“I want to say that disabled people also want to live as human beings”: Stigma Experiences of Women with Disabilities in Pakistan

Amy Dixon

DClinPsy Thesis (Volume 1), 2023

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: [redacted]

Name: Amy Dixon

Date: 16th June 2023

Overview

People with disabilities experience significant discrimination which threatens their quality of life. Further research is needed to improve our understanding of stigma and how it manifests, in order to develop effective stigma-reduction interventions and support the rights of people with disabilities. This thesis is presented in three parts, focussing, overall, on measuring and understanding disability-related stigma.

Part 1 presents a systematic review of available stigma measures designed to be completed by people with disabilities. It provides an overview and critical appraisal of the psychometric quality of the identified measures, and concludes that, currently, there is lack of evidence regarding the quality of self-report disability stigma measures. Further development and validation of stigma scales for people with disabilities is needed.

Part 2 comprises of an empirical study conducted in Pakistan, that focussed on the implementation of the Women with Disabilities Stigma Inventory (WDSI), a new self-report stigma measure that was culturally adapted and co-designed with women with disabilities. The findings indicated that women with disabilities in Pakistan experience significant levels of stigma, aspects of which are influenced by sociodemographic variables.

Part 3 sets out a critical appraisal of the empirical paper, reflecting on the process of conducting research cross-culturally in partnership with international agencies. This is followed by a discussion of the ethical considerations raised during the project. Further, an exploration of the challenges of participatory research and designing a quantitative measure of stigma sensitive to the effects of intersectionality is provided. Finally, recommendations are made for future research and dissemination of the findings.

Impact Statement

The insights from this thesis add to the scarce literature relating to the first-hand stigma experiences reported by people with disabilities. People with disabilities are rarely given a voice and it is hoped that this research provides a platform to emphasise the persistent discrimination faced by this group and, further, the need for fundamental systemic changes to improve the lives of people with disabilities.

The research systematically reviewed available measures of disability stigma that can be completed by people with disabilities. Some key debates are discussed, for example whether stigma is a generalisable construct and if measures can be reliably translated for use in different countries or adapted and applied to people with different disability types. The results highlight the lack of reliable measures of stigma that can be completed by people with disabilities, and the need for the development and further validation of such measures. The conclusions will guide researchers in developing, selecting, or adapting reliable stigma measures suitable for use with their intended sample. This will allow for a more extensive analysis of disability stigma, which is essential for the development of effective stigma interventions.

Stigma experienced by people with disabilities can differ significantly depending on intersectionality with other identities, including gender. However, the effects of intersectionality are often overlooked in disability research and human rights policies, and the lack of protection and rights of women with disabilities remains a global issue. The empirical study focuses on the intersect of disability and gender, to assess the experiences of women with disabilities in Pakistan utilising a new self-report measure, the Women with Disabilities Stigma Inventory (WDSI). The WDSI is the first measure designed to recognise and compare the diverse experiences women with disabilities. It is a reliable measure that can be used to continue to gather data on intersectional stigma and the realities of women with disabilities, inform policies and legislation, and evaluate the effectiveness of stigma-reduction strategies.

The results of the empirical paper provide evidence that women with disabilities continue to face stigma and discrimination. Moreover, data emphasises the need to apply intersectionality frameworks to research and the design of interventions. The data gathered triggered conversations with important stakeholders including Ministry officials in Pakistan, and it is hoped that the momentum gained can be carried forward to continue to focus on the needs of women with disabilities. A Policy Dialogue was held at the beginning of June with government officials and individuals who contributed to the project to disseminate the findings and discuss the changes that should be made across multiple levels in Pakistan to reduce stigma and support the rights of people with disabilities. Here, it was recognised that to remove the barriers faced by women with disabilities changes to policy and legislation are needed, in addition to changes in community and familial attitudes towards women with disabilities. Several ideas were shared to enable changes, such as creating a shared definition of disability, simplifying the process to register a disability, producing guidelines regarding assistive measures to ensure that women with disabilities can access their communities and digital information, and the provision of affordable and accessible education.

The findings from this thesis will be disseminated through further meetings and conferences. Finally, it is hoped that the systematic review and empirical paper will be published as two separate papers in academic journals.

Table of Contents

List of Tables

Part 1: Literature Review

Part 2: Empirical Paper

List of Figures

Part 1: Literature Review

List of Abbreviations

AD	Amy Dixon (Researcher)
KS	Professor Katrina Scior (Research Supervisor)
AH	Dr Aseel Hamid (Research Supervisor)
LMK	Lisa-Marie Köppl (University College London Unit for Stigma Research Intern)

Acknowledgements

This thesis would not have been possible without the willingness and courage of the women in Pakistan who shared their stories and experiences with us. I am enormously grateful to them and will always remember, and admire, their determination to evoke positive change. Thank you, also, to the country teams in Pakistan whose dedication, passion, and expertise made this project a success. I have tremendous respect for the work that you are doing to support people with disabilities.

To my brilliant supervisors, Professor Katrina Scior and Dr Aseel Hamid, thank you for generously sharing your time and knowledge with me. I have learnt so much from working alongside you both and would like to emphasise my gratitude for the incredible opportunity to be part of this project. I witnessed first-hand the humour and kindness you bring to your work, and the great things that can happen when you work together and take chances as they present themselves. Throughout the process of completing this thesis, I was continually inspired by your enthusiasm and commitment to stigma research, and the impact that you are both having in the field.

Additionally, I would like to thank my friends for keeping me grounded and connected to what's important. Even though we live far away from each other, you have given me the escape and fun that I have needed. To my family, I would not be here without you. Thank you for always being there to encourage me and, above all, for instilling the belief that anything is possible. I am incredibly grateful to my fiancé for his unwavering support through this process; you have kept things steady when they have felt so testing, inspired me when I have been demotivated, and always put things into perspective when I have felt overwhelmed. Lastly, to our beautiful dog who, without knowing, kept me smiling and made sure that I got out into nature every day.

Part 1: Literature Review

Stigma Experienced by People with Disabilities: A Systematic Review of Self-Report Measures

Abstract

Aims: High levels of stigma have been associated with people with disabilities, yet little is known about the psychometric quality of measures of disability stigma at the level of the person with a disability. This systematic review provides an overview and critical appraisal of the psychometric quality of measures that can be completed by people with disabilities to assess disability stigma.

Method: Three electronic databases were systematically reviewed to identify relevant stigma measures. The attributes and applicability of each measure were summarised, and the measures' psychometric quality were critically appraised using the COsensus-based Standards for the selection of health Measurement INstruments (COSMIN) checklist as a guide.

Results: Systematic searches identified 34 measures, of which 31 were quality appraised. Where measures were used in a psychometric validation study, most of the properties assessed were rated as good. However, the majority of measures had been used as outcome measurement tools without thorough appraisal of their quality. For these, the ratings were mixed, suggesting that the scales used may not be reliable for the population and setting in which they were applied. Of all the measures included, the Perceived Stigma of Intellectual Disability scale received the best ratings, although data were available from only two studies.

Conclusions: Although several scales have been used with people with disabilities, for most there was a lack of evidence regarding their psychometric quality, creating significant challenges in selecting a suitable measure to assess stigma. Overall, there is a need for further development and validation of stigma scales for people with disabilities.

Introduction

Stigma and disability

People with disabilities make up approximately 16% of the world's population (World Health Organisation [WHO], 2023). The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD; 2006) defines people with disabilities as "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." They are one of the most disadvantaged and devalued groups, facing marginalisation, exploitation, oppression, hostility, and violence due to disability stigma that prevails within and across countries (UN High Commissioner for Refugees [UNHCR], 2016).

Disability stigma encompasses prejudiced attitudes, negative stereotypes about people with disabilities, and discriminatory behaviours that result from these beliefs (Link & Phelan, 2001). This definition is broad and multifaceted, inferring that stigma is likely to result from the consequences of many variables. Stigma is a social process and stigma experiences of people with disabilities are influenced by stigma at the family, community, and institutional levels, for example, attitudes about disabilities held by a person's community and family (Groce & McGeown, 2013) and discriminatory legislation and institutional policies (Rohwerder, 2018). The manifestation of stigma depends on cultural and contextual values systems, that are entrenched in religious, political, and historical factors. Therefore, several variables may affect the experience of stigma which can be viewed as highly individualised, dependent on a person's identity and sociodemographic variables (UNHCR, 2016). This creates challenges in designing quantitative stigma measures that rely on the idea that there are commonalities in our experiences of stigma (Fox et al., 2018).

Nevertheless, existing stigma frameworks conceptualise stigma at the level of the stigmatised person as a multidimensional construct including perceived stigma, anticipated stigma, experienced stigma, and self-stigma (Stangl et al., 2019), as defined in Table 1. Thus, the measurement of stigma has focussed on these domains (LeBel, 2008). However, the literature varies in how stigma is conceptualised and defined (Fox et al., 2018), and there is not always consistency in the terminology used to describe constructs. The terms used to describe the stigma experiences of people with disabilities are often applied interchangeably, causing significant difficult in interpreting findings.

Table 1

Stigma Domains at the Level of Stigmatised Person

Domain	Definition
Perceived stigma	Perceptions of how the stigmatised group is viewed and treated by others
Anticipated stigma	Expectations of bias being perpetrated by others if the stigmatised identity becomes known
Experienced stigma	Exposure to instances of stigmatisation, including exclusion and discrimination
Self-stigma	Internalisation of societal prejudices and feelings associated with the stigmatised identity and cognitive, emotional, and behavioural responses to stigma

High levels of stigma have been associated with people with disabilities, including individuals with intellectual disabilities (IDs; Ali et al., 2012), and sensory disabilities (Livneh et al., 2014). Lower levels of stigma have been reported in relation to people with physical disabilities, however, stigma is still associated with this population (Kowalski & Peipert, 2019; Rohwerder, 2018; Werner, 2015). As such, theoretically driven scales that are sensitive to different disabilities and stigma constructs are necessary to understand how stigma manifests.

Systematic reviews published to date have focused on the measurement of stigma experiences in people with mental health difficulties (Boyd et al., 2014; Brohan et al., 2010; Fox et al., 2019), neurological conditions including epilepsy (Kwon et al., 2022; Van Brakel, 2006), or long-term health conditions, like Tuberculosis (Bergman et al., 2021) or HIV (Nyblade, 2006). Several validated self-report stigma measures exist within these fields; for example, the Internalized Stigma of Mental Illness Scale (ISMI; Ritsher et al., 2003), Discrimination and Stigma Scale (DISC-12; Thornicroft et al., 2009), Stigma Scale of Epilepsy (Fernandes, 2007), Chronic Illness Tuberculosis Stigma Scale (Van Rie et al., 2008) and Berger et al.'s (2001) HIV Stigma Scale.

No existing review offers a systematic evaluation of the psychometric quality of self-report measures assessing perceived, anticipated, experienced and self-stigma experienced by people with disabilities. Accurate measures are important to understand the experiences of individuals directly affected and to inform the development of evidence-based approaches to address disability stigma and evaluate their effectiveness.

Aims and objectives

The aims of this systematic review were to: (a) identify measures of disability related stigma at the level of the person with a disability, designed for self-report; (b) summarise the measures' attributes and application, including the stigma construct(s) covered and (c) critically appraise their psychometric quality using the COsensus-based Standards for the selection of health Measurement INstruments (COSMIN) checklist (Mokkink et al., 2017; Prinsen et al., 2018; Terwee et al., 2018) as a guide.

This review evaluated stigma measures focused on stigma related to physical disabilities, intellectual and developmental disabilities (IDDs), and sensory disabilities. Due to the amount of existing literature on self-report stigma measures relating to long-term health and neurological conditions, and mental health, stigma measures specific to these conditions were not included.

For the purpose of this review, a physical disability is defined as a "limitation on a person's physical functioning, mobility, dexterity or stamina" (Equality Act, 2010). An ID is "a reduced intellectual ability and difficulty with everyday activities which affects someone for their whole life" (MENCAP, 2023). Developmental disabilities are conditions associated with an impairment in physical, learning, language, or behaviour areas, impacting on day-to-day functioning. They begin during the developmental period and usually last throughout a person's lifetime (Centers for Disease Control and Prevention, 2023). IDDs is the term often used to capture both IDs and developmental disabilities. A sensory disability includes those with congenital or acquired hearing loss or deafness, blindness or low vision, and sensory processing disorder.

Method

Design

The methodology for the present review was informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist and followed a pre-defined protocol registered with Prospero (https://www.crd.york.ac.uk/prospero/; registration number: CRD42022363176).

Search strategy

After completing scoping searches, three electronic databases (PsycINFO, MEDLINE and SCOPUS) were searched on 17th November 2022 with no date limit. The search strategy used for each database is summarised in Table 2. Differences between the searches reflects variations in the syntaxes of the databases. Subject headings and key terms were identified based on existing reviews focussing on the measurement of disability stigma (Stevelink et al., 2012; Werner et al., 2011) to explore three key concepts: (1) stigma (2) measurement and (3) disability.

Search terms were truncated and combined using the Boolean terms 'OR' and 'AND'. As the focus of the review was identifying measures of stigma, a proximity indicator was used so that "stigma", or its synonyms, had to appear within five words of "measure", or its synonyms.

Table 2

Terms Used in Database Searches

Database	Construct		
	Stigma	Measurement	Disability
PsycINFO	exp Stigma/ Stigma* or discriminat* or prejudice* or stereotyp*	exp Test Types/ Measur* or questionnair* or survey* or scale* or tool*	exp Disabilities/ exp Neurodevelopmental Disorders/ Disabilit* or disable* or handicap*
MEDLINE	exp Social Stigma/ Stigma* or discriminat* or prejudice* or stereotyp*	exp Surveys and Questionnaires/ Measur* or Questionnair* or survey* or scale* or tool*	exp Disabled Persons/ exp Neurodevelopmental Disorders/ Disabilit* or disable* or handicap*
SCOPUS	Stigma* or discriminat* or prejudice* or stereotyp*	measur* or questionnair* or survey* or scale* or tool*	Disabilit* or disable* or handicap* or "neurodevelopmental dis*"

Inclusion and exclusion criteria

For an article to be included, it had to (1) include participants with a physical disability, IDD, or sensory disability, aged 18 and above (2) be a quantitative or mixed-methods study, using a measure of disability stigma that was completed by the member of the stigmatised group (3) report results specifically referring to the measurement of disability stigma at the level of the stigmatised individual and (4) be an original empirical paper published in English in a peer-reviewed journal, although articles reporting on measures using languages other than English were included.

Articles were excluded if they only included participants with a mental health difficulty, neurological condition, or long-term health condition. Moreover, articles with only a single-item measure of disability stigma were excluded because stigma is a complex construct (Allen et al., 2022).

The COSMIN manual recommends that articles where a measure has only been used as an outcome measure are excluded. However, scoping searches indicated that very few measurement development studies were available in the literature. Therefore, the search was not limited to articles solely reporting on the development or evaluation of measures.

Screening process

Duplicate articles were identified by their digital object identifier (DOI) and removed before screening. The remaining articles were initially reviewed based on their titles and abstracts. Articles that appeared relevant were retrieved and read to determine whether they met the inclusion criteria. Two reviewers (AD and LMK) independently screened the articles to check for accuracy and consistency in selection. Discrepancies were discussed and resolved with a third reviewer (KS).

The reference lists of included articles were manually searched for further relevant articles. A list of measures used in the eligible studies was comprised. The name of each measure was entered into a search to find any additional papers developing or validating the measure that could be relevant for the review. When the articles included in the review were established, emails were sent to all authors of the included studies to request any psychometric data for the identified measures not reported in the article.

Quality appraisal of identified measures

Disability stigma measures reported on in the included articles were quality appraised using the COSMIN manual as a guide. The COSMIN manual provides a comprehensive methodology to evaluate health-related patient-reported outcome (HR-PRO) questionnaires and other tools. It has previously been used to appraise mental health stigma measures (Brohan et al., 2010; Stevelink et al., 2012).

The framework groups psychometric properties into three domains: reliability (internal consistency, measurement error and reliability), validity (content, structural, cross-cultural, and criterion validity, and hypothesis testing), and responsiveness. See Appendix A for an overview of the psychometric measurement properties as defined by the COSMIN authors. As the review focuses on papers published in English, cross-cultural validity was not included. Similarly, criterion validity was not relevant to the review because there is no established gold standard measure that could be used as a comparison for identified measures.

To determine the quality of a measure, each measurement property was reviewed against pre-defined criteria for good measurement properties based on Terwee et al. (2007). See Appendix B for the adapted COSMIN checklist used in this review (Park et al., 2013). Authors recommend first assessing content validity and excluding measures where there is evidence that the measure is neither relevant nor comprehensible in respect to the construct of interest and target population. However, very few measure development studies that assessed content validity were identified by the search. Thus, reviewers initially assessed the internal consistency of the measure. For a measure to be included in the quality appraisal, it had to have a Cronbach's alpha or McDonald's omega of at least 0.7 in a study that met the criteria for the review.

Two sets of reviewers (AD and LMK, and AD and AH) independently extracted data from the included articles and appraised the internal consistency, measurement error, reliability, content validity, structural validity, hypothesis testing and responsiveness of each measure as good (+), unknown (?) or poor (-) against the COSMIN checklist. Where an article presented multiple studies using the same measure, data from each study were separately evaluated and rated. All discrepancies were resolved through discussion between the reviewers.

Results

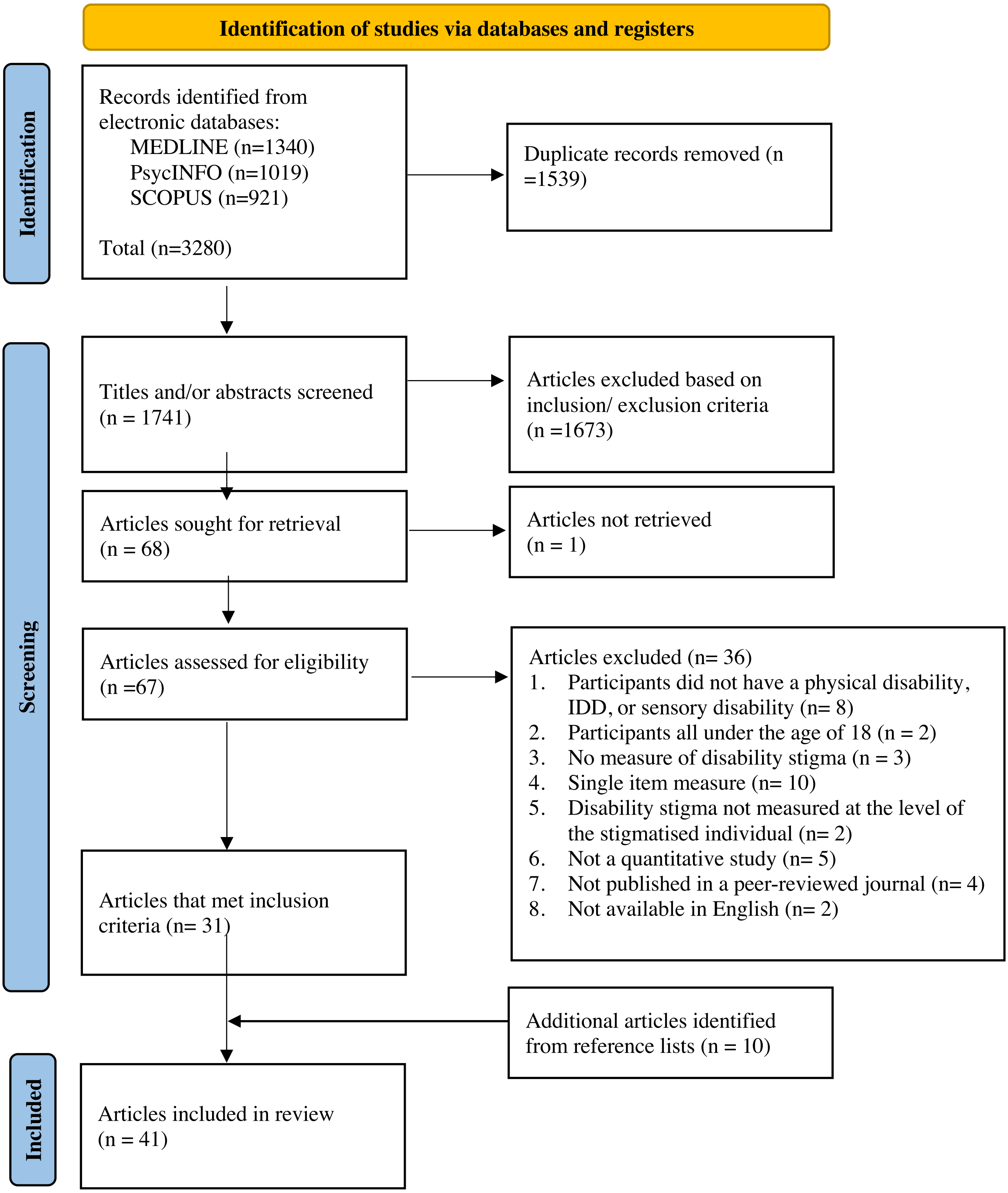
Summary of included articles

The database searches and application of the inclusion criteria identified 41 articles. Figure 1 illustrates the search process and reasons for exclusion of articles at each stage. Only seven of the articles focussed on the development or validation of a stigma measure (Ali et al., 2008; Chung & Lam, 2018; Conover et al., 2017; Kock et al., 2012; Privado et al., 2019; Szivos, 1991; Szivos-Bach, 1993).

The majority reported on studies that used a stigma measure as an outcome measurement tool. Some assessed the level of stigma experienced by people with disabilities (Bettlach et al., 2022), models of stigma processes (Pérez-Garín et al., 2021), and the impact of stigma, for example on quality of life (Silván-Ferrero et al., 2020), loneliness (Zhang et al., 2014), self-esteem (Mushtaq et al., 2020), job satisfaction (Petrovski & Gleeson, 1997), or depression and anxiety (Mousley & Chaudoir, 2018). Most of the studies aimed to examine factors associated with experiences of stigma. These studies suggested that age (Ali et al., 2016), ethnicity (Ali et al., 2015), educational attainment (Bachmann et al., 2019), type, visibility and severity of disability (Mills, 2007), environmental accessibility (Ma & Mak, 2022), marital status (Milačić-Vidojević et al., 2017), self-acceptance (Kong et al., 2020), social support (Ji et al., 2019) and social comparison (Dagnan & Waring, 2004) influence the severity of stigma experienced by people with disabilities.

Figure 1

PRISMA Flowchart of Identification of Included Articles



Additionally, most of the identified measures were originally designed to capture stigma relating to other minoritised identities. For example, the Explanatory Model Interview Catalogue (EMIC) Stigma scale (Weiss et al., 1992) was designed for people with leprosy and the short version of the Neurological Quality of Life-Stigma Questionnaire (Cella et al., 2012) focusses on neurological conditions. Authors of studies included in the present review mostly made adaptations to the scales for use with people with disabilities, such as changing key terms and removing irrelevant items.

Overview of disability stigma measures identified

The articles yielded 34 self-report disability stigma measures, described in Table 3, that were administered online, in paper format or by interview. For clarity, each measure is named once, followed by a description of adaptations and different versions of the measure. The measures were grouped by stigma construct.

Although not included in the review because stigma was not the underlying construct, the search highlighted measures of related constructs that could be considered to assess the impact of stigma, such as the Participation Scale (Van Brakel et al., 2006), which is used to evaluate participation restriction in people with disabilities, the Stereotype Vulnerability Scale (Spencer, 1994) that quantifies the extent to which people feel threatened by a negative stereotype about their academic success, and the Social Comparison Scale (Allen & Gilbert, 1995), a measure of an individual's perception of their achievements, social attractiveness and group membership compared to others.

Table 3

Summary of Included Stigma Measures

Stigma Construct(s)	Measure	Author (Year), Country	Target Population	Adaptation(s) to original measure	Language(s)	Mode of administration	(Sub)Scale(s) (number of items)	Sample item(s)	Response options
Perceived Stigma	**Abbreviated Stereotype Content Model Questionnaire (SCMQ; Fiske et al., 2002)**	Heydarian et al. (2022), USA	Sensory Disabilities	Participants were instructed to rate each item according to how strongly they believe society views members of the blind and low vision community	English	Self-report or interview	Warmth (2) Competence (2) Competition (2) Status (2)	"Resources that go to blind people are likely to take away from other people"	5-point Likert scale from 'not at all' to 'extremely'
	Devaluation-Discrimination Scale (Link et al., 1989)	Green (2007), USA	Mixed Disabilities	Six items were removed as not relevant for people with disabilities and two items were added. Additionally, items were reworded.	English	Self-report	Labelling/stereotyping (2) Status loss/discrimination (3) Separation (3)	"Most people think less of a person with a disability"	5-point Likert scale from 'strongly agree' to 'strongly disagree'
	Disability Discrimination Perception Questionnaire (DDPQ; Li, 2013)	Ji et al. (2019), China	Physical Disabilities	None	Chinese	Self-report	Unidimensional (10)	"The tone of the people around me makes me feel unhappy"	5-point Likert scale from 'strongly disagree' to 'strongly agree'
	EMIC Stigma Scale (Weiss et al., 1992)	Chung & Lam (2018), China	Physical Disabilities	Original term 'leprosy' was changed to 'physical disability', and the scale was translated into Chinese	Chinese	Interview	Unidimensional (15)	"If they knew about it, would your neighbours, colleagues or others in your community think less of your family because of your physical disability?"	'Yes', 'possibly', 'uncertain', or 'no'

Stigma Construct(s)	Measure	Author (Year), Country	Target Population	Adaptation(s) to original measure	Language(s)	Mode of administration	(Sub)Scale(s) (number of items)	Sample item(s)	Response options
	Individual Perceived Stigma Scale (IPSS; Zhang, 2018)	Zheng et al. (2022), China	Sensory Disabilities	None	Chinese	Self-report	13 items Opportunity deprivation (*nr)* Social distancing (*nr)* Devaluation (*nr)*	"Some hearing people think I'm not smart enough"	5-point Likert scale from 'totally disagree' to 'totally agree'
	Multidimensional Perceived Discrimination Scale (Molero et al., 2013)	Molero et al. (2019), Spain	Physical Disabilities	Items were specified to relate to people with physical disabilities. The original authors propose a 4-factor scale. However, here 2 factors were used: group discrimination and personal discrimination.	Spanish	Self-report	Group discrimination (10) Personal discrimination (10)	"Spanish society treats people with physical disabilities unfairly" "I have felt personally rejected for being a person with physical disability"	4-point Likert scale from 'do not agree at all' to 'agree completely'
		Pérez-Garín et al (2021), Spain	Sensory Disabilities	Items were specified to relate to people with hearing and visual impairments. The original authors propose a 4-factor scale. However, here 2 factors were used: group discrimination and personal discrimination.	As above	As above	As above	"People with hearing/visual impairments suffer from rejection in their daily social relations" "I have felt personally rejected for being visually/hearing impaired"	As above
	Neurological Quality of Life-Stigma Questionnaire Short Form (Cella et al., 2012)	Bettlach et al. (2022), USA	Physical Disabilities	Included instructions to answer questions in reference to participants' digital amputation	English	Self-report	Unidimensional (8)	*nr*	5-point Likert scale from 'not at all' to 'very much'

Stigma Construct(s)	Measure	Author (Year), Country	Target Population	Adaptation(s) to original measure	Language(s)	Mode of administration	(Sub)Scale(s) (number of items)	Sample item(s)	Response options
	Perceived Stigma Measure (Brown, 2015)	Ma & Mak (2022), Hong Kong	Physical Disabilities	None	English	Self-report	Unidimensional (7)	"People stare at you because of your physical limitation"	5-point Likert scale from ‘never’ to ‘always’
	Perceived Stigma of Intellectual Disability (Ali et al., 2008)	Ali et al. (2008), UK	IDD	None	English	Self-report with support from administrator	Perceived discrimination (6) Reaction to discrimination (4)	"People talk down to me" "I worry about the way people act towards me"	‘Yes; or ‘no’
		Ali et al. (2016), UK	IDD	None	As above	As above	As above	As above	As above
	Perceived Stigma of Intellectual Disability (Kock et al., 2012)	Kock et al. (2012), South Africa	IDD	None	English, Xhosa and Afrikaans	Interview	Felt stigma (6) Reaction to felt stigma (4)	"People on the street make fun of me" "The way people talk to me makes me angry"	‘Yes’ or ‘no’
		Ali et al. (2015), South Africa	IDD	None	As above	As above	As above	As above	As above

Stigma Construct(s)	Measure	Author (Year), Country	Target Population	Adaptation(s) to original measure	Language(s)	Mode of administration	(Sub)Scale (s) (number of items)	Sample item(s)	Response options
	Postsecondary Student Survey of Disability Related Stigma (PSSDS; Trammell, 2009)	Mushtaq et al. (2020), Pakistan	Physical Disabilities	Translated into Urdu	Urdu	Self-report	Perceived academic success (*nr)* Quality of peer relationships (*nr*) Measurable sense of self and identity (*nr*) Global awareness and/or concern about accommodations and disability-related issues (*nr*)	"I do poorly on tests in part due to my disability" "I feel that I am treated fairly on campus"	5-point Likert scale from 'never' to 'all the time'
		Herrick et al. (2022), USA	Mixed Disabilities	None	English	As above	As above	As above	As above
	Stigma Consciousness Scale (SCQ; Pinel, 1999)	Gonzalez-Bernal et al. (2021), Morroco	Mixed Disabilities	Translated from English into Spanish and adapted for people with sensory and physical disabilities	Spanish	Self-report	Unidimensional (10)	*nr*	5-point Likert scale from 'totally disagree' to 'totally agree'
		Privado et al. (2019), Spain	Sensory Disabilities	Translated from English into Spanish and two items removed to improve the reliability of the scale	Spanish	As above	Unidimensional (8)	*nr*	As above
	Stigma Perception Scale (DSPS; Lin et al., 2009)	Zhang et al. (2014), China	Mixed Disabilities	No adaptations reported although DSPS originally developed to measure stigma experienced by migrants	Chinese	Self-report	Unidimensional (10)	*nr*	5-point Likert scale from 'strongly disagree' to 'strongly agree'

Stigma Construct(s)	Measure	Author (Year), Country	Target Population	Adaptation(s) to original measure	Language(s)	Mode of administration	(Sub)Scale(s) (number of items)	Sample item(s)	Response options
	Stigma Perception Questionnaire (Szivos, 1991; Szivos-Bach, 1993)	Szivos (1991), UK	IDD	None	English	Interview	Feeling different (4) Anxiety (3) Poor ingroup concept (3)	"I wish I were someone different" "I am uncomfortable in the company of strangers"	5-point Likert scale from 'always' to 'never'
		Szivos-Bach (1993), UK	IDD	None	As above	As above	As above	As above	As above
		Petrovski & Gleeson (1997), Australia	IDD	Visual representation of response scale added	As above	As above	As above	As above	As above
		Dagnan & Waring (2004), UK	IDD	Each item presented on a separate A4 sheet in large print. 5-point visual analogue scale with blocks of increasing size used as well as written and spoken response options.	As above	As above	As above	As above	As above

Stigma Construct(s)	Measure	Author (Year), Country	Target Population	Adaptation(s) to original measure	Language(s)	Mode of administration	(Sub)Scale(s) (number of items)	Sample item(s)	Response options
		Paterson et al. (2012), UK	IDD	A five-point visual analogue scale was used consisting of blocks of increasing size with the words 'never true', 'hardly ever true', 'sometimes true', 'often true' and 'always true' underneath	As above	As above	As above	As above	As above
	Stigma Scale (King et al., 2007)	McDonald (2017), USA	IDD	Term 'mental health problems' was changed to 'a diagnosis of Asperger's/autism'	English	Self-report	Discrimination (13) Disclosure (10) Positive aspects (5)	"I am scared how other people will react if they find out about my diagnosis of Asperger's/autism"	5-point Likert scale from 'strongly disagree' to 'strongly agree'
	Stigma Scale (Szivos, 1991)	Szivos (1991), England	IDD	None	English	Interview	Positive self (6) Social competence (4) Being different (4) Anxiety (4) Work competence (6)	"I am good at making friends" "I make a mess of things I try"	5-point Likert scale from 'always' to 'never'
Anticipated Stigma	**Anticipated Stigma Measure (Quinn & Chaudoir, 2009)**	Mousley & Chaudoir (2018), USA	Sensory Disabilities	Asked to rate the likelihood of different experiences "because of their hearing status"	English	Self-report	Unidimensional (26)	"Not getting hired for a job" "Discouraged by a teacher from continuing education"	7-point Likert scale from 'unlikely to occur' to 'extremely likely to occur'
Experienced Stigma	**Ableist Microaggressions Scale (AMS; Conover et al., 2017)**	Conover et al. (2017), USA	Mixed Disabilities	None	English	Self-report	Helplessness (5) Minimization (3) Denial of Personhood (5) Otherization (7)	"People express pity for me because I have a disability" "People stare at me because I have a disability"	6-point Likert scale from 'never' to 'very frequently'. 3 items include a 'N/A' option

Stigma Construct(s)	Measure	Author (Year), Country	Target Population	Adaptation(s) to original measure	Language(s)	Mode of administration	(Sub)Scale (s) (number of items)	Sample item(s)	Response options
		Conover & Israel (2019), USA	Mixed Disabilities	None	As above	As above	As above	As above	As above
	Enacted Stigma Measure (Mousley & Chaudoir, 2018)	Mousley & Chaudoir (2018), USA	Sensory Disabilities	None	English	Self-report	Unidimensional: (26)	"Not getting hired for a job"	'Yes this happened to me' or 'No, this has never happened to me'
	Everyday Discrimination Scale (Williams et al., 1997)	Mills (2017), USA	Mixed Disabilities	Wording of measure adapted so that statements referred to disability-related discrimination	English	Self-report or interview	Unidimensional (8)	"In your day-to-day life, how often have the following things happened to you due to your use of a service dog: You have been threatened or harassed"	4-point Likert scale from 'never' to '4 or more times'
	Everyday Discrimination Scale-Short (Williams et al., 1997)	Shakarchi et al. (2020)	Sensory Disabilities	None	English	Self-report	Unidimensional (5)	"You are treated with less courtesy or respect than other people"	6-point Likert scale from 'never' to 'almost every day'
	Overt Discrimination Survey (Snyder et al., 2010)	Snyder et al. (2010), USA	Mixed Disabilities	None	English	Self-report	Unidimensional (8)	"I have experienced the discomfort of discrimination at [organization name]"	5-point Likert scale from 'strongly disagree' to 'strongly agree'

Stigma Construct(s)	Measure	Author (Year), Country	Target Population	Adaptation(s) to original measure	Language(s)	Mode of administration	(Sub)Scale (s) (number of items)	Sample item(s)	Response options
	Participation and Activity Limitation Survey (PALS) Discrimination Domain (Lindsay, 2011)	Lindsay (2011), USA	Mixed Disabilities	None	English	Interview	Unidimensional (4)	"Have you ever been refused a promotion?" "Have you ever been denied job accommodation?"	'Yes' or 'no'
	Procedural Injustice Survey (Snyder et al., 2010)	Snyder et al. (2010), USA	Mixed Disabilities	Wording adapted to refer to diversity context	English	Self-report	Unidimensional (7)	"My diversity background has limited the consistent application of these procedures"	5-point Likert scale from 'strongly disagree' to 'strongly agree'
	Subtle Discrimination Survey (Snyder et al., 2010)	Snyder et al. (2010), USA	Mixed Disabilities	None	English	Self-report	Unidimensional (12)	"I have been ignored in a group or meeting"	5-point Likert scale from 'never' to 'often'
	Inferiorization Questionnaire (Gomez & Trierweiler, 1999)	Gomez & Trierweiler (1999), USA	Mixed Disabilities	Wording of questionnaire changed dependent on minoritised identity being evaluated	English	Self-report	23 domains sorted by item type and context	"When with a group of able-bodied people, how often have you felt that you were being treated differently because you have a disability?"	5-point Likert scale from 'always' to 'never'
	Veterans Survey - Discrimination Domain (Semeah et al., 2019)	Semeah et al. (2019), USA	Physical Disabilities	None	English	Self-report	Unidimensional (2)	"Housing provider refused to show or rent a dwelling to me because of my disability"	'Yes' or 'no'

Stigma Construct(s)	Measure	Author (Year), Country	Target Population	Adaptation(s) to original measure	Language(s)	Mode of administration	(Sub)Scale (s) (number of items)	Sample item(s)	Response options
Experienced and Anticipated Stigma	**DISC-12 (Brohan et al., 2013)**	Milačić-Vidojević et al. (2017), Serbia	Physical Disabilities	Translated into Serbian, and term 'mental illness' replaced with 'physical disability'	Serbian	Interview	Experienced discrimination (21) Anticipated discrimination (4) Overcoming stigma and discrimination (2) Positive discrimination (3)	"Have you been treated unfairly in your levels of privacy" "Have you stopped yourself having a close personal relationship"	4-point Likert scale from 'not at all' to 'a lot'
		Milačić-Vidojević et al. (2020), Serbia	Physical Disabilities	As above	As above	As above	As above	As above	As above
Self-stigma	**Brief version of the Internalized Stigma of Mental Illness scale (ISMI-10; Boyd et al., 2014)**	Bachmann et al. (2019), Germany	IDD	Translated into German and term 'mental illness' replaced with 'ASD'	German	Self-report	Alienation (2) Stereotype endorsement (2) Discrimination experience (2) Social withdrawal (2) Stigma resistance (2)	"People ignore me or take me less seriously just because I have a ASD" "People with ASD make important contributions to society"	4-point Likert scale from 'strongly disagree' to 'strongly agree'
	ISMI (Ritsher et al., 2003)	Milačić-Vidojević et al. (2020), Serbia	Physical Disabilities	Translated into Serbian and term 'mental illness' replaced with 'physical disability'	Serbian	Interview	Alienation (6) Stereotype endorsement (7) Discrimination experience (5) Social withdrawal (6) Stigma resistance (5)	"I feel out of place in the world because I have a physical disability"	4-point Likert scale from 'strongly disagree' to 'strongly agree'

Stigma Construct(s)	Measure	Author (Year), Country	Target Population	Adaptation(s) to original measure	Language(s)	Mode of administration	(Sub)Scale (s) (number of items)	Sample item(s)	Response options
		Bury et al. (2022), Australia	IDD	7 items omitted and term 'mental illness' replaced with 'autism spectrum'	English	Self-report	Alienation (*nr)* Stereotype endorsement (*nr)* Discrimination experience (*nr)* Social withdrawal (*nr*) Stigma resistance (*nr*)	"Stereotypes about people with autism apply to me"	As above
	Negative Self-image Subscale from the HIV Stigma Scale (Berger et al., 2001)	Mousley & Chaudoir (2018), USA	Sensory Disabilities	Term 'HIV' replaced with 'deaf/hard-of-hearing'	English	Self-report	Unidimensional (5)	"Being deaf/hard-of-hearing makes me feel like I am a bad person"	7-point Likert scale from 'strongly disagree' to 'strongly agree'
	Self-Stigma of Disabled Scale (Li & Yang, 2018)	Kong et al. (2020), China	Sensory Disabilities	None	Chinese	Self-report	23 items Alienation (*nr)* Discrimination experience (*nr*) Social withdrawal (*nr*) Stigma resistance (*nr*)	*nr*	4-point Likert scale from 'strongly disagree' to 'strongly agree'
	Self-Stigma Scale-Short (Mak & Cheung, 2010)	Pyszkowska & Stojek (2022), Poland	Mixed Disabilities	Translated into Polish	Polish	Self-report	Affect (3) Cognition (3) Behaviour (3)	"I feel uncomfortable because I have a disability" "My identity as a person with a disability is a burden to me"	4-point Likert scale from 'strongly disagree' to 'strongly agree'
		Chen (2021), Taiwan	Mixed Disabilities	None	Chinese	As above	As above	As above	As above

Stigma Construct(s)	Measure	Author (Year), Country	Target Population	Adaptation(s) to original measure	Language(s)	Mode of administration	(Sub)Scale(s) (number of items)	Sample item(s)	Response options
	Stigma Scale for Chronic Illness 9-item Version (SSCI-9; Rao et al., 2009)	Molero et al. (2019), Spain	Physical Disabilities	Term 'illness' changed to 'disability'	Spanish	Self-report	Unidimensional (9)	"I felt embarrassed about my disability"	4-point Likert scale from 'never or almost never' to 'always or almost always'
		Silván-Ferrero et al. (2020), Spain	Physical Disabilities	None	As above	As above	As above	"Because of my illness, I feel emotionally distant from other people"	As above
		Pérez-Garín et al. (2021), Spain	Sensory Disabilities	Scale items reworded to refer to people with 'visual disabilities'	As above	As above	As above	"When someone criticises people with visual disabilities, it feels like a personal insult"	As above

Note. *nr* = data not reported

Perceived stigma measures

Sixteen measures were used across 24 studies to assess perceived stigma in people with disabilities. Seven measures had been used with people with physical disabilities (Bettlach et al., 2022; Chung & Lam, 2018; Ji et al., 2019; Ma & Mak, 2022; Molero et al., 2019; Mushtaq et al., 2020), five with people with IDD (Ali et al., 2008; Ali et al., 2015; Ali et al., 2016; Dagnan & Waring, 2004; Kock et al., 2012; McDonald, 2017; Paterson et al., 2012; Petrovski & Gleeson, 1997; Szivos, 1991; Szivos-Bach, 1993), and five with people with sensory disabilities (Herrick et al., 2022; Heydarian et al., 2022; Pérez-Garín et al., 2021; Privado et al., 2019; Zheng et al., 2022). Three measures were used in a study including people with different types of disabilities (Gonzalez-Bernal et al., 2021; Green, 2007; Zhang et al., 2014).

Anticipated stigma measures

The Anticipated Stigma Measure (Quinn & Chaudoir, 2009) was the only unidimensional measure of anticipated stigma identified by the search. Originally validated in people with marginalised identities, not including people with sensory disabilities, it was adapted for people who are deaf or hearing impaired (Mousley & Chaudoir, 2018).

Experienced stigma measures

Ten measures of experienced stigma were identified from nine studies. The discrimination domain from the Veterans Survey was the only scale used with a sample of people with physical disabilities (Semeah et al., 2019). No measures of experienced stigma were identified for people with IDD. Two measures were designed for people with sensory disabilities (Mousley & Chaudoir, 2018; Shakarchi et al., 2020) and seven were used in studies assessing experienced stigma relating to different types of disabilities (Conover et al., 2017; Conover & Israel, 2019; Gomez & Trierweiler, 1999; Lindsay, 2011; Mills, 2017; Snyder et al., 2010).

Experienced and anticipated stigma measures

The DISC-12 (Brohan et al., 2013) measures both anticipated and experienced stigma. The measure was translated into Serbian and the term 'mental illness' was replaced with 'physical disability' for two studies included in the review (Milačić-Vidojević et al., 2017; Milačić-Vidojević et al., 2020). Participants were asked to indicate how frequently they have experienced stigma.

Self-stigma measures

Six measures of self-stigma were used in 10 studies included in the review. One measure was adapted for people with IDD (Bachmann et al., 2019) and two for people with sensory disabilities (Kong et al., 2020; Mousley & Chaudoir, 2018). Two were used with people with different types of disabilities (Chen, 2021; Pyszkowska & Stojek, 2022). The ISMI (Ritsher et al., 2003) and shorter ISMI-10 (Boyd et al., 2014), were used in two studies: one in a sample of participants with physical disabilities (Milačić-Vidojević et al., 2020) and one with a sample of Autistic people, (Bury et al., 2022). The SSCI-9 (Rao et al., 2009) was used in three studies; two with people with physical disabilities (Molero et al., 2019; Silván-Ferrero et al., 2020), and one with people with sensory disabilities (Pérez-Garín et al., 2021).

Quality appraisal of measurement properties

As aforementioned, to be included in the quality appraisal, a measure had to have a Cronbach's alpha or McDonald's omega of 0.7 or above in a study that met the criteria for the review. Internal consistency data were available for 31 measures from 36 studies. All 31 measures had a Cronbach's alpha or McDonald's omega of at least 0.7, indicating good internal consistency, and met the criteria for inclusion in the quality appraisal. The ratings of the psychometric properties of each measure are presented in Table 4. Data regarding measurement error and responsiveness were missing for all eligible measures. As such, these properties are not included in Table 4 or reported on further.

To avoid repetition, the following section will focus on measures where the available psychometric data goes beyond the scope of internal consistency. Where data on reliability, content validity, and structural validity are not discussed, it indicates that the authors did not report them. To determine hypothesis testing, specific hypotheses had to be predefined by authors. Where these were not formulated, hypothesis testing is not discussed.

Although the COSMIN manual recommends pooling ratings to make recommendations for the most appropriate measure to use with a particular population, here the quality of the evidence for the measures will be qualitatively summarised as only a limited number of studies presented psychometric data per measure.

Terwee et al. (2007) suggest that a sample size of above 100 and at least seven times the number of items is necessary to determine the structural validity, by performing a factor analysis, and internal consistency, using Cronbach's alpha, of a measure. A sample size of 50 subjects per subgroup included in the analysis is considered adequate to establish the remaining quality aspects.

Table 4

Quality Appraisal of Included Measures

Stigma Construct(s)	Measure	Author (Year), Country	Sample (sample size, age range (M, SD), Gender, disability) and Setting	Internal Consistency	Reliability	Content Validity	Structural Validity	Hypothesis Testing
Perceived Stigma	**Abbreviated SCMQ (Fiske et al., 2002)**	Heydarian et al. (2022), USA	264 participants, aged 18+ (*M*= 49.5, *SD*= 15.5), 72% females, blind. Participants were recruited via community organisations for blind people and social media groups across the USA	+	?	?	+	?
	Devaluation-Discrimination Scale (Link et al., 1989)	Green (2007), USA	223 undergraduate students, aged 18+ (*M*= 24.2, *SD*= 6.0), 71% females, 13% had a disability including physical disabilities (43%), specific learning disabilities (1%), deafness (1%), blindness (1%), medical conditions (18%), mental health difficulties (18%). Participants completed the measure during one of their classes.	+	?	?	?	?
	DDPQ (Li, 2013)	Ji et al. (2019), China	210 participants, aged 40-80 (*M*= 50.0, *SD*= 9.0), 100 females, physical disabilities. Participants were recruited from communities in Nanjing.	+	?	?	?	-
	EMIC Stigma scale (Weiss et al., 1992)	Chung & Lam (2018), China	264 participants, aged 18+ (*nr*), 56% females, physical disabilities associated with ankylosing spondylitis (12%), spinal cord injury (17.4%), congenital physical disabilities (7%), acquired brain injury (27%), rheumatoid arthritis (39%) and orthopaedic injuries (10%). Participants were recruited via local organisations for persons with physical disabilities.	+	?	+	-	?
	IPSS (Zhang, 2018)	Zheng et al. (2022), China	151 participants, aged 8-19, (*M* = 13.9, *SD* = 1.3), 50% females, hearing impaired. Participants were all students at special needs schools in China.	+	?	?	?	?

Stigma Construct(s)	Measure	Author (Year), Country	Sample (sample size, age range (M, SD), Gender, disability) and Setting	Internal Consistency	Reliability	Content Validity	Structural Validity	Hypothesis Testing
	Multidimensional Perceived Discrimination Scale (Molero et al., 2013)	Molero et al. (2019), Spain	288 participants, aged 18-82 (*M*= 45.1, *SD*= 12.3), 53% females, physical disabilities. Students on final courses in social work recruited participants who were mostly their personal contacts.	+	?**	?	?	+
		Pérez-Garín et al. (2021), Spain	200 participants, aged 17 - 89 (*M* = 45.2; *SD* = 12.9), 54% females, hearing impaired and visually impaired. Participants were recruited online by social work students who searched for people with visual or hearing impairments.	+	?**	?	?	?
	Perceived Stigma Measure (Brown, 2015)	Ma & Mak (2022), Hong Kong	98 participants, aged 18-68 (*M*= 36.4, *SD*= 14.5), 58% males, physical disabilities. Participants were recruited via non-governmental organisations listed on the website of the Social Welfare Department in Hong Kong which service people with disabilities.	+	?	?	?	+
	Perceived Stigma of Intellectual Disability (Ali et al., 2008)	Ali et al. (2008), England	109 participants, aged 18–73 (*M*= 41.0, *SD*= 13.6), 62 females and 47 males, mild and moderate ID. Participants were recruited from ID services and supported housing schemes.	+	+	+	+	?
		Ali et al. (2016), England	229 participants, aged 19–73 (*M* =40.9, *SD* = 11.4), 52% males, 82% white, mild and moderate ID. The study was conducted at 12 sites in England. Participants were recruited from community ID services and via health and social care professionals who knew the individual well.	+	?	?	?	?

Stigma Construct(s)	Measure	Author (Year), Country	Sample (sample size, age range (M, SD), Gender, disability) and Setting	Internal Consistency	Reliability	Content Validity	Structural Validity	Hypothesis Testing
	Perceived Stigma of Intellectual Disability (Kock et al., 2012)	Kock et al. (2012), South Africa	191 participants, aged 18+ *(nr)*, 45% males, mild (56%) and moderate ID. Participants were identified by occupational therapists, supervisors, nurses or social workers attached to various organisations for people with ID. Participants were interviewed at their workshops, homes or clinics.	+	-***	+	+	?
	PSSDS (Trammell, 2009)	Mushtaq et al. (2020), Pakistan	300 participants, aged 11-20 (*M* = 14.5, *SD* = 2.0), 53% males, students with physical disabilities: congenital (37%), resulting from an accident (26%), associated with a disease (37%). Students were recruited via a special education institution.	+	?	?	?	+
		Herrick et al. (2022), USA	145 participants, *nr*, 62.1% females, with attention deficit disorder (16%), brain injury (4%), blindness or visual impairment (2%), developmental disability (5%), health impairment (5%), hearing impairment (4%), mental health difficulty (15%), mobility or orthopaedic impairment (8%), specific learning disability (22%), speech or language impairment (1%), or other type of disability (17%). Undergraduate college students were recruited via disability support service offices across 16 colleges and universities in five US states.	+	?	?	?	+
	SCQ (Pinel, 1999)	Privado et al. (2019), Spain	216 participants, aged 18+ (*M*= 38.2, *SD* = 13.0), 53% females, deaf and hearing impaired. Participants were recruited via three associations of persons with hearing disability.	+	?	+	+	?
	DSPS (Lin et al., 2009)	Zhang et al. (2014), China	129 participants, aged 21-79 (*M*= 50.0, *SD*= 11.0), 80 males and 49 females, *nr*. Participants were randomly selected from eight communities in China.	+	?	?	?	+

Stigma Construct(s)	Measure	Author (Year), Country	Sample (sample size, age range (M, SD), Gender, disability) and Setting	Internal Consistency	Reliability	Content Validity	Structural Validity	Hypothesis Testing
	Stigma Perception Questionnaire (Szivos, 1991; Szivos-Bach, 1993)	Szivos (1991), England	50 participants, aged 16-21 (*M*=18.0, SD=*nr*), 20 females and 30 males, mild or moderate ID. Participants were all students attending further educational courses for people with ID.	+	?	?	?	?
		Szivos-Bach (1993), England	Same as Szivos (1991)	+	?	?	?	?
		Dagnan & Waring (2004), England	39 participants, aged 13-65 (*M*= 38.0, *SD* = 9.6), 54% males, ID. Participants were recruited from three day centres and a supported employment programme.	+	?**	?	?	+
		Paterson et al. (2012), Scotland	43 participants, aged 20-66 (*M*= 40, *SD* = 12.7), 42% males, ID. Participants were recruited from adult resource centres in a local health board in central Scotland.	+	?	?	?	-
	Stigma Scale (King et al., 2007)	McDonald (2017), USA	1139 participants, aged 18+ (*nr*), 59.1% females, Autism Spectrum Condition (ASC). Participants were recruited by contacting different organisations across 50 US states, including autism and self-advocacy societies and support groups.	+	?	?	?	+
	Stigma Scale (Szivos, 1991)	Szivos (1991), England	Same as Szivos (1991)	+	?	?	?	?
Anticipated Stigma	**Anticipated Stigma Measure (Quinn & Chaudoir, 2009)**	Mousley & Chaudoir (2018), USA	171 participants, aged 18–29 (*M*= 22.2, *SD*= 4.2), 63% females, deaf or hearing-impaired students. Participants were all current or recent students at a small university for deaf and hard of hearing individuals.	+	?	?	?	-

Stigma Construct(s)	Measure	Author (Year), Country	Sample (sample size, age range (M, SD), Gender, disability) and Setting	Internal Consistency	Reliability	Content Validity	Structural Validity	Hypothesis Testing
Experienced Stigma	**AMS (Conover et al., 2017)**	Conover et al. (2017a), USA	9 participants, *nr*, *nr*, congenital physical disabilities	?	?	+	?	?
		Conover et al. (2017b), USA	559 participants, aged 18-80 (*M*= 35.5, *SD*= 13.4), 57% females, mixed disabilities: medical condition or chronic illness (42%), mobility or physical impairment (34%), blind or visual impairment (20%), 18% deaf or hearing impairment (18%), brain injury (5%), other (5%). Participants were recruited via MTurk.	+	?	?	+	?
		Conover et al. (2017c), USA	833 participants, aged 18-72 (*M*=34.3, *SD*= 13.0), 53% females, medical condition or chronic illness (40%), mobility or physical impairment (34%), blind or visually impaired (24), deaf or hearing impaired (17%), brain injury (5%), other (4%). Participants were recruited via MTurk.	+	?**	?	+	?
		Conover & Israel (2019), USA	192 participants, aged 18-66 (*M*= 29.3, *SD*= 8.7), 62% females, medical condition, or chronic illness (46%), mobility or physical impairment (33%), blind or vision impairment (19%), deaf or hearing impairment (18%), brain injury (6%), other (4%). Participants were recruited via MTurk.	+	?	?	?	?
	Enacted Stigma Measure (Mousley & Chaudoir, 2018)	Mousley & Chaudoir (2018), USA	Same as Mousley & Chaudoir (2018)	+	?	?	?	+

Stigma Construct(s)	Measure	Author (Year), Country	Sample (sample size, age range (M, SD), Gender, disability) and Setting	Internal Consistency	Reliability	Content Validity	Structural Validity	Hypothesis Testing
	Everyday Discrimination Scale (Williams et al., 1997)	Mills (2017), USA	482 participants, aged 18+ (*nr)*, 841% females, 86% invisible disability and 14% visible disability. Participants were recruited via organisations that train service dogs and the online service dog communities.	+	?	?	?	?
	Everyday Discrimination Scale-Short (Williams et al., 1997)	Shakarchi et al. (2020)	13,092 participants, aged 51+ (*M*= 68.2, *SD*= *nr)*, 50% females, visually impaired (12%), hearing impaired (13%, dual sensory impairments (8%). Participants were recruited as part of a large-scale Health and retirement study.	+	?	?	?	+
	Overt Discrimination Survey (Snyder et al., 2010)	Snyder et al. (2010), USA	1,880 participants, *nr,* 54% females, of whom 90 self-identified as disabled, with 64 individuals reporting physical disabilities and 23 reporting non-physical disabilities, 3 respondents did not indicate the nature of their disability. Participants were employees at a large state university.	+	?	?	?	?
	Procedural Injustice Survey (Snyder et al., 2010)	Snyder et al. (2010), USA	Same as Snyder et al. (2010)	+	?	?	?	+
	Subtle Discrimination Survey (Snyder et al., 2010)	Snyder et al. (2010), USA	Same as Snyder et al. (2010)	+	?	?	?	+
	The Inferiorization Questionnaire (Gomez & Trierweiler, 1999)	Gomez & Trierweiler (1999), USA*	263 participants, aged 18+ (*M*= 20.4, *SD*= *nr),* of whom 23 had a disability, including a hearing impairment (n = 6), visual impairment (n = 2), muscular dystrophy (n = I), multiple sclerosis (n = 1), cerebral palsy (n = 1). Participants were students who took part as part of their introductory psychology course and received course credit.	+	?	+	-	?

Stigma Construct(s)	Measure	Author (Year), Country	Sample (sample size, age range (M, SD), Gender, disability) and Setting	Internal Consistency	Reliability	Content Validity	Structural Validity	Hypothesis Testing
Experienced and Anticipated Stigma	**DISC-12 (Brohan et al., 2013)**	Milačić-Vidojević et al. (2017), Serbia	119 participants, aged 18-70 (*M*= 35.7, *SD*= 14.6), 50% females, with physical disabilities, including cerebral palsy (14%), spinal cord injury (21%), muscular dystrophy (13%), multiple sclerosis (8%), and amputation (22%). Participants were recruited via public and non-governmental organisations for people with physical disabilities.	+	?	?	?	?
		Milačić-Vidojević et al. (2020), Serbia	Same as Milačić-Vidojević et al. (2017)	+	?	?	?	?
Self-stigma	**ISMI-10 (Boyd et al., 2014)**	Bachmann et al. (2019), Germany	149 participants, aged 18-67 (*M*= 31.8, *SD*= 11.4), 79% males, ASC. Data for this study was collected in four German ASC outpatient clinics.	+	?	?	?	?
	ISMI (Ritsher et al., 2003)	Bury et al. (2022), Australia	198 participants, aged 18-71 (*M*= 34.9, *SD*= 12.3), 52% females, ASC. Participants were recruited via universities, autism advocacy and community groups, and employers throughout Australia.	+	?	?	?	-
	Negative Self-image Subscale from the HIV Stigma Scale (Berger et al., 2001)	Mousley & Chaudoir (2018), USA	Same as Mousley & Chaudoir (2018)	+	?	?	?	-
	Self-Stigma of Disabled Scale (Li & Yang, 2018)	Kong et al. (2020), China	78 blind and visually impaired college students, aged 18+ (*nr*), 55% males. Participants were recruited from two universities in China.	+	?	?	?	+

Stigma Construct(s)	Measure	Author (Year), Country	Sample (sample size, age range (M, SD), Gender, disability) and Setting	Internal Consistency	Reliability	Content Validity	Structural Validity	Hypothesis Testing
	Self-Stigma Scale-Short (Mak & Cheung, 2010)	Pyszkowska & Stojek (2022), Poland	238 participants, aged 18+ (*M*= 37.9, *SD*= 17.0), 68% females, mixed disabilities: physical disability (36%), sensory disability (19%), neurological disease/genetic disorders (15%), metabolic disease (11%), cancer (6%) cardiovascular disease (5%), other (8%). Participants were recruited via internet forums and groups for people with disabilities.	+	?	?	?	?
	SSCI-9 (Rao et al., 2009)	Molero et al. (2019), Spain	288 participants, aged 18-82 (*M*= 45.1, *SD*= 12.3), 53% females, physical disabilities. Students on final courses in social work recruited participants who were mostly their personal contacts.	+	?	?	?	+
		Silván-Ferrero et al. (2020), Spain	Same as Molero et al. (2019)	+	?	?	?	-
		Pérez-Garín et al. (2021), Spain	200 participants, aged 17 - 89 (*M* = 45.2; *SD* = 12.9), 54% females, hearing impaired and visually impaired. Participants were recruited online by social work students who searched for people with visual or hearing impairments.	+	?	?	?	+

Note. nr = data not reported

* Quality ratings relate to the seven factors analysed within the study

** Rated as ? because only Pearson's r available for correlations between the scales, rather than intraclass correlation coefficients, Cohen's kappa or test-retest as specified by the COSMIN criteria

*** Rating is based on kappas per item not weighted kappa

The studies initially appeared to have good sample sizes to support the precision of the results. However, for some, the proportion of participants with disabilities that met the inclusion criteria for the review were minimal, significantly impacting on the generalisability of results. In particular, only 13% of 223 participants included to evaluate the Adapted Devaluation-Discrimination Scale (Green, 2007), 23 of 263 participants who completed the Inferiorization Questionnaire (Gomez & Trierweiler, 1999), and just 90 of 1,880 participants responding to the Overt Discrimination Survey, Procedural Injustice Survey and Subtle Discrimination Survey (Synder et al., 2010) identified as having a disability.

Psychometric quality of perceived stigma measures

Abbreviated SCMQ (Fiske et al., 2002). This eight-item, multidimensional measure of perceived stigma was shown to have good structural validity (comparative fit index [CFI] = .98/.96, root mean square error of approximation [RMSEA] = .05, standardized root mean square residual [SRMR] = .03) when applied to a sample of 264 blind adults in the USA (Heydarian et al., 2022).

DDPQ (Li, 2013). The DDPQ asks participants how strongly they agree with ten statements about people with disabilities. It had a good internal consistency ($\alpha = .90$) when used as a unidimensional measure of perceived stigma in a sample of adults with physical disabilities (Ji et al., 2019). The authors hypothesised that perceived discrimination, as reflected by the DDPQ score, would mediate the relationship between social support and subjective wellbeing. However, this hypothesis was not supported by the results and hypothesis testing was rated as poor. The path between social support and perceived discrimination ($\beta = -.10$, $p > .05$) and perceived discrimination and subjective wellbeing ($\beta = .01$, $p > .0.5$) was not significant.

EMIC Stigma Scale (Weiss et al., 1992). The EMIC Stigma Scale had good content validity for use with people with physical disabilities in China, as reviewed by a group of academic and clinical experts (Chung & Lam, 2018). However, the amount of variance explained by the items was only 26%, indicating poor structural validity.

Multidimensional Perceived Discrimination Scale (Pérez-Garín et al., 2017). Molero et al. (2019) tested a model of the consequences of perceived stigma in a sample of people with physical disabilities. Hypothesis testing was rated as good because, as predicted, results suggested that perceived personal stigma is correlated with self-esteem ($r = -.43, p < .01$), a relationship that is mediated by self-stigma ($\beta = -.42, p = .00$). Similarly, perceived group stigma is associated with self-esteem via group identification and collective action ($\beta = -.03, p = .00$).

Pérez-Garín et al. (2021) tested the same model in people with hearing and visual impairments. Findings confirmed that self-stigma mediates the relationship between perceived personal stigma and self-esteem in participants with hearing impairments ($\beta = -.26, p =.00$) and visual impairments ($\beta = -.26, p = .00$). However, the second pathway between perceived stigma and self-esteem was only partly supported by the data. In participants with hearing impairments, perceived group stigma led to group identification ($\beta = .33, p < .01$) and subsequently collective action ($\beta = .60, p < .01$). Collective action did not influence self-esteem ($\beta = .13, p = .13$). Equally, perceived group stigma was not related to group identification in participants with visual impairments ($r = .15, p > .05$).

Perceived Stigma Measure (Brown, 2015). The associations between stigma, assessed using the Perceived Stigma Measure, perceived environmental inaccessibility, self-coldness, and self-warmth were tested in people with physical disabilities (Ma & Mak, 2022). As predicted, the stigma scores were positively correlated with perceived environmental inaccessibility ($r = .48, p < .01$) and self-coldness ($r = .59, p < .01$). However, no relationship was found between self-warmth and perceived stigma ($r = -.07, p > .05$), disconfirming the authors' hypotheses.

Perceived Stigma of Intellectual Disability (Ali et al., 2008). The content validity of the scale was confirmed by a group of six men and women aged 25-55 with a mild or moderate ID, who were asked about the comprehensibility and completeness of the scale. The measure had good test-retest reliability ($k = .71$) and the factors explained 60% of the total variance in the data, indicating good structural validity.

Kock et al. (2012) adapted the scale so the items and images incorporated were relevant for South-African communities, and translated it into Xhosa and Afrikaans. Focus groups were held with individuals with ID who represented different language and cultural groups. The scale was found to have good content validity. Additionally, the measure had good structural validity; the two factors jointly explained 56% of the variance. Test-retest reliability for the scale items were poor (kappa scores ranging from 0.41 to 0.59), which the authors suggest could be due to a small sample size.

PSSDS (Trammell, 2009). The PSSDS is a measure developed to assess perceived stigma experienced by college students with disabilities. Herrick et al. (2022) used the PSSDS to explore the effect of stigma on adaptation to college. As predicted, a significant negative relationship was found between perceived stigma and adaptation to college ($r = -.17, p = .05$). The measure was translated into Urdu (Mushtaq et al., 2020) and had good internal consistency in a sample of physically disabled students ($\alpha = .73$). Additionally, scores on the measure were positively associated with social phobia ($r = .56, p < .01$) and negatively correlated with self-esteem scores ($r = -.54, p < .01$). Stigma scores were predictive of levels of social phobia ($\beta = .40, t = 5.78, p < .01$) and self-esteem ($\beta = .34, t = 3.64, p < .00$), confirming all hypotheses.

SCQ (Pinel, 1999). The scale was reviewed by experts in sensory disabilities, five who were deaf and two who were hearing impaired to ensure the content validity and useability of the scale for a Spanish sample of people with hearing impairments (Privado et al., 2019). A confirmatory factor analysis showed that the measure had good structural validity (CFI = .98, RMSEA = .03, Parsimony Normed Fit Index [PNFI] = .59).

DSPS (Lin et al., 2009). Zhang et al. (2014) examined the relationships between perceived stigma, self-esteem, and social alienation in adults with disabilities, although details on the disabilities of participants were not provided. As predicted, participant scores on the DSPS were positively correlated with scores on a measure of social alienation ($r = .42, p < .00$) and self-esteem mediated the relationship between stigma and social alienation ($Z = 4.18, p < .00$). As such, hypothesis testing was rated as good.

Stigma Perception Questionnaire (Szivos, 1991; Szivos-Bach, 1993). The Stigma Perception Questionnaire is an interview-based scale developed from Szivos' earlier Stigma Scale (Szivos, 1991) for use with adolescents with ID. The development of the Stigma Perception Questionnaire is described within two studies (Szivos, 1991; Szivos-Bach, 1993), both which seem to use data from the same sample. Of the identified measures, the scale was the most frequently used measure of stigma. Dagnan and Waring (2004) used the measure with adolescents and adults with ID. Hypothesis testing was rated a good because scores on the stigma measure confirmed a positive relationship between perceived stigma and negative social comparisons ($r = .55, p < .05$), and this relationship was mediated by negative evaluations ($\beta = -.56, p = .00$).

Conversely, Paterson et al. (2012) found no association between social comparison with peers and perception of stigma ($r = .29, p > .05$), nor did social comparison with the community have a moderating effect on the relationship between self-esteem and perception of stigma ($\beta = 1.55, p = .25$). A relationship was found between stigma and self-esteem, whereby greater stigma was associated with lower self-esteem as hypothesised ($r = .41, p < .01$).

Stigma Scale (King et al., 2007). The Stigma Scale was used in a study evaluating the discriminative and criterion validity of a new scale, the Autism Spectrum Identity Scale (ASIS; McDonald, 2017). As predicted, the three domains of perceived stigma were empirically distinguishable from a measure of autism identity, the ASIS. Significant correlations were found between the discrimination domain and the positive difference ($r = -.24, p < .01$) and changeability ($r = -.24, p < .01$) subscales of the ASIS. No relationship was found between discrimination and context dependent ($r = .02, p > .01$) or spectrum abilities subscales ($r = -.02, p > .01$). Disclosure was related to positive difference ($r = -.39, p < .01$) and context dependent ($r = .12, p < .01$) but not spectrum abilities ($r = -.07, p > .01$) or changeability ($r = -.09, p > .01$). As expected, significant correlations were found between positive aspects and positive difference ($r = -.38, p < .01$), spectrum abilities ($r = -.14, p < .01$) and changeability ($r = .19, p < .01$), but not context dependent ($r = .01, p > .01$).

Psychometric quality of anticipated stigma measures

Anticipated Stigma Measure (Quinn & Chaudoir, 2009). Mousley and Chaudoir (2018) explored anticipated, experienced, and self-stigma in a group of hearing-impaired young adults. Anticipated stigma was positively correlated with depression ($r = .28, p < .01$), anxiety ($r = .32, p < .01$) and quality of life ($r = -.28, p < .01$), but not alcohol use ($r = .08, p > .01$). The predictive relationships between anticipated stigma and depression (β = .07, $p > .05$), alcohol use (β = -.13, $p > .05$) and quality of life (β = -.14, $p > .05$) were disconfirmed. However, as hypothesised anticipated stigma predicted anxiety (β = .15, $p = .07$).

Psychometric quality of experienced stigma measures

AMS (Conover et al., 2017). Three studies developed and validated the AMS (Conover et al., 2017). Feedback was gathered from three academics who conduct research relating to physical disabilities and/or microaggressions and people with disabilities, and the scale was piloted with seven participants with physical disabilities. As such, the measure has good content validity. Exploratory and confirmatory factor analyses found that a four-factor structure fit the data well (RMSEA = .05, CFI = .96, SRMR = .02; RMSEA = .07, CFI = .89, and SRMR = .07). Convergent and discriminant validity were tested. In line with the hypotheses, small, positive relationships were found between the AMS and stress (r =.24, $p < .01$) and depression (r = .29, $p < .01$). However, discriminant validity could not be confirmed given a small, negative correlation between stigma and social desirability (r = -.13, $p < .01$). In a later study with sexually minoritised participants with physical disabilities, AMS scores were negatively related to social support (r = -.15, $p < .15$) and positively correlated to depression (r = .22, $p < .05$) as predicted (Conover & Israel, 2019). However, no relationship was found with perceived stress (r = .13, $p > .05$) and no moderator effects were detected. These mixed findings resulted in an unknown rating for hypothesis testing.

Enacted Stigma Measure (Mousley & Chaudoir, 2018). The Enacted Stigma Measure uses the same items as the Anticipated Stigma Measure but asks participants if they have ever had any of the 26 stigmatising experiences. The majority of hypotheses about the measure were confirmed in Mousley and Chaudoir's (2018) study. Enacted stigma was positively correlated with depression (r = .36, p < .01), anxiety (r = .33, p < .01) and quality of life (r = -.34, p < .01). The predictive relationships between enacted stigma and depression (β = .34, p < .00), anxiety (β = .28, p < .01) and quality of life (β = .25, p < .01) were confirmed. However, no relationship was found between enacted stigma and alcohol use (r = .09, p > .01).

Everyday Discrimination Scale-Short (Williams et al., 1997). As part of the USA health and retirement study, Shakarchi et al. (2020) administered the Everyday Discrimination Scale and found that scores distinguished between groups, confirming the authors' hypothesis that older adults with dual sensory impairments perceive more stigma (β = .23, p < .00) than those with visual impairments (β = .16, p = .03) or hearing impairments (β = .16, p = .01) alone.

Overt Discrimination Survey; Procedural Injustice Survey; Subtle Discrimination Survey (Snyder et al., 2010). Three stigma measures were developed to compare the stigma experienced by employees with physical and non-physical disabilities at a US university. In each, participants were asked whether they had experienced discrimination at work. Scores on the measure of overt discrimination confirmed that employees with disabilities experience greater discrimination than those without disabilities (F= 16.66, p < .01), but no difference was found between employees with physical and non-physical disabilities (F= 0.71, p > .05). The subtle discrimination and procedural injustice measures distinguished between groups and supported the hypotheses that employees with disabilities experience more subtle discrimination (F= 17.65, p < .01) and procedural injustice (F= 11.24, p < .01), with employees with non-physical disabilities experiencing the highest levels of subtle discrimination (F= 4.83, p < .05) and procedural injustice (F= 4.90, p < .05). Perceived organisational support only moderated the relationship between disability status and procedural injustice ($\beta = -.22, p < .05$). No predictions were confirmed regarding the moderator effect of perceived supervisor support on variables ($\beta = -.03, p > .10$).

The Inferiorization Questionnaire (Gomez & Trierweiler, 1999). The Inferiorization Questionnaire was designed to capture the discrimination experienced by any person who identifies as part of a group about which a negative stereotype exists. As such, it was validated in a college-student sample of whom only 23 participants identified as having a physical disability. The applicability of the scale to people with disabilities was considered by 12 reviewers who confirmed the measure's content validity. Only seven of the measure's 23 factors were analysed within the study. As such, the quality ratings only extend to the presented factors. However, all seven factors explained less that 50% of the variance in the data, which indicated poor structural validity.

Psychometric quality of self-stigma measures

ISMI (Boyd et al, 2014; Ritsher et al, 2003). The ISMI showed good internal consistency ($\omega = .84$) in a sample of adults diagnosed with Autism (Bury et al., 2022). Although, as predicted, scores on the ISMI were associated with a lower preference for the use of the identity-first labels Autistic ($r = -.26, p < .00$) or Autistic person ($r = -.18, p < .05$), there was no interaction between felt autism identity and self-stigma on preference for identity-first labels (*nr)*, disconfirming the authors' hypothesis.

Negative Self-image Subscale from the HIV Stigma Scale (Berger et al., 2001). In a sample of hearing-impaired young adults, stigma scores were not related to levels of depression ($r = .11, p > .05$), anxiety ($r = .10, p > .05$), and alcohol use ($r = .14$, $p > .05$), disconfirming most hypotheses (Mousley & Chaudoir, 2018). However, as hypothesised, self-stigma was negatively associated with quality of life

(r = -.19, p < .05), although the predictive relationship between these factors was disconfirmed (β = -.13, p > .05)

Self-Stigma of Disabled Scale (Li & Yang, 2018). In a Chinese study, the measure was able to reflect close relationships between stigma and self-acceptance (r = .63, p < .01), and loneliness (r = .48, p < .01) (Kong et al., 2021). Moreover, self-acceptance was found to mediate the relationship between self-stigma and loneliness in college students with visual impairments (β = - .38, p < .00).

SSCI-9 (Rao et al., 2009). Two studies used the SSCI-9 with people with physical disabilities (Molero et al., 2019; Silván-Ferrero et al., 2020), and one used it to measure self-stigma in a sample of people with sensory disabilities (Pérez-Garín et al., 2021).

Results suggested that perceived personal stigma is correlated with self-stigma (r = .62, p < .01), which subsequently negatively impacts on self-esteem (β = -.42, p = .00) (Molero et al., 2019). As predicted, self-stigma is negatively associated with quality of life (r = -.51, p < .01) and this relationship was mediated by resilience (β = -.29, p < .00), but not group identification and collective action as predicted (β = -.01, p = .86) (Silván-Ferrero et al., 2020). The results from these two studies appear to be taken from the same sample.

Similarly to Molero et al. (2019), Pérez-Garín et al. (2021) used the SSCI-9 to test a model of the consequences of perceived stigma in adults with sensory disabilities. In line with the model, self-stigma mediated the relationship between perceived personal stigma and self-esteem in both the hearing impairment (β = −.26, p = .00) and visual impairment (β = −.26, p = .00) groups.

Discussion

This review summarises the application and psychometric quality of existing self-report measures of stigma experiences in people with physical, IDD, and sensory disabilities, highlighting the limitations of available measures. The systematic search identified 34 measures, most of which focussed on perceived stigma or experienced stigma. Fewer scales assessed the elements of self-stigma and anticipated stigma. After the application of the inclusion criteria, 31 measures were quality appraised using data from 36 studies.

Only seven of the eligible articles focussed on the development or validation of a stigma measure for people with physical, IDD, or sensory disabilities. The measures from these studies were the most promising in terms of the psychometric data available.

Firstly, the Perceived Stigma of Intellectual Disability (Ali et al., 2008) scale was most positively rated in the quality appraisal. The authors adhered to best practice guidelines for the development of measures (Boeteng et al., 2018) and followed several steps, including a literature search for existing measures and discussions with people with IDs to establish content validity and ensure that the format of the measure was feasible for use. Authors incorporated feedback from people with IDs and chose a dichotomous response option accompanied by a pictorial depiction. Although this response scale may make it more challenging to assess changes or differences between groups, it is useful in providing clarity and consistency to the scale. The measure is relatively short and easy to administer and score. Furthermore, the sample size was good, and a clear description of the target population and participant demographics was provided. The measure was tested in a large sample of adults with mild and moderate ID, a third of whom also had a mental health difficulty, recruited from a range of community settings in the UK. No significant differences were found in the total stigma score dependent on participant demographics, suggesting that the measure is appropriate for use with individuals with an ID of different ages, genders, and ethnicities, although 74% of the sample were White. The measure had good internal consistency, test-retest reliability, and structural validity. The initial findings suggest that it is a useful measure to assess and understand perceived stigma. The methodology of the validation study had many strengths to support the findings, however, data were taken from only two studies and the measure, including the language and pictorials used, is currently specific to English-speaking participants with mild and moderate IDs from Western countries.

The Perceived Stigma of Intellectual Disability scale has been successfully adapted to a South African context and translated into Afrikaans and Xhosa (Kock et al., 2012). This study provides a good methodology for translating and culturally adapting measures but highlights important issues in attempting to standardise the measurement of stigma across different cultures. Initially, the wording and images of the item pool developed by Ali et al. (2008) were assessed by professionals and adults with IDs and adapted as necessary before the measure was field tested. The measure had good internal consistency, content validity, and structural validity when applied to a diverse sample of adults. Test-retest reliability was poor, thought to be because the sample size was too small to reflect the cultural diversity of South Africa, indicating the need for further evaluation before the measure can be recommended for use. Although the measure retained the same two-factor structure as the English version, the item loadings appeared to reflect different constructs. The South African scale focuses on ‘felt stigma’ which captures aspects of self-stigma and the impact of perceived stigma, thus highlighting cultural differences in features of stigma. This raises questions around the universality of stigma constructs, and suggests that the use of qualitative approaches, such as focus groups, are needed to understand what stigma represents within a particular setting. This is an important provisional step in developing or culturally adapting scales to ensure that they accurately reflect the construct that they are intended the measure. If this step is not followed when adapting measures, key concepts relevant to populations may not be included and the language used may be inappropriate or have a different intended meaning.

The SCQ appeared the most promising measure of perceived stigma for people who are deaf or hearing impaired. Privado et al. (2019) translated the scale and experts in sensory disabilities reviewed the items to establish content validity before the scale was tested. This procedure aimed to ensure that the items remained true to the original scale but were simultaneously relevant to the stigma experiences of people with hearing impairments. The format was altered as items were removed and added but the scale retained the same unidimensional structure which fit the data well and accurately reflected perceived stigma. The generalisability of the results is supported by the large sample size and diversity in participant demographics. This suggests that with careful adaptations to adapt the language used but retain the meanings of items, the SCQ is a short measure suitable for participants with diverse stigmatised identities from different countries.

The most frequently used scale was the Stigma Perception Questionnaire (Szivos, 1991; Szivos-Bach, 1993). Data on the psychometric quality of this scale were available from four UK studies, each with a moderate sample size comprised of adolescents and adults with mild or moderate ID. The scale had good internal consistency in all studies suggesting that the items accurately and consistently measure perceived stigma. However, many of the items seem to be about self-stigma and identity, with fewer items concentrating on perceptions of other peoples' behaviours and feelings. Additionally, the scale's content validity and structural validity have not been evaluated. As such, it is difficult to draw conclusions about the suitability of this scale and further psychometric assessment would be beneficial, particularly to assess the suitability of some of the complex language used.

The AMS was the most extensively researched measure of experienced stigma developed for people with different types of disabilities (Conover et al., 2017; Conover & Israel, 2019). Like Ali et al. (2008), the authors used a comprehensive approach to developing and evaluating the measure. Emerging from the literature on microaggressions experienced by individuals with stigmatised identities, items were reviewed by researchers and draft surveys were administered to a small sample of people with disabilities to check the useability of the scale. It received three good ratings for content validity, internal consistency, and structural validity. Convergent validity was confirmed but discriminant validity could not be established, and, as such, hypothesis testing was rated as unknown. Although the sample size is large and participants have a range of disabilities, a large proportion of participants had a chronic illness. Furthermore, using MTurk to recruit participants is likely to have introduced bias to the results. To enable considered recommendations about where the scale is best applied, future research could evaluate the reliability of the measure for participants from different populations.

Finally, the EMIC Stigma Scale was translated and adapted for people with different types of physical disabilities. Although it is described as a measure of perceived stigma, some of the items seem to reflect self-stigma and experienced stigma, measuring participants' feelings of being "ashamed or embarrassed" in relation to their disability or experiences of "others avoiding" them. It had good internal consistency but poor structural validity, indicating that the variance in scores were not captured by the scale items. Even though a comprehensive translation process was used, and the content of the scale was reviewed by experts, very few adaptations were made to the scale. Authors only replaced the word ‘leprosy’ with ‘physical disability’. As such, the poor structural validity could result from a lack of cultural sensitivity to the concept of stigma being assessed by the measure. Further input from people with disabilities to modify the scale may have improved its validity.

Most studies utilised adapted versions of stigma measures designed for people with mental health difficulties, long-term health conditions, neurological conditions or other minoritised identities. Although these measures have been validated with the populations for which they were designed, the majority had not undergone thorough psychometric evaluation with samples of people with disabilities. It is likely that utilising measures that have not undergone psychometric evaluation or shown poor reliability and validity will produce inaccurate and untrustworthy results. Moreover, many studies only presented a Cronbach’s alpha for the measures utilised and no data were available regarding measurement error or responsiveness for any of the stigma measures. As can be expected due to the nature of the included studies, in addition to internal consistency, hypothesis testing was the most frequently assessed aspect. Generally, the stigma measures were able to distinguish between groups and identify hypothesised relationships in line with predictions. However, the results were mixed, which could suggest that the measures used were not accurately measuring stigma experiences of people with disabilities.

Although not all psychometric properties need to be tested to establish the reliability and validity of a measure (Johnston & Graves, 2008), there was a general lack of available data relevant to people with disabilities. Most measures had been used in a single study, meaning that few comparisons could be made between studies and the generalisability of data from the included studies are limited. Whilst the internal consistency data captured in this review are encouraging and suggests that several measures could be appropriate for people with different types of disabilities, without research to establish the reliability and validity of measures for different study populations, the accuracy of results could be compromised (Ginty, 2013).

Overall, at this point none of these measures had fully comprehensive and acceptable psychometric properties, indicating the need for further evaluation and refinement to ensure that measures accurately capture and assess the stigma experiences of people with disabilities.

Limitations

Theoretical limitations

Evidence suggests that stigma experiences can depend on disability type. However, there is not a clear and consistent definition of disability to direct who is included in the studies and measures are often applied irrespective of disability type. For example, in some studies the term ‘learning disability’ is used to describe people with specific learning difficulties, whilst in others the term ‘disability’ refers to a chronic illness. As such, the measures used may not be appropriate or sensitive to the specific experiences of some populations.

Researchers are met with the dilemma of designing a measure for a specific population, which is time consuming, or modifying existing measures that may have undergone extensive evaluation in a different population or setting. Adapting measures may be necessary for several reasons, for example, existing scales may include irrelevant items, lack an important dimension of interest, or have an unsuitable format for the population of interest. Minor modifications, such as adding a visual aid to a response scale to aid understanding or making small changes to the wording of items that don't change the content or meaning of items carry less risk in altering the psychometric adequacy of the scale. However, more substantial changes, such as deleting items, or adapting items significantly, will likely alter the content of the scale and formal assessment of the measure should be considered. It is unclear how much modification can be made before previous findings evidencing the psychometric quality of the measure becomes invalid, but Stewart et al. (2012) have developed a useful framework to guide the adaptation of measures. Some studies included in the review (Privado et al., 2019) demonstrated how measures can be successfully adapted. However, it could be argued that it is inappropriate to adapt measures for populations for which they were not designed, and that researchers should invest time initially in developing and evaluating new measures.

Similarly, there is no standardised method of conceptualising stigma, and how stigma is understood and expressed is significantly impacted by culture. Given the variance in how stigma is experienced and the challenges in constructing a collective definition, it could be argued that qualitative methods should be used to explore individual experiences of stigma, with less focus on the generation of generalisable, quantitative data.

It appears that many of the authors of the included studies did not use stigma frameworks to guide the development and implementation of measures. The consequences of these theoretical limitations are evident in the results of this review. The measures included do not appear sensitive to the different components of stigma at the level of the stigmatised person as defined by this review (Stangl et al., 2019), nor do they represent it consistently as a multidimensional theoretical construct. Although not formally assessed in many of the included studies, by paying attention to the sample items, the face and content validity of measures should be questioned. Several of the measures focus on different elements of stigma or use different terms to describe the same stigma constructs which creates difficulties in consolidating findings. In particular, there was significant overlap between many of the items used to explore experienced or self-stigma stigma and those used within perceived stigma measures. For example, perceived stigma measures that contain items that ask whether people with disabilities have been 'talked down to' or 'stared at' could be better suited to assessing experienced stigma. Likewise, some measures of perceived stigma incorporate items relating to, what is defined in this review as, the emotional and cognitive aspects of self-stigma, for example feelings of being 'scared', 'worried' or 'uncomfortable', or 'wishing to be someone different'. Concurrently, some of the measures include items that may not relate to stigma, like 'not doing well in tests' or 'not being smart enough'. Attempts should be made to ensure that participants perceive that stigma in relation to their disability is contributing to their negative experiences.

Furthemore, the appropriateness of applying a measure across cultures without careful consideration and evaluation can be questioned. Van Widenfelt et al. (2005) discuss the barriers in translating and culturally adapting instruments, emphasising the difficulties researchers can have in assessing the equivalence of measures due a lack of transparency as to how the measure has been adapted. They propose that simply translating and back-translating measures is not sufficient and outline a combination of techniques that are needed. The methodology applied to make changes to existing measures should be clearly reported. Two studies included in the review (Chung & Lam, 2018; Kock et al., 2012) demonstrated how the content and meaning of scales can change when they are translated and culturally adapted. Thus, the factor structure of the measure changes or reflects a different concept. When developing, translating, or adapting measures, researchers should consider both the existing stigma measurement literature and qualitative information regarding the culturally specific experiences of people with disabilities. Ideally, it would be preferable for stigma measures to be constructed and tested in many different countries to get an intercultural understanding of their reliability and validity.

Methodological limitations of the included studies

Many of the identified studies were published relatively recently, which is encouraging as it suggests an increasing interest in disability stigma. The greatest methodological limitation of the studies is that there was little focus on measure development or validation. As a result, for many, the appropriateness of the measure for the participants or study design was not established and so the reliability of results from the studies can be questioned.

Furthermore, details regarding the study design or methodology were often lacking. For example, a description of how measures were adapted or participants' disabilities were defined was often missing which makes it difficult to make inferences about the results. Where described, the sampling strategies used in some studies likely introduced bias to the results. For instance, recruiting participants from platforms like MTurk or solely using a student population limits the extent to which results can be extrapolated. Finally, for some studies only a small proportion of participants had disabilities.

Limitations of the review

Only published studies available in English were included, meaning the results are comprised mostly of studies from Western countries, and relevant studies from other countries and the grey literature were excluded. Furthermore, one study could not be retrieved and for some of the scales data were missing regarding the scale development and items. Lastly, cross-cultural validity and criterion validity were not assessed.

Implications

As demonstrated by this review, the measurement of disability stigma at the level of the stigmatