=0.57) and Superstitious Beliefs (M=2.26, SD=0.88) when compared to participants with post-graduate

qualifications ( $M_{\text{Discomfort}}$ = 2.41, SD= 0.78),  $M_{\text{interaction}}$  = 2.42, SD= 0.62;  $M_{\text{causes}}$  = 2.22, SD= 0.69;  $M_{\text{Superstitions}}$  = 2.06; SD=0.83).

Where participants resided influenced attitudes across five factors: Discomfort  $(F(2,493)=10.97, p<0.001, n^2=0.04)$ ; Sensitivity  $(F(2,493)=7.36; p=0.001 n^2=0.03)$ ; Knowledge of Capacity  $(F(2,493)=5.280, p=0.005; n^2=0.03)$ ; Interaction  $(F(2,493)=14.932, p=.000, n^2=0.06)$  and Knowledge of Causes  $(F(2, 16.31)=6.82, p=0.007, n^2=0.02)$ . Post-hoc test using the Games-Howell correction showed that Nigerians living in Eastern countries (i.e. Asian countries) had less favourable attitudes around causes of ID (M=2.88; SD=0.41) than Nigerians living in their country of origin (M=2.34; SD=0.59). Furthermore, Nigerians living in their home country reported less favourable attitudes on Discomfort (M=2.64; SD=0.81), Sensitivity (M=3.73; SD=0.71), Capacity (M=2.89; SD=0.79), and willingness to Interact (M=2.60; SD=0.63) with people with ID compared to their Western counterparts  $(M_{Discomfort} = 2.22, SD=0.80; M_{sensitivty} = 3.44, SD=0.82; M_{capacity} = 2.58, SD=0.69; M_{interaction} = 2.25; SD=0.57)$ .

In regards to contact variables, there was a significant difference in feelings of Discomfort between participants who knew someone with ID and those who did not: t (497) =3.308, p=0.003, d=0.3. Participants who reported no prior contact with a person with ID were more likely to report feelings of Discomfort (M= 2.73, SD=0.79) than those reporting prior contact (M= 2.47; SD=0.84). No other significant association was found.

When looking specifically at those who reported prior contact with a person with ID, there was a significant association between the nature of the contact relationship and feelings of Discomfort (F(5,330) = 2.850, p=0.016,  $n^2 = 0.041$ ). Post-

hoc test using the Games-Howell correction revealed that participants classified as having a more distant relationship (i.e. acquaintances/ secondary relationships) felt more discomfort around people with ID (M=2.61; SD=0.85) than family members (M=2.25; SD=0.69). There were no other significant associations between nature of contact relationship and any other components of attitudes.

Lastly, using a paired t-test, participants' mean scores were compared to assess if there was a relationship between level of functioning of the persons depicted in the vignettes (i.e. moderate or severe ID) and attitudes held. In general, participants' attitudes towards both Jide (moderate ID) and Uche (severe ID) were positively correlated for all three factors in which severity was measured: r=0.56, p < .001 (Interaction); r=0.60, p < .001 (Sensitivity); and r=0.63, p < .001 (Discomfort). However, attitudes toward people with ID based on severity only differed on Discomfort (t (570) =-5.39, p<0.001, d=0.22), and Sensitivity (t (570) = 12.62, p< 0.001, d=0.53). Participants were more likely to report Discomfort (M=2.64; SD=0.95) and Sensitivity (M=3.88; SD=0.79) towards Uche (severe ID), than Jide whose level of functioning was higher ( $M_{Discomfort} = 2.47$ ; SD=0.84;  $M_{sensitivty} = 3.49$ ; SD=0.86). There was no significant difference found with Interaction (t (570) = -1.85, p=0.065).

## Effect of Intervention by Group across time

A series of linear mixed models were computed to test for intervention effects across all five ATTID factors and superstitious subscale of the IDLS. Table 3 shows the means and standard deviations of each group at all three time points.

# Table 3

	Treatment group			Control group			
-	Pre	Post	FU	Pre	Post	Fu	
Factor 1: Discomfort	2.58(0.80)	2.16 (0.76)	2.40 (0.86)	2.54 (0.82)	2.49 (0.83)	2.39 (0.79)	
Factor 2: Sensitivity and Tenderness	3.68 (0.75)	3.36 (0.85)	3.50 (0.77)	3.68 (0.73)	3.60 (0.83)	3.51 (0.84)	
Factor 3: Interaction	2.56 (0.64)	2.21 (0.63)	2.39 (0.67)	2.50 (0.64)	2.46 (0.67)	2.48 (0.66)	
Factor 4: Knowledge of Rights	1.91 (0.72)	1.83 (0.69)	1.93 (0.67)	1.85(0.78)	2.03 (0.76)	2.10 (0.86)	
Factor 5: Knowledge of Capacity	2.81 (0.75)	2.13 (0.68)	2.47 (0.79)	2.91 (0.79)	2.71 (0.78)	2.75(0.66)	
Factor 6: Knowledge of Causes	2.38 (0.63)	2.37 (0.71)	2.36 (0.72)	2.39 (0.65)	2.41 (0.74)	2.47 (0.71)	
IDLS Subscale: Superstitious Beliefs	2.22 (0.89)	1.78 (0.78)	1.85 (0.85)	2.14 (0.85)	1.97 (0.87)	1.95 (0.86)	

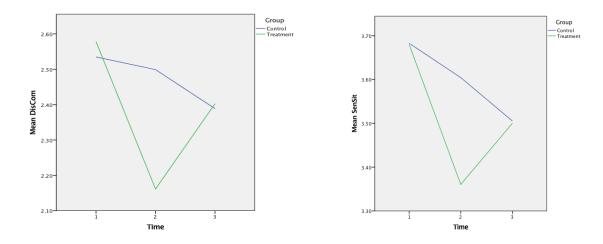
*Estimated Marginal Means (Standard Deviations) of Outcome Variables at all three Time points* 

**Change in the Affective Components of Attitudes.** There were significant time x group interactions observed for Discomfort and Sensitivity ( $F_{\text{Discomfort}}$  (2,750) =21.23, p<0.001;  $F_{\text{Sensitivity}}$  (2,750) =11.13, p<0.001). To further understand these effects, post hoc analyses of least significant difference (LSD) comparisons were conducted. Also, separate multilevel analyses were conducted to assess the effects of time and group respectively.

These analyses revealed that for people who watched the experimental film there was a significant increase in positive attitudes post-intervention (Discomfort: b=0.22, t(759)=2.75, p=0.006; Sensitivity: b=0.18, t(414)=3.21, p=0.001), which was maintained at follow-up when compared to baseline (Discomfort: b=0.18, t(418)=2.98, p=0.003; Sensitivity: b=-0.13, t(411)=-2.34, p=0.020). However, this group experienced a significant decrease in positive attitudes between post-intervention and follow-up (Discomfort: b=-0.23, t(415)=-3.81, p=0.001; Sensitivity: b=-0.13, t(411)=-2.34, p=0.020). Thus indicating that for the experimental group while attitudes continued to be more positive at follow-up compared to baseline, the magnitude of the positive change observed at time point 2 was not maintained at follow-up.

Within the control group there was no significant change in attitudes over time for Discomfort (F(2, 344) = 0.85, p = 0.426). However, for Sensitivity there was a gradual increase in positive attitudes over time (F(2, 347) = 3.71, p = 0.03), which was significant at follow up when compared to baseline (b=0.13, t(354) = 2.53, p = 0.012).

Looking at group effects, there was a significant difference between groups postintervention (i.e. at time point 2) for both Discomfort (b=0.31, t (777) =4.54, p<0.001) and Sensitivity (b=0.25, t (768) =3.71, p<0.001). The interaction effect therefore reflects the different ways both group reacted over time and in comparison to each other, see Figure 2.



*Figure*`2: Graphs of mean plots for Discomfort and Sensitivity over time and between Groups

**Change in the Behavioural Components of Attitudes**. For Interaction, factor 3, an effect was found for the interaction of time x group (F(2,751) = 23.14, p < 0.001). Further analyses showed that within the experimental group there was a significant decrease in scores (i.e. more positive attitudes) post film (b=0.34, t(519) = 12.07, p < 0.001) but then a slight increase at follow-up (i.e. slightly more negative): b=-0.17, t(245) = -3.77, p < 0.001. Despite this rise, attitudes at follow-up were still significantly more positive than at baseline (b=-0.22, t(274) = 4.38, p < 0.001). There was no significant change over time in the control group (F(2,348) = 1.16, p < 0.31). In regards to between group effects, the attitudes scores reported by the experimental group postfilm significantly differed from the scores of the control group (b=0.25, t(511)=4.38, p < 0.001). As such, the interaction effect revealed that compared to the control group, participants in the experimental group experienced a positive significant change in attitudes post intervention, which was maintained at follow-up, see Figure 3.

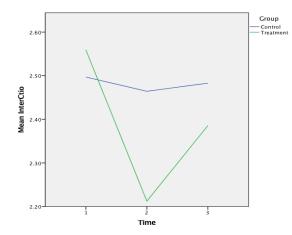


Figure 3: Graph of mean plots for Interaction over time and between groups.

**Change in the Cognitive Components of Attitudes.** Only the interaction effect of time x group was significant for Knowledge of Rights (F(2,791) = 10.74, p < 0.001). An LSD comparison showed that for participants in the experimental group, there was an increase in positive attitudes post film (i.e. higher endorsements for the rights of people with ID). However, this group showed a decrease in favourable attitudes at follow-up compared to baseline. The control group, on the other hand, showed a steady increase in negative attitudes over time (i.e. lower endorsements for the rights of people with ID). However, these changes were not significant within each group over time (F(2,791) = 2.30, p = 0.101), nor between groups (F(1,650) = 2.72, p = 0.099), see Figure 4.

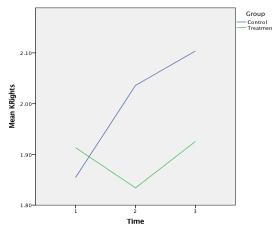
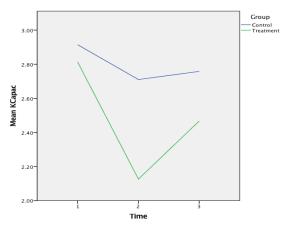


Figure 4: Graph of mean plots for Knowledge of Rights over time and between groups

The effect of time (*F* (2, 840) =75.26, p<0.001), group (*F* (1, 687) =40.80, p<0.001), and the interaction of time x group (*F* (2, 841) =23.84, p<0.001) were all significant for Knowledge of Capacity. LSD comparisons revealed that compared to the control group, attitudes were significantly more positive for participants who watched the experimental film over time (b=0.35, t (1290) =3.57, p<0.001). Positive attitudes were maintained at follow-up when compared to baseline (b=0.36, t (482) =5.29, p<0.001) and post-film (b=0.29, t (674) =2.98, p=0.003). As such, participants who watched the experimental film and at one-month follow-up than those that watched the control film, see Figure 5.



*Figure 5:* Graph of mean plots for Knowledge of Capacity over time and between groups

In the case of the Superstitious Beliefs, the interaction between time x group were found to be significant (F(2,784) = 11.13, p<0.001). Further analyses revealed that both groups experienced a significant decrease in the endorsement of superstitious causes of ID post intervention ( $b_{control}=0.17$ , t(258) = 3.98, p<0.001;  $b_{treatment}=0.44$ , t (286) =10.0, p<0.001). However, for the control group this change was not maintained at follow up when compared to baseline (b=0.44, t (376) =0.67, p=0.503). In contrast, the change in the experimental group was maintained at follow-up when compared to baseline attitudes ( $b_{treatment}=0.33 t$  (434) =5.38, p<0.001). A significant difference was found between groups at follow-up (b=0.22 t (510) =3.94, p<0.001). Therefore, participants who watched the intervention were less likely to endorse superstitious causes of ID post-intervention (i.e. held more positively polarised attitudes), which was maintained at follow-up when compared to the control condition, see figure 6.

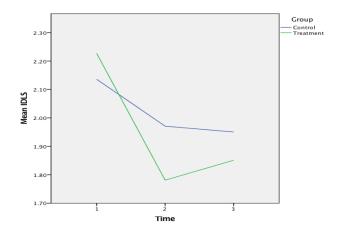


Figure 6: Graph of mean plots for Superstitious Beliefs over time and between groups

There was no significant effect found for time (F(2, 796) = 0.40, p = 0.673), group (F(1, 655) = 01.1, p = 0.290) or the interaction of time x group (F(2, 796) = 0.69, p = 0.503) for Knowledge of Causes.

### **Process Evaluation**

**Reach of the Study.** To ascertain the reach of the study, the representativeness of the sample was determined by comparing the demographics of participants in this study to known demographic statistics of internet users in Nigeria (Pew Research Centre, 2016). The Pew Research Centre (PRC) is a "fact tank that informs the public about issues, attitudes and trends shaping...the world" (Poushter, 2016, p.1). In 2013 and 2015, they conducted global surveys of the trends in internet use around the world (Poushter, 2016). Looking specifically at their 2015 survey results for Nigeria, a total of 411 people (39%) out of the 1044 interviewed reported that they use the internet. Four demographic variables collected from the Nigerian internet users in the PRC study overlapped with our study. As such, these four variables were used to assess representativeness: Gender, Religion, Education and Age. See Table 4 for comparisons between this study and the national trends in Nigeria regarding typical internet users, as reported by the PRC study.

While PRC reported that Nigeria was one of the countries with the largest gender gap in internet use (i.e. 2:1 male to female ratio), this study had almost three times the number of women as men taking part. Similar to the PRC reports, this study for the most part captured the age distribution of Nigerian internet users, with the majority of participants being within the 24-35 age group. However, it had lower reach within the 18-24 age group, the second largest age group that use the internet in Nigeria (Poushter, 2016).

Within the PRC study, majority of Internet users had a university degree or less, with participants with secondary degrees being the highest represented. In contrast, there was a much higher percentage of Nigerians holding a university or post-graduate degree in this study. As a matter of fact, in this study, for every one participant with a secondary school qualification or less that took part, nine participants held a postgraduate degree. Lastly according to the national trend, Christians and Muslims are roughly equivalent in their internet use (Poushter, 2016). However, this study reached 48 times more

Christians than it did Muslims.

**Appropriateness of method of delivery.** A total of 494 participants provided information about how they accessed and navigated through the study. Within this sample, 420 (85.0%) accessed the study through their personal devices. About 293 (59.3%) finished the first part of the study (i.e. excluding follow up) within 20 minutes or less, 141 (28.5%) took 20 to 40minutes, and only 50 (10.1%) reported that they did not finish the study in one sitting.

Only 62 (12.5%) participants reported difficulties with internet connectivity when taking part the in study, with the majority (n=43, 69.4%) attributing this problem to slow connection speed. Others reported difficulties such as no 'Wi-Fi signal' (n=7, 11.3%), and 'insufficient data package' (n=2, 3.2%), amongst others. Despite difficulties, the majority of participants reported that this had little to no effect on their ability to access (80.7%) and complete (79.7%) the study. However, 32 (53.3%) out of 60 participants answered "a lot" or "somewhat" about how internet connectivity affected their ability to watch the film. See Appendix G for more details.

Acceptability of the Study. To assess the acceptability of the study, participants were asked their opinion on the length and content of the study and film. These questions were voluntary and so not all participants provided answers. Out of a total of 492 (for questions) and 486 (for film), 82.9% of participants felt the length of the questions was just right, while 85.4% said the same for the length of the film. When asked about content, 92.5% of participants out a total of 494 rated the questions as excellent or good and 93.9% rated the content of the film (both in the control and intervention group) the same. See appendix G for details.

# Table 4

	Pew Research Centre (411)		Present stud	resent study (500 <sup>1</sup> , 501 <sup>2</sup> )	
	Ν	Ratio	N	Ratio	
Gender					
Female	263	1:2	383	3:1	
Male	148		117		
Age					
18-24	132	7:10:3:1	90	3:9:3:1	
25-34	194		283		
35-44	64		91		
45+	19		36		
Education					
< Secondary	213	23: 21:1	22	1:12:9	
Secondary/University	189		275		
Post-graduate	9		204		
Religion					
Christian	290	48: 56: 1	487	121: 3: 1	
Muslim	337		10		
Traditional religion/other	6		4		

# Reported Demographics of internet users in Nigeria compared to this study

<sup>1</sup>Total for age and gender; <sup>2</sup>Total for education and religion

### Discussion

This discussion summarises and evaluates the findings in relation to the research questions and hypotheses.

## **Baseline Attitudes and Demographics**

The results from this study revealed that attitudes towards people with ID within a subset of Nigerian internet users are generally positive along all threeattitudinal dimensions. Participants reported more positively polarised attitudes, scoring less than 3 (measure mean) on all but one of the seven factors assessed. Only one factor, Sensitivity and Tenderness, elicited less favourable attitudes, with an average above 3. This factor assessed emotions such as sadness, pity and being moved by people with both moderate and severe levels of ID. However, no factor had an overall mean score of 4 or above; thus none indicated typically more negative attitudes.

The result also highlighted the variability in attitudes held within certain factors. For example, there were certain items that elicited either less positive attitudes or more neutral attitudes, despite an overall positive mean. These included: feeling wary when around lower functioning people with ID (Discomfort); being advised in an electronics store by a person with higher functioning ID (interaction); abilities for people with ID to hold down a job (Knowledge of Capacity); and attributing ID to lack of stimulation (Knowledge of Causes). Also, being touched and moved (Sensitivity) when encountering a lower functioning person with ID received the highest level of negative attitudes. These items, in addition to factor 3 (Sensitivity and tenderness) as a whole, are therefore areas for further intervention.

Overall, these findings are in contrast to other Nigerian studies cited above (Abasiubong et al., 2008; Ajuwon & Brown, 2012; Mbubaegbu, 1985; Siperstein et al. 2013) that reported high levels of negative attitudes towards people with ID among the Nigerian general population. For example, causes of ID, which have been reported by several researchers (Ajuwon & Brown, 2012; McKenzie et al., 2013) to be heavily misunderstood in the Nigerian population- being attributed to superstitious causes- were amongst some of the more favourable attitudes held in this study. In comparison to other studies that have used the ATTID, attitudes reported in this study much more resembled reports of positive attitudes held in Western countries where there is a large presence of community inclusion and social participation of people with ID (e.g. Morin et al., 2013; Sermier-Dessemontet, Morin, & Crocker, 2014).

One could argue that the contrast found between this study and other Nigerian studies is due to a general shift of attitudes towards people with ID in Nigeria over time. However, with reports as recent as this year suggesting that there remains an absence of anti-stigma initiatives in Nigeria (Sango, 2017), it is unclear what could have contributed to this shift. On the other hand, the sample population of this study differs from those of previous Nigerian studies and may explain some of the variability found. For one, the majority of previous studies were conducted on-ground (i.e. in the country), and included people in rural areas with more traditional beliefs (Abah, 2009; Ajuwon, 2012). In contrast, this current study was one of the first to target Nigerian internet users; a sample that predominately live in urban areas and are known to be younger, more educated and higher-incomers (Poushter, 2016). Looking closely at our sample, respondents were predominantly females, Christians, professionals, and graduate degree holders. All of which differ from the general demographic of the country, whereby there is a higher population of men and Muslims, with only 59.6% of population considered literate (CIA, 2017). In addition, 68.5% of participants in this study had prior contact with a person with ID, which has been found to positively correlate with positive attitudes (Scior & Werner, 2016). The percentage of prior contact found in this study is higher than available figures from other studies. For example, Scior, Addai-Davis, Kenyon and Sheridan (2012) found that only 44% of black Africans in their UK study had prior contact with a person with ID. As such, it appears that this study assessed a different sample of the Nigerian population compared to previous studies. Thus this may explain the more favourably attitudes reported by participants at baseline.

This study also explored the association between individual characteristics and attitudes held towards people with ID and found that gender, age, education, place of residence, prior contact and nature of contact all influence attitudes. In terms of gender, women reported higher levels of Discomfort and less favourable attitudes to the rights of people with ID in comparison to men. This finding is different from the study by Akindenor (2007), which found no significant association between gender and attitudes held.

In terms of education, participants with secondary or less education reported less favourable attitudes pertaining to Interaction, Knowledge of Causes, and Superstitious beliefs (IDLS). In addition, living in Western countries was found to positively impact attitudes in regards to Knowledge of Capacity and Interaction.

However, this was not the case for Nigerians residing in Eastern countries. They held more negative attitudes regarding the causes of ID in comparison to Nigerians living in their home country. Indeed, the influence of living outside of Nigeria on attitudes held towards people with ID has been reported by a number of researchers (Aguoji 2007; Akindenor, 2007). There was also a significant difference between perceived level of functioning and attitudes held, with participants expressing more negative attitudes towards people with lower functioning. This is consistent with the wider ID literature on how greater perceived severity of ID elicits more negative attitudes (Scior & Werner, 2015).

Although significant differences were found between the age of participants and the attitudes held towards individuals with ID, this factor warrants further exploration in future studies due to the highly uneven sample sizes in the present study.

Lastly, participants with little to no contact with people with ID were more likely to report feelings of Discomfort than those with more contact. No association was found between attitudes and participants' occupation, religious affiliation or frequency of contact with people with ID.

These findings further support the notion that the effects of socio-demographic variables on attitudes vary within different cultural groups in regards to the direction and strength of the association (Lee, 2016). In addition, despite the significant associations found, these differences had very little impact on the quality of attitudes held. That is, except for Sensitivity, participants' attitudes were all positively polarised irrespective of their individual characteristics. However, it is important to note that Sensitivity and Discomfort had the highest number of correlations with individual characteristics. As

such, these factors should be a focal point for future anti-stigma initiatives, regardless of the sample demographics.

### **Effects of Intervention on Attitudes**

The main aim of this study was to investigate the effect of a brief film based e-intervention integrating education and indirect contact on attitudes towards people with ID. Its effects on all three dimensions of attitude (cognition, affect and behaviour) were assessed immediately post-intervention and at one-month follow-up. In summary, the film was found to have a small to medium size positive effect on Discomfort (16.2% decrease in negative attitudes post film), Sensitivity (8.7% decrease), Interaction (13.7% decrease), Knowledge of Capacity (24.1% decrease), and Superstitious beliefs (19.8% decrease). About 35.3% of these changes were maintained at follow-up.

The magnitude of attitude change observed in this study is relatively high when compared to other anti-stigma interventions. For example, *Time to Change*, a mental health campaign, was one of the few anti-stigma interventions that set out targets for attitude change, aiming to achieve a 5% positive shift in attitudes over the span of three years. The authors described the intervention as the largest anti-stigma programme in England, with an objective to tackle stigma towards people with mental health disorders across an estimated 30 million English adults (Henderson & Thornicroft, 2013). The intervention included social marketing campaigns, public relation events and opportunities for social contact. Our results showed that over-time, a 6-minute film intervention run over a course of 6 months attainted higher percentages of attitude change across all three attitudinal dimensions when compared to the Time to Change intervention; an intervention that was run for a longer duration, with a wider reach and

substantial financial backing. Although this 5% threshold is somewhat arbitrary, it does allow for comparisons between interventions and highlights the effectiveness of the integrated approach used in this study.

Overall, these findings are promising and support evidence from previous studies (Lindau et al., 2017 and Walker & Scior, 2013) that a brief film-based intervention focused on education and indirect contact can change attitudes towards people with ID. It also strengthens the notion that indirect contact is a reliable and effective way to change attitudes and, when combined with educational approaches, its effects are maintained over time (Chan, Mak, & Law, 2009; Walker & Scior, 2013).

Whilst Knowledge of Capacity saw the highest reduction in negative attitudes, which was maintained at follow-up, the film intervention had little effect on Knowledge of Rights and no effect on Knowledge of Causes. This is despite all three factors loading on the cognitive dimension of attitudes. For Knowledge of Causes, other African studies have reported different outcome than what was observed in this study. For example, Hassanein (2015) found that an integrated approach was effective in changing misunderstandings around causes of ID in Egypt. Indeed, looking at the theory behind an integrated approach, one would expect that the cognitive aspect of attitudes would be affected, given that an educational component is used to target misconceptions (Lindau et al., 2017).

One explanation for the lack of change in Knowledge of Causes may be due to the conceptual divide between fidelity and adaptation (Chambers & Norton 2016). Hassanien (2015) found that participants were more likely to elicit a change in attitudes along cognitive dimensions when there was a match between the instrument

and intervention fidelity, that is, the active ingredients in the intervention match the composite elements measured by the instrument. Indeed, to assess for Knowledge of Causes, the ATTID-SF focuses on environmental myths around the aetiology of ID. However, research in Nigeria, which informed this study, has shown that misconceptions around causes are less about environmental and more about superstitious myths (Ajuwon & Brown, 2012; McKenzie et al., 2013). As such, the intervention in this study was deliberately adjusted to be relevant to the Nigerian context by demystifying more superstitious myths than environmental myths. This may explain why while Knowledge of Causes was not affected by the intervention, the Superstitious beliefs subscale of the IDLS, showed a 20% reduction in stigmatising causal beliefs post-film. As such, it could be said that the intervention did in fact have an impact on the cognitive dimension of attitudes but specifically the aspects that were targeted in the film intervention.

In terms of Knowledge of Rights, while there was a short-term positive shift post intervention, this shift did not reach significance and was not maintained over time. The study by Abah (2009) may provide a possible explanation for this may. When looking at the influences of religion on the perceived rights of people with ID, Abah (2009) found that Nigerians belonging to a religious group, irrespective of the type of religion, were more likely to hold less favourable attitudes towards the rights of people with ID. Given that the current study reached a subset of Nigerians with a high religious membership (i.e. over 90% of the sample was Christian), it is possible that the effects of the intervention were minimal when it came to promoting the rights of people with ID via the internet. Indeed, judging by the slight decrease in positive attitudes at follow-up

when compared to baseline, it could be that the educational component of the intervention led to unintentional consequences of reducing positive attitudes, a feature that has been found in a number of studies (Phelan, 2005; Read, 2007; Thachuk, 2011).

Irrespective of the explanation, others may argue that targeting cognitive aspects of attitudes as a whole does little to reduce prejudice and discrimination and that focusing on these latter parts of stigma has more meaningful implications in the real world (Corrigan & Fong, 2014; Hassanien, 2015; Hastings, Hewes, Lock, & Witting, 1996). Indeed, this study has shown that irrespective of Knowledge of Causes and Rights, all affective and behavioural factors saw a positive shift that was maintained over time.

Despite attempts to reduce ascertainment bias and ensure blinding, there were higher dropout rates within the control group than in the experimental group, with the majority of dropouts occurring immediately after watching the film. One explanation for this could be the use of an unrelated control video, as opposed to an alternative intervention. Indeed, the use of an alternative intervention has been found to lead to lower dropout rates in the control group when conducting RCTs (Schulz et al., 2013). For example, when comparing two groups, Walker and Scior (2015) found no differences in dropout rates following the film interventions when using two indirect contact interventions. In addition, research has shown that the presence of differential attrition can lead to bias in the estimate of treatment effects (Bell, Kenward, Fairclough, & Horton, 2013). However, in line with recommendations from Bell et al. (2013), the statistical analysis used to test effectiveness in this study, a mixed model design, helped to control for this bias. This is because 'information from patients with complete data

was used to implicitly impute the missing values' (p. 2), thus allowing the estimates of treatment effects to be unbiased.

In addition, the change in attitudes within the control group over time also warrants consideration. For all six factors that showed a change in attitude, the control group also experienced a positive shift in attitudes, though for the most part this shifts were not significant. However, for Discomfort and Sensitivity, attitudes at follow-up were roughly equivalent between the control and intervention groups. That is, the control group in both cases experienced a gradual increase in positive attitudes over time that resulted in similar levels of attitudes to the intervention groups at follow-up.

Walker and Scior (2013) reported similar findings for their study pertaining to behavioural intentions, stating that all participants experienced a short-term positive shift in attitudes regardless of what material they were presented with. A number of researchers have discussed the impact of measurement effects on attitude shift (Antonak & Livneh, 1995; Triandis, 1971; Walker & Scior, 2013). These effects are believed to "create a small but transient positive shift in attitudes, which could be erroneously attributed to the intervention" (Walker & Scior, 2013, p. 2309). As such, what this may suggest is that while the intervention may have had an impact on Discomfort and Sensitivity post-intervention, it is unlikely to have sustained the impact at follow-up when taking into account measurement effects. Given that part of the mechanism of change for contact approaches is to reduce anxiety and increase empathy (Stephan & Stephan, 1985; Swart, et al., 2011), this may suggest that more emphasis needs to be placed on dealing with these emotions in anti-stigma initiative in order to ensure more lasting effects.

However, despite the impact of measurement effects, for Interaction, Knowledge of Capacity, and Superstitious beliefs, the impact of the intervention was sustained at follow-up, with all three factors showing more positive attitudes overtime compared to the control group.

# **Process Variables and Limitations**

This study showed that online platforms are an appropriate and acceptable way to deliver change interventions in Nigeria. Despite evidence of poor internet connectivity, this barrier did not significantly affect the delivery of the intervention or data collection. However, the reach of the study seemed to be quite affected by the chosen method of delivery. Due to the economic state of the country, only a fraction of the population has access to the internet. It is estimated that about 40% of the country use the internet, with the majority of these users living in more urban areas and having a post –secondary degree, as discussed above (Pew Research Centre, 2016). As such, the sample in this study was unrepresentative of the Nigerian population as a whole and the findings should be interpreted with great caution and not generalised to the Nigerian population. Furthermore, the author's religious background and contacts may have also affected the uptake of more Christian respondents.

Having said that, it was not the intention of this study to target a representative Nigerian sample but more to explore the effectiveness of a brief digital intervention within a Nigerian context. It is also important to note that the respondents' characteristics (i.e. educated, generally young and reporting prior contact with people with ID) have all been associated with more positive attitudes in previous studies

(Lindau et al., 2017; Scior, 2011), and as such may have contributed to the success of this intervention in changing attitudes.

Lastly, the absence of gender diversity within the ATTID vignettes (i.e., both male examples) may have introduced a possible confounding variable. Given the predominately female sample in this study, it is unclear if participants' emotional and behavioural reactions to the vignettes were based on gender differences, the presence of ID or both.

# **Conclusion and Implications**

This study evaluated the impact of an integrated brief digital film-based intervention to combat stigma with a convenience sample of Nigerian internet users . While the findings support the evidence of an integrated approach and the use of e-interventions to combat stigma with Nigerian internet users, the generalisability of the findings needs to be tested with other samples from the population. For one, this study looked at Nigerians irrespective of their place of residence, resulting in the participation of 23% of Nigerians who reside outside the country. Given that past research has shown that place of residency can significantly influence attitudes held amongst Nigerians, the findings from this study may not fully represent the attitudes and opinions of Nigerians who reside in their home country. This is an area for further research. Until then, great caution should be taken when reviewing these results as evidence of the effectiveness of an integrated approach in Nigeria.

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Part 3: Critical Appraisal

### Introduction

In this appraisal I will critically reflect on my experience conducting an international research study while on the clinical psychology doctoral programme (DClinPsy). I will discuss the need for more global research as a thesis option and demonstrate its feasibility by highlighting the factors that led to the successful implementation of my empirical research study. Lastly, I will discuss the personal benefits of conducting global research as an international student.

# A Call for More Global Health Research

Within the global health field, the term *mental health* refers to mental, neurological and substance use (MNS) disorders (World Health Organisation, 2017). Since the early 1990s, there has been increasing evidence that the state of global mental health, especially in low-income and middle-income countries (LMICs), is both a global health crisis and a violation of human rights (Lancet Global Mental Health Group, 2007; Patel, Minas, Cohen & Prince, 2013; Tomlinson, 2013; World Health Organisation, 2004). In 2004, four mental health disorders were identified as being amongst the ten leadings causes of higher mortality rates in people with disabilities in LMICs (World Health Organisation, 2004). In another study, suicide was identified as one of the leading causes of death for all ages globally (Phillips, Li & Zhang, 2002). The consequences of untreated mental health difficulties have been associated with higher levels of stigma and other social disadvantages, poorer health and productivity as well as higher risks of acquiring additional mental health difficulties, amongst other things (Desjarlais, Eisenberg, Good & Kleinman, 1995; Sartorius, 2007). However, despite these findings, two-thirds of those affected receive no treatment and available support continues to be disproportionate to the magnitude of need across the world (Lancet Global Mental Health Group, 2007). This treatment gap has led to several calls for action to scale up interventions as well as reduce factors that limit access (Lancet Global Mental Health Group, 2007; Scior et al., 2016). Numerous stakeholders have answered this call, leading to the development of programmes and centres dedicated to reducing the treatment gap (Centre for Global Mental Health, 2014; Patel, Minas, Cohen, & Prince, 2013; World Health Organisation, 2016). However, according to the Director of the Department of Mental Health and Substance Abuse at WHO, "there remains a wide gap between available health systems capacity and resources, as well as what is urgently needed and what is available to reduce the burden" (World Health Organisation, 2016, p. 3).

The role of psychology in shifting the global mental health burden has been highlighted in a number of studies (Byrne-Davis et al, 2017; Shelton & Waldman, 2013). In their article, *Global Health Psychology: Research, Volunteering and Consultancy*, Byrne-Davis et al. (2017) demonstrate how the research competences that psychologists possess can be useful in furthering the global mental health agenda. While reflecting on their contribution in an international project, in which they partnered with UK health professionals to promote practice change in Uganda and Mozambique, Byrne-Davis et al., (2017) wrote:

What we have given our partners is a) the desire to 'think behaviourally' about education and training; b) a framework to think about what their interventions are trying to change; and c) a theory-based way of thinking about how change might happen. For some of them, we helped them tweak their education and training (e.g., adding implementation intentions), which previous evidence would suggest would make practice change more likely ... (pp. 324).

In addition to our research skills, psychologists are equipped to deliver evidencebased interventions and monitor the effectiveness of these approaches. We therefore can play an important role in reducing the treatment gap in global mental health and should be at the frontlines promoting research, improving/changing policies and training healthcare professionals in prevention, treatment and care of MNS disorders.

As UCL doctoral candidates we are in a good position to use our skills to make a change beyond the UK context. The programme's international presence further allows for global collaboration and partnerships. Indeed, the empirical study that my colleague, Winnie Chege, and I undertook for our DClinPsy thesis is proof that global health research is feasible for doctoral candidates to undertake while on the programme. Through support from our supervisor, Katrina Scior, the UCL Africa and Middle East Network and local partnerships, we were able to run studies in two African countries (Kenya and Nigeria) simultaneously. As such, more global health research should be encouraged and supported within the programme.

# **Conducting an International DClinPsy Research Study**

A number of factors led to the successful implementation of the international study I undertook. I discuss three factors below, which I consider to have played a key role in ensuring the study's feasibility and relevance. Also, throughout this section, I share my experience from two perspectives: one as part of a team conducting a joint research and the other from my specific role in the team, which was to conduct the study in Nigeria.

# **Factor 1: The Need for Collaboration**

The idea for the study came about from the findings from a global review conducted by Scior et al. (2015) on stigma associated with intellectual disability (ID). This study highlighted the high levels of stigma experienced by people with ID and their families in LMICs and called for global action to improve the wellbeing of those stigmatised (Scior et al., 2016). Given that both Winnie and I are from African countries that were identified in the Global review as showing a large gap between the levels of ID stigma evident and the paucity of interventions in place to tackle these, we discussed the possibility of conducting research in our respective countries. However, there were a number of unknowns when it came to deciding on a focus of the work; what was the immediate need? How were we going to carry out an international study given the limited resources we had and the time constraints of the programme?

To answer these questions, our supervisor suggested that we get in touch with the Nigerian and Kenyan respondents from the recent global review to share our intentions, seek their expertise on the area and potentially develop some local partnerships. This was an important first step for the progression of the study. The respondents in the global review were experts, researchers and representatives of organisations/ advocacy networks in the ID field. Some of them also held dual roles as parents of people with ID (Scior et al., 2015). As such, they knew first-hand what the current state of ID was in our respective countries and could provide answers to some of our questions.

The process of contacting these experts was one of my first experiences of liaising with other professionals and I quickly learned that having a shared goal was important for successful collaboration. For the Nigerian experts, there was both a

personal and professional investment in the work they did. As such, they were not interested in tokenistic research and only sought out meaningful collaborations that would better the lives of service users and individuals with ID in general. This meant that when I first approached them, they were more inclined to ask questions about my intentions for the research, how it was going to be used and what direct impact it was going to have on the lives of people with ID. These were questions that I had not giving much thought to until that point. Reflecting back now, at the early stages of research planning I was more driven by the goal of completing my thesis than the actual impact my research could potentially have. However, as the work progressed, finding the balance between both agendas (i.e. completion of thesis versus conducting meaningful research) was something that I often struggled with. At some points, it felt that attending to one meant the other was less achievable.

I was able to strengthen my resolve with the words of Corrigan and Fong (2014), who cautioned researchers to remember the importance of seeing research as more than just another academic exercise but to constantly hold in mind that what we research, be it stigma or mental health difficulties, are real issues and need to be handled as such. In addition, observing my supervisor's enthusiasm and the many ways she used research to promote positive real life change for people with ID both in the UK and globally further reinforced this point. With this understanding came multiple discussions with the experts and over time there was a bi-directional transfer of knowledge, which resulted in a practical and culturally relevant focus for the work. They also became willing partners and opened their centres for me to meet and involve people with ID in the study.

**Managing Expectations through Transparency.** Once it was decided through conversations with the experts that there was a need to tackle public stigma towards people with ID in Nigeria, a number of ideas were proposed from all involved parties about what the intervention might look like. Suggestions included co-facilitating an evidence-based intervention with the experts in Nigeria, as well as running a two-day workshop in a religious and higher education institution to increase our reach.

At these times, having multiple discussions as a team (i.e. my supervisor, the other trainee involved, and I) was tremendously helpful in keeping me true to what I could offer and communicating this to the experts. Indeed, my supervisor, acting in her role as both a supervisor and the academic director of the programme, often reinforced the importance of our research not getting in the way of other programme requirements. My trainee fellow researcher, who had less expert involvement, often reflected on the feasibility of carrying out ideas with limited local support in Kenya. Having lived in Nigeria for many years, I was able to use my experience and understanding of local cultures and practices to discuss issues around acceptability and feasibility of interventions under discussion. Of course, I also relied on research evidence to guide my decision on what intervention would be most effective.

Generally speaking, collaboration in research is a scientific and social imperative (Kahn & Prger, 1994). Within my research, local collaborations were beneficial in numerous ways, including: (1) defining the focus of the work and identifying the target population; (2) gaining access to people with ID to be involved and feature in my project so that their voice would be central in the intervention; (3) ensuring the cultural

appropriateness of measures and content used; (4) ensuring the relevance of the research undertaken; and (5) securing funding for the study.

#### **Factor 2: Overcoming Obstacles**

As the planning progressed, obstacles began to arise. Overcoming these allowed for greater clarity and significant adaptations that were vital in ensuring the cultural relevance/appropriateness of the work.

The first difficulty I faced was derived from our decision to use an online platform as the method for delivering our intervention. As a team, we had decided to use this delivery method after reviewing the literature and finding evidence showing that an indirect approach via film delivered through the internet can be effective in changing attitudes and has the potential to reach larger audiences (Lindau, Amin, Zambon, & Scior, 2017; Walker & Scior, 2013). It also allowed us to control the quality of contact between the general public and people with ID, a main condition for attitude change (Scior & Werner, 2015). Lastly, it increased the feasibility of successfully carrying out the study in Nigeria while enrolled in the DClinPsy programme in London. This last point was vital in getting my research proposal approved by the programme. Interestingly, it also had a close fit with the strategic plans of some of our collaborators in Africa, namely to exploit the use of the internet and social media to achieve change for people with ID.

However, I found that trying to translate the evidence from the wider ID research to the Nigerian context came with its own barriers. For example, Nigeria is known to experience regular power outages and despite a massive increase in internet use over the past decade, poor internet connectivity remains a continuous problem in the country

(Ericsson, 2015). This had significant implications for the design of the study in a number of ways. For one, the potential reach of the study had to be adjusted. As discussed in other parts of my thesis, statistics showed that internet users in Nigeria are mostly young and educated (Ericsson, 2015; Pew Research Center, 2016). However, this is not representative of the population as a whole (CIA, 2017).

Furthermore, as identified by some of the experts, there was a risk that an online study would exclude the rural areas of the country, areas believed to harbour the highest percentage of people with ID as well as the highest levels of stigma (Sango, 2017). To solve this dilemma, I looked to the literature. Evidence shows that there is a lack of government involvement nationally, people with ID are being excluded from schools both within cities and in rural areas, and limited social welfare is still a constant reality for those living with ID in the country, amongst other things (Ajuwon & Brown, 2012; Siperstein, Norins, Corbin, & Shriver, 2013). As such, these findings increased my belief that there remained an important need to take action, regardless of the extent of the reach. It was also hoped that the findings from my study would encourage more research in the country, thus expanding those reached over time. Based on these findings, I decided that it was best to limit my target demographic to Nigerian internet users, as discussed with the team.

Secondly, the methodology of the study had to be considered. When developing an online intervention it is important to consider how participants interact with all aspects of the study, i.e. the content and the online platform (Horvath, Ecklund, Hunt, Nelson & Toomey, 2015). Holding in mind participants' perspectives (i.e. what it would

be like to take part in an online study with limited internet connectivity) helped me anticipate and account for possible barriers.

Similar to previous research (Lindau et al., 2017; Walker & Scior, 2013), it was my intention to produce a study with high methodological rigour (i.e. a randomised control trial with data collection at three time points). However, this was complicated by the struggle to find an attitude measure that had good psychometric properties, including good test-retest reliability, yet was short enough to limit the amount of time research participants had to spend online (the rationale being that a short study would reduce the impact of poor internet connectivity).

In their review of the literature, Scior and Werner (2015) deemed the Attitudes towards Intellectual Disability (ATTID) questionnaire (Morin, Rivard, Crocker, Boursier, & Caron, 2012) superior to other attitude measures (such as the widely used Community Living Attitudes Scale- Intellectual Disability version; Henry, Keys, Jopp & Balcazar, 1996) due to its ability to: 1) distinguish between the three components of attitudes (cognition, affect and behaviour), and (2) capture the diversity of the ID population (Scior & Werner, 2015). As such, as a team, we decided on this measure as the primary outcome measure. However, we quickly realised that the length of the ATTID, 67 items in its original form, was not conducive for our online study. This was further complicated by the input from the collaborators in Nigeria, who had mixed feelings about using a quantitative approach to collect data. Some highlighted that questionnaire surveys using Likert scales were not common practice in the country and that by using the ATTID I ran the risk of obtaining inaccurate information. Instead, they pushed for a more qualitative approach. Others disagreed and felt that reducing the

measure's length would suffice. Byrne-Davis et al. (2017) faced a similar dilemma in their work in Uganda. They found that both the use of qualitative methods and simplification of Likert responses to three options of 'agree', 'disagree', or 'don't' know' resulted in the collection of rich data.

In my case, the option of a quantitative approach was less feasible for the same reasons I could not conduct the whole study on-ground; I did not have the time nor the resources to carry out qualitative studies in Nigeria. Furthermore, given the chosen target population (i.e. the more educated subset of the population) there was less of a risk that the response choices would be misunderstood. After discussing these dilemma with the team, we agreed it was best to shorten the length of the ATTID in partnership with the authors of the measure (which is discussed in detail in the empirical paper).

In the end, having a shortened ATTID measure helped increase participants' engagement and reduce the amount of attrition in the study. Indeed, participants' feedback showed that the length of the survey was deemed entirely acceptable. Also, the process of adapting the ATTID allowed for further international collaboration while personally increasing my confidence as a researcher. I discovered that I had the skills to critically evaluate a validated measure, assess its appropriateness to my target population and cultural context, propose a shortened version by reviewing its psychometric properties, and have constructive conversations with other psychologists about how to maintain the face validity and reliability of the measure.

Lastly, gaining ethical permission to conduct an international online study came with its own difficulties. Although gaining ethical approval from the Nigerian authorities was considered, the nature of the research (which was an online study targeting

Nigerians despite their place of residency) meant that the study was not confined to any particular institution in the country. As such, we were faced with the dilemma of including participants living in different parts of the world to which different national ethical standards may apply. As the study took place in an online environment, it was agreed that ethics approval from the conducting institutional body would suffice.

# **Factor 3: Cultural Competency in Research**

Cultural competency refers to a researcher's ability to understand his/her target population and to use this understanding to drive all aspects of research, including, design, conduct and interpretation (Shiu-Thronton, 2003). Within this research, being culturally competent played a critical role in the development of the intervention, the measures used, and the analysis and interpretation of the results, just to name a few.

When it came to deciding on the content for the film intervention, I looked to past research and my local partners for guidance. Through past research, I received guidance on what mechanisms needed to be included in order for change in attitudes to occur. From previous studies, I was able to see examples of how theory was translated into practice. In my case, there had been past student research that had conducted similar research to mine, albeit in the UK. As such, this provided initial thoughts regarding how to adapt existing material to fit our study demographic.

However, consultations with experts and discussions within our team revealed that there were core cultural differences in how stigma presented itself in the UK versus in an African context. Indeed, Townsend (2011) highlighted in his study how differences in culture result in differences in need, thus there could not be a one-size-fits all intervention. Therefore, simply adapting pre-existing material was not an option for me.

I had to create a video intervention to specifically fit my target population. To create a culturally appropriate video, it was important that the people featured in the video as well as their experiences were relatable to the target audience and that the information being shared was credible. In addition, it was important that the intervention targeted relevant misconceptions in order to increase the likelihood of attitude change. As such, the videos had to be made in my home countries. My research colleague also produced a film for her study as well.

The majority of the planning for the Nigerian video was coordinated with the help of local partners in Nigeria. This allowed for a smooth recording process when I arrived home. The recordings were done over a two-week period and did not interfere with other programme requirements.

Furthermore, understanding the cultural beliefs and misconceptions around ID, led to the addition of another measure to supplement the ATTID, the supernatural beliefs subscale of the Intellectual Disabilities Literacy Scale (IDLS) (Scior & Furnham). This was done to ensure that the measures used accurately captured multiple facets of attitudes to ID within Nigerian and Kenyan contexts. Indeed, despite the ATTID being quite a comprehensive measure, it lacked common superstitious misconceptions of ID that are held in most African societies. Overall, striving for cultural appropriateness in the research process helped to ensure that the research was applicable to the Nigerian population.

# **Personal Relevance**

The research excellence framework (REF) is a system that assesses the quality of research in UK higher education institutions (Manville et al., 2015). In 2014, the REF

redefined excellence of research to include not just academic quality but also the quality of social and economic impact (University of Sheffield, 2017). As an international doctoral candidate, the temptation for research to become another tick-box exercise is quite high. With limited programme resources and time constraints, it is easy to find oneself conducting research that neither has personal relevance, nor direct social impact in one's home countries. This sometimes reduces the opportunity to learn the values of research outside of the academic environment. However, I was fortunate to experience otherwise by being deliberate in seeking out research that had present relevance in my home country; Nigeria, as well as having a supervisor who not only supported this decision but created opportunities to ensure that the study was feasible and of doctoral level standards.

Through my research, I witnessed first-hand the social benefits of research on a systemic level. With tremendous help from my supervisor, I: (1) met Nigerian experts in the field who are constantly finding innovative ways to combat stigma with limited resources and consulted with them on how to support their agenda through my own research; (2) spoke in conferences about the opportunities for global partnerships, highlighting the different ways we as academics/clinicians can improve the well-being of people with ID around the world; (3) met and heard first-hand experiences from Nigerians with ID and collaborated with them on how to change public misconceptions; (4) got involved in a multi-national collaboration aimed at creating a shortened version of an attitudes measure that is more conducive for regions of the world where environmental factors limit the extent to which research can be done; and most importantly (5) was involved in combatting stigma in my home country and raising

awareness of the capabilities and rights of people with ID. As a researcher, I am proud of the work I have done and finish the programme with a desire to expand on this work and continue to make meaningful impact.

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# Appendices

Appendix A: Quality Appraisal Checklist (Hawker et al., 2002)

Quality Appraisal Checklist (Hawker et al., 2002)

1. Abstract and titl		title: Did they provide a clear description of the study?
	Good (4)	Structured abstract with full information and clear title.
	Fair (3)	Abstract with most of the information.
	Poor (2)	Inadequate abstract.
	Very poor	No abstract.
	(1)	
2.	Introduction a	and aims: Was there a good background and clear statement of the
	aims of the re	
	Good	Full but concise background to discussion/study containing up-
		to date literature review and highlighting gaps in knowledge.
		Clear statement of aim AND objectives including research
		questions.
	Fair	Some background and literature review. Research questions
		outlined.
	Poor	Some background but no aim/objectives/questions, OR
		aims/objectives but inadequate background.
	Very poor	No mention of aims/objectives. No background or literature
		review.
3.		lata: Is the method appropriate and clearly explained?
	Good	Method is appropriate and described clearly (e.g., questionnaires
	<b>.</b> .	included). Clear details of the data collection and recording.
	Fair	Method appropriate, description could be better. Data described.
	Poor	Questionable whether method is appropriate. Method described
		inadequately. Little description of data.
	Very poor	No mention of method, AND/OR method inappropriate, AND/OR no details of data.
		AND/OK no details of data.
4.	Sampling: Was the sampling strategy appropriate to address the aims?	
	Good	Details (age/gender/race/context) of who was studied and how
		they were recruited. Why this group was targeted. The sample
		size was justified for the study. Response rates shown and
		explained.
	Fair	Sample size justified. Most information given, but some missing.
	Poor	Sampling mentioned but few descriptive details.
	Very poor	No details of sample.
5.	Data analysis	: Was the description of the data analysis sufficiently rigorous?
	Good	Clear description of how analysis was done. Qualitative studies:
		Description of how themes derived/respondent validation or
		triangulation. Quantitative studies: Reasons for tests selected
		hypothesis driven/numbers add up/statistical significance
		discussed.
	Fair	Descriptive discussion of analysis.
	Poor	Minimal details about analysis.
	Very poor	No discussion of analysis.

6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?

	Good	Ethics: Where necessary issues of confidentiality, sensitivity
		and consent were addressed. Bias: Researcher was reflexive
		and/or aware of own bias.
	Fair	Lip service was paid to above (i.e., these issues were
		acknowledged).
	Poor	Brief mention of issues.
	Very poor	No mention of issues.
7.	Results: Is th	here a clear statement of the findings?
	Good	Findings explicit, easy to understand, and in logical progression Tables, if present, are explained in text. Results relate directly to aims. Sufficient data are presented to support findings.
	Fair	Findings mentioned but more explanation could be given. Date
		presented relate directly to results.
	Poor	Findings presented haphazardly, not explained, and do no
		progress logically from results.
	Very poor	Findings not mentioned or do not relate to aims.
0	Transforabil	its an annualizability. Are the fundings of this study transformabl
٥.		ity or generalizability: Are the findings of this study transferable le) to a wider population?
	Good	Context and setting of the study is described sufficiently to allow
	0000	comparison with other contexts and settings, plus high score in
		Question 4 (sampling).
	Fair	Some context and setting described, but more needed to replicat
		or compare the study with others, PLUS fair score or higher in
		Question 4.
	Poor	Minimal description of context/setting.
	Very poor	No description of context/setting.
9.		and usefulness: How important are these findings to policy an
	practice?	
	Good	Contributes something new and/or different in terms of
		understanding/insight or perspective.
		Suggests ideas for further research. Suggests implications fo
	-	policy and/or practice.
	Fair	Two of the above (state what is missing in comments).
	Poor	Only one of the above.
	Very poor	None of the above

#### Appendix B: Joint Thesis

A joint study was conducted with Winnie Chege, Trainee Clinical Psychologist (University College London). The empirical paper examined: (1) the baseline attitudes towards people with intellectual disabilities within a subset of Nigerian internet users and (2) evaluated the impact of a brief e-intervention in changing negative attitudes towards the former group. Winnie Chege carried out these aims within a Kenyan sample. Both Winnie Chege and I worked together on the following things: conceptualisation of study, decisions on methods and measures to be used. However, the production of the intervention, recruitment, data collection and data analysis were entirely conducted separately.

#### Appendix C: UCL Ethics Approval Letter

#### 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.

- 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': <u>http://ethics.grad.ucl.ac.uk/responsibilities.php</u>
- 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 (<u>ethics@ucl.ac.uk</u>) 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 (<u>ethics@ucl.ac.uk</u>) 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.

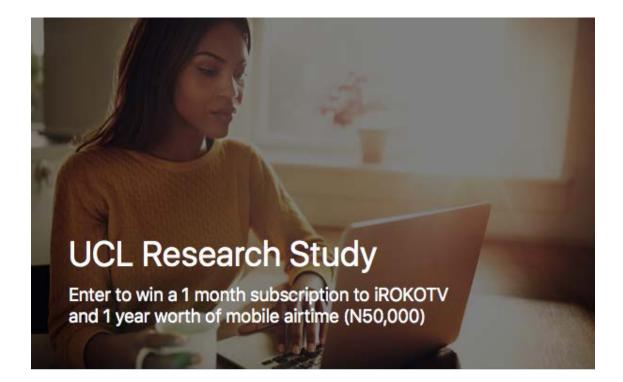
On completion of the research you must submit a brief report of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

Yours sincerely

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 3 108 8216 Email: <u>ethics@ucl.ac.uk</u> <u>http://ethics.gend.ucl.ac.uk/</u> Appendix D: Flyers and Vouchers Advertising the Study



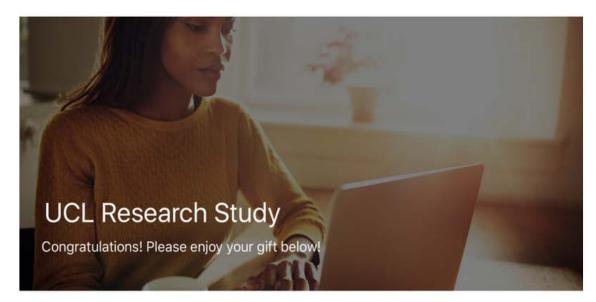
# How to enter

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

ENTER TO WIN





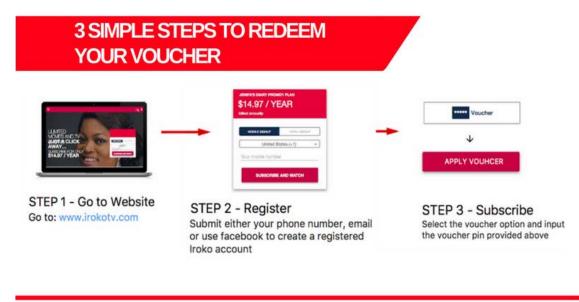


Thank you for completing the research study!

Your IrokoTV Voucher Pin is

With this, you will enjoy free unlimited African movies for the

next 30 days by just following the 3 simple steps below.







Appendix E: Details of Film Intervention

### Full Video Link

https://youtu.be/2MpipkGk9Zs

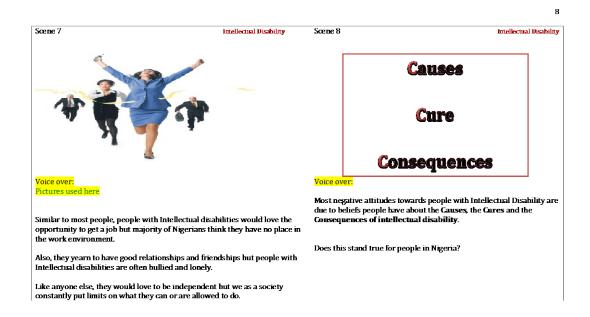
## **Proposed Storyboard for Film**

Please note, several amendments were made during recording, see link above for final version of film.

Story Board The of Project: Combuting Styre 2: Testing an e-Anterovation in Lagar, Vigeria Deadline, for Video: Sentabri 2015 Required Testing of Video: Samines Budget Short Anter SI Known: Last Guly or Each September Short Anter Strangel audience: Nigrian Interret User Last on canagelor of video that chowcare the spor par tests video	Structure of Board Top part of table: Visual Illustration (Examples of what will appear on the screen)
#FundaMentalSDG	Bottom part of table:
Special Olympics	Script of Video (This will be said by a voiceover or a person)

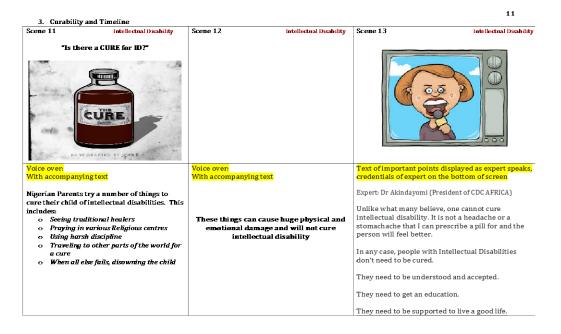
	tellectual Scene 3 Disability	Intellectual Disability
	Nige	eria
	1	
here if possible	In Nigeria, people wi sometimes called: Mentally Retz Handicapped Imbeciles In Yoruha: "ù In Hausa : "Du In Hausa : "Ony Although these term	ith Intellectual Disabilities are arded de" or "Dindinrin" olo" or "Wawa"
	Voice over: Background music begins; graphi here if possible It is estimated that around 2 out of 100 people have an intellectual	Disability Disabi

Scene 4	Intellectual Disability	Scene 6	Intellectual Disability
		No Education Y O	rk No love
 Voice over: Pictures used here		Voice over: Pictures used here	
It is common for People v symbol of shame or disgr A people to be hidden aw	ace.	However, people with Intell social and emotional needs general population.	
	ttitude is that people with to avoid the family being drome Nigeria)		
"Majority of mothers of cl difficulties in some parts or embarrassed to be see Ofovwe and Ofovwe	of Nigeria were ashamed		

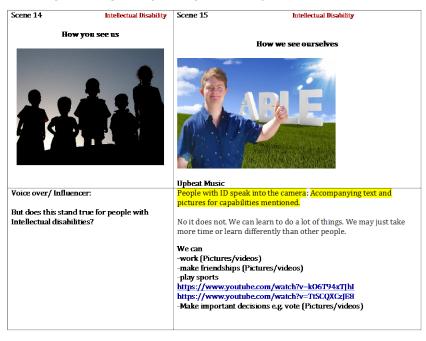


2. Causes, (Stats on that), Theory used: educational Strategies.

Scene 9 Intellectual Disability	Scene 10 Intellectual Disability
CAUSES	
Voice over: With accompanying text	Text of important points displayed as expert speaks, credentials of expert on the bottom of screen Expert: Mrs Mordi Head of Down Syndrome Nigeria
	Intellectual disabilities happen because the brain gets injured or a problem prevents the brain from developing normally. Research shows that 60% of all cases of Intellectual disabilities are caused by biological and environmental factors:
So what causes ID?	30% of these cases are caused by Genetic conditions that are inherited from parents. Examples of genetic conditions are Down syndrome, and Fragile X syndrome.
	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. However, in about 40% of cases, the causes of intellectual disabilities are not known.
	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.



4. Consequences of having an ID. People with ID speak. Contact theory.



Scene 15	Intellectual Disability	Scene 16	Intelectual Disability			
r		Video clips of people with ID talking				
Voice over/ Influ	encer:	People with ID mentioned.	speak into the camera: Accompanying text for capabilities			
Our message:		mencioneu.				
0		So don't write	us off before you get to know us.			
beliefs different i	nd religion, might make our n little ways but being born n intellectual disability does	When you see	us, these are a few things you can do to help.			
not make us diffe	rent from one another. We all	-Be sincere				
	gs in life, which is to be free	-Listen				
to live the life we	want.	-Make eye con				
			much or too quickly			
		-Be patient -Be sensitive.				
			uencer, Note the famous person will now say this part).			
		End with a hug				

Form. Morin et al., (2017)

#### The Attitudes Toward Intellectual Disability ATTID Questionnaire – Short Form

D. Morin, P. Valois and A.G. Crocker

Using the following scale, please shade in the circle that corresponds to your response. There is no right or wrong answer.

Totally agree	ally agree Agree Neither agree Disa nor disagree			gree		Totally disagree		Not applicab or don't know	
1	2	3	4			5		9	
1A In your opin by:	ion, intellectual of	disability may be o	aused	1	2	3	4	5	9
1A a malnutrit	ion of the mothe	r		-{	-{	- {	£	-{	{
1A b serious h	nead injury incur	red by the child		-{	{	{	{	{	{
1A c lack of st	timulation during	childhood		{	{	{	{	£	{
1A d chemica	ls in the environr	ment		{	{	{	{	{	{
	otion of drugs or egnancy	alcohol by the mo	other	{	{	{	{	{	{
1A f problems	s during birth			{	{	{	{	{	{
are able:	-	ITY of people with	n an ID	1	2	3	4	5	9
	own a job?			{	{	{	{	{	<u>{</u>
	e money?			{	{	{	{	{	{
1C d to carry o	on a conversatio	n?		-{	-{	Ł	Ł	-{	- {
1C j to make	decisions?			- {	{	{	£	{	{
1D I your opinion, people with ID: 1 2 3 4 5 9								9	
1D d should have the right to get married					{	{	{	{	{
1D f should have the right to have sex				{	{	{	{	{	{
1D g should have the right to vote					{	{	{	-{	{
1D h should have the right to have children					-	£	{	{	

The ATTID – short form may not be reproduced or used without the written authorization of the author, Diane Morin.

May 2017

1234592AIf you met Dominic on the street and Dominic tried to talk to you, do you think you would:1234592A a feel afraid? $\{$ <td< th=""><th>Totally agree</th><th>Agree</th><th>Neither agree nor disagree</th><th>Disag</th><th colspan="2">Disagree</th><th>Fotally sagree</th><th></th><th colspan="2">Not applicat or don't kno</th></td<>	Totally agree	Agree	Neither agree nor disagree	Disag	Disagree		Fotally sagree		Not applicat or don't kno	
talk to you, do you think you would:2A a feel afraid? $\{$ </td <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td></td> <td></td> <td>5</td> <td></td> <td>9</td> <td></td>	1	2	3	4			5		9	
ZA bfeel pity?Image: Constraint of the constraint				tried to	1	2	3	4	5	9
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ZA eexperience anxiety?ICCC <thc< th="">CCCC<th< td=""><td>2A b feel pity?</td><td>?</td><td></td><td></td><td>{</td><td>{</td><td>{</td><td>{</td><td>{</td><td>{</td></th<></thc<>	2A b feel pity?	?			{	{	{	{	{	{
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$2A g$ be wary? $\{$	2A f feel inse	cure?			{	{	{	{	{	{
2A hfeel touched, moved?{{2D nling3D nling <td>2A g be wary?</td> <td>?</td> <td></td> <td></td> <td>-</td> <td>{</td> <td></td> <td></td> <td></td> <td></td>	2A g be wary?	?			-	{				
2B f       would you agree to supervise Dominic at your       {       <	2A h feel touc	hed, moved?			-					
work?       Image: Constraint of the end of the	2B In your opir	nion,			1	2	3	4	5	9
a clothing store?       i		you agree to sup	ervise Dominic at	your	{	{	{	{	{	{
an electronics store?iiiiiii2B iwould you accept Dominic as your son or daughter's friend?iiiiiii3A If you met Raphael on the street and Raphael tried to talk to you, do you think you would:1234593A afeel afraid?iiiiiiiii3A afeel afraid?iiiiiiii3A bfeel pity?iiiiiiii3A cfeel sad?iiiiiiii3A ffeel insecure?iiiiiiii3A hfeel touched, moved?iiiii <tdi>iiii3A hfeel touched, moved?iiiiii<tdi>iiian electronics store?iiiii<tdi>i<tdi>iiiiian electronics store?iiiiiiiiiiian electronics store?iiiiiiiiiiiian electronics store?iiiiiiiiiiiiiiiiiii<t< td=""><td></td><td></td><td>advised by Dom</td><td>inic in</td><td>{</td><td>{</td><td>{</td><td>{</td><td>{</td><td>{</td></t<></tdi></tdi></tdi></tdi>			advised by Dom	inic in	{	{	{	{	{	{
daughter's friend?       1       2       3       4       5       9         3A If you met Raphael on the street and Raphael tried to talk to you, do you think you would:       1       2       3       4       5       9         3A a feel afraid?       { <td< td=""><td></td><td></td><td>advised by Dom</td><td>inic in</td><td>{</td><td>{</td><td>{</td><td>{</td><td>{</td><td>{</td></td<>			advised by Dom	inic in	{	{	{	{	{	{
talk to you, do you think you would: $3A a$ feel afraid?{{{{ $3A b$ feel pity?{{{{{ $3A c$ feel sad?{{{{{ $3A e$ experience anxiety?{{{{{ $3A f$ feel insecure?{{{{{ $3A g$ be wary?{{{{{ $3A h$ feel touched, moved?{{{{{			nic as your son o	r	{	{	{	{	{	{
$3A b$ feel pity? $\{$ $3A f$ feel touched, moved? $\{$	•	•		tried to	1	2	3	4	5	9
3A b       feel pity?         3A c       feel sad?         3A c       feel sad?         3A e       experience anxiety?         3A f       feel insecure?         3A g       be wary?         3A h       feel touched, moved?	3A a feel afr	raid?		-	{	{	{	{	{	{
3A c       feel sad?         3A e       experience anxiety?         3A f       feel insecure?         3A g       be wary?         3A h       feel touched, moved?	3A b feel pit	y?		-	-					{
3A e       experience anxiety?       { <td>3A c feel sa</td> <td>d?</td> <td></td> <td>-</td> <td>-</td> <td></td> <td></td> <td></td> <td></td> <td>{</td>	3A c feel sa	d?		-	-					{
3A f       feel insecure?       {	3A e experie	ence anxiety?		-	5	ş	ş	ş		ş
3A g       be wary?       { <td< td=""><td>3A f feel ins</td><td>secure?</td><td></td><td>-</td><td>-</td><td></td><td></td><td></td><td></td><td>{</td></td<>	3A f feel ins	secure?		-	-					{
3A h         feel touched, moved?         {	3A g be war	·y?		-	-	{				{
	3A h feel tou	uched, moved?		-	-	{				{
	3A i feel co	mfortable talking	to him?	-	{	{	{	{	{	{

Totally ag	ree	Agree	Neither agree nor disagree	Disagr	ee		otally sagree		lot appl or don't	
1		2	3	4			5		9	
3B In you	3B In your opinion,						3	4	5	9
3B e would you agree to supervising Raphael at your work?				{	{	{	{	{	{	
3B f would you accept Raphael as your son or daughter's friend?				{	{	{	{	{	{	

#### AUTHOR'S NOTE

A manuscript about the ATTID – Short Form will be submitted soon. Morin, D., Valois, P., & Crocker, A. G. (in preparation). *Validation of the Attitudes Toward Intellectual Disability – ATTID Short Form.* 

For the ATTID questionnaire – long form, please refer to the following. Morin, D., Crocker, A. G., Beaulieu-Bergeron, R., & Caron J. (2012). Validation of the Attitudes toward intellectual disability –ATTID questionnaire. *Journal of Intellectual Disability Research*, 57

#### **Adjusted Vignettes Used:**

(Moderate ID) Jide 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. Jide 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. Jide knows how to use the telephone and can write.

(Severe ID) Uche is an adult with ID. He communicates using sounds and gestures. He is able to show by gestures that he needs to go to the toilet. Since Uche 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.

#### Appendix G: Questions assessing Participant Experiences

- (1) How did you access this study?
  - a. Personal device (smartphone, tablet, computer or other),
  - b. Internet café
  - c. Educational centre
  - d. Place of work
  - e. Other.
- (2) Approximately how long did it take you to complete the study?
  - a. Less than 20 minutes
  - b. 20-40 minutes
  - c. 1 hour
  - d. I didn't complete it in one sitting
  - e. Other
- (3) Did you experience any difficulties with Internet connectivity while completing the

study?

- a. Yes
- b. No.

If yes answer questions 4, if no move on to question 6

- (4) What was the nature of these difficulties? (Please select all that apply)
  - a. Slow connection speed
  - *b*. No Wi-Fi signal
  - c. Insufficient data package
  - d. Other

(5) How did these difficulties affect your ability to:

	A lot	Somewhat	A little	Not at all
Access the study				
Answer the question				
Watch the film				
Complete the study				

- (6) On average, how many times did you have to visit the site complete the study?
- (7) Overall, what did you think about:

	Too long	Too Short	Just right
The length of the			
questions			
The length of the			
film			

	Excellent	Good	Average	Poor	Terrible
The content					
of the film					
The questions					
asked					

	Canadian (Shortened version)		Nigerian (Shortened Version)
Number of factors	5		6
Method used to determine factors	Screen plot		Screen plot
	Proportion	n of variance	
Total Variance:	47.60%	Total Variance:	54.55%
Factor 1:	13.12	Factor 1: Discomfort	12.65
Discomfort			
Factor 2:	11.21	Factor 2: Sensitivity &	9.25
Knowledge of		Tenderness	
Rights and capacity			
Factor 3:	9.08	Factor 3: Interaction	9.19
Interaction			
Factor 4:	7.59	Factor 4: Knowledge	8.82
Sensitivity &		of Rights	
Tenderness		C C	
Factor 5:	6.60	Factor 5: Knowledge	7.67
Knowledge of		of Capacity	
Causes		1 ·	
		Factor 6: Knowledge of Causes	6.97
	Factor	Loading	
		Discomfort	
alpha	α=.87	alpha	α=.87
-		-	
Experience anxiety	.752	Feel insecure (Severe)	.774
Moderate)			
<b>C</b> 1.	724	F 1'	720
Feel insecure	.734	Feel insecure	.738
(Moderate)		(Moderate)	
Be wary	.723	Experience anxiety	.713
(Moderate)	.125	(Severe)	./15
(widderate)		(SEVELE)	
Be wary (Severe)	.682	Feel afraid (Severe)	.702
se wary (severe)	.002		.102
Feel afraid	.666	Experience anxiety	.678
(Severe)	.000	(Moderate)	.070
		(110001000)	
Feel afraid	.665	Be wary (severe)	.648
		• × /	

Appendix H: Results of Exploratory Factor Analysis: Comparison between the Nigerian and Canadian dataset.

(Moderate)
------------

Feel insecure (Severe)	.652	Feel afraid (Moderate)	.647
Experience anxiety (Severe)	.633	Be wary (Moderate)	.618
	vledge of Rights and	Factor 2: Sensitivit	y and Tenderness
alpha	pacity α= .811	alpha	α=.82
To make decisions	.693	Feel touched, moved? (Severe)	.710
Should have the right to get married	.671	Feel sad (Moderate)	.708
To handle money	.665	Feel touched, moved? (Moderate)	.692
Should have the right to vote	.664	Feel pity (Moderate)	.688
Should have the right to have children	.645	Feel pity (Severe)	.685
To carry on a conversation	.635	Feel Sad (Severe)	.678
Should have the right to have sex	.624		
To hold down a job	.583		
	Factor 3	: Interaction	
alpha	α=.80	alpha	α=.79
Would you agree to supervise (Severe) at your work?	.742	Would you agree to supervise (Severe) at your work?	.720

Would you accept (Severe) as your son or daughter's friend?	.642	Would you accept (Severe) as your son or daughter's friend?	.679
Would you agree to supervise (Moderate) at your work?	.607	Would you accept being advised by (Moderate) in an electronic store?	.626
Would you accept (Moderate) as your son or daughter's friend?	.588	Would you agree to supervising (Moderate) at work?	.611
Would you accept being advised by (Moderate) in a clothing store?	.587	Would you accept being advised by (Moderate) in a clothing store	.598
Feel comfortable talking to him (Severe)	.578	Feel comfortable talking to him (Severe)	.595
Would you accept being advised by (Moderate) in an electronics store?	.534	Would you accept (Moderate) as your son or daughter's friend?	.559
Factor: 4: Sensitivity and alpha $\alpha = 1$		Factor 4: Know alpha α=	ledge rights = .89
Feel sad (Severe)	.746	Should have the right to have sex	.866
Feel sad (Moderate)	.689	Should have the right to get married	.865
Feel touched,	.633	Should have the right	.852

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moved? (Severe)			to have children		
Feel pity (Severe)		.625	Should have the right to vote		.773
Feel touched, moved?		.618	Factor 5: Knowledge	of Capacit	У
(Moderate)			alpha	α=.82	
Feel pity (Moderate)		.537	To carry on a conversation		.809
			To handle money		.803 .777
			To hold down a job		.///
			To make decisions		.763
	(7	Factor: Know	ledge of Causes	(0	
alpha	α=.67		alpha	α=.68	
Consumption of drugs or alcohol by the mother during pregnancy		.683	Serious head injury		.712
Malnutrition		.673	Consumption of drugs or alcohol by the mother during the pregnancy		.707
Problems during birth		.62	Chemical in the environment		.644
Chemical in the environment		.595	Problems during birth		.637
Serious head injury		.585	Malnutrition in the mother		.579
Lack of stimulation		.519	Lack of Stimulation		.442

Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalisation. Rotation converged in 6 iterations.

# Appendix I: Data from Process Evaluation

Appropriateness of Study			
	Frequency		%
Access Study		(n=494)	
Personal device (e.g. mobile	420	8	35.0
phone, laptop, iPad)			
Internet cafe	5		1.0
Educational Centre	1		.2
Place of work	27		5.5
Other	41		8.3
Length of Completion			
Less than 20 minutes	293	4	59.3
20-40 minutes	141	2	28.5
1 hour	8		1.6
Didn't complete in one sitting	50	1	10.1
Other	2		.4
Internet Difficulties		(* 105)	
Experienced		(n=495)	
Yes	62	1	12.5
No	433	8	37.5
Nature of Difficulty		(n=62)	
Slow connection speed	43	ť	59.4
No Wi-Fi signal	7	1	11.3
Insufficient data package	2		3.2
Other (e.g. power cut;	10	1	16.1
intermittent Wi-Fi signal)			
Impact of Difficulty on		(n=57)	
Study Access			
A lot	2		3.5
Somewhat	9	1	15.8
A little	18		31.6
Not at all	28	2	49.1

Appropriateness of Study

	Frequency	%
Impact of Difficulty on	(n=60)	
Video Streaming		
A lot	15	2.6
Somewhat	17	3.0
A little	13	2.3
Not at all	15	2.6
Impact of Difficulty on	(n=	=59)
Study Completion		
A lot	2	.4
Somewhat	10	1.8
A little	22	3.9
Not at all	25	4.4
No of Times Study	(n=432)	
Accessed		
Once	341	78.9
Twice	69	15.9
Thrice	19	4.39
4+	3	0.7

# Acceptability of Study

	Frequency	%
Length of questions		
Too long	79	16.1
Too short	5	1.0
Just right	408	82.9
Length of Video		
Too long	68	14.0
Too short	3	0.6
Just right	415	85.4
Content of Questions		
Excellent	263	53.2
Good	194	39.3

Average	33	6.7
Poor	3	0.6
Terrible	1	0.2
Content of Video		
Excellent	191	38.8
Good	271	55.1
Average	24	4.9
Poor	6	1.2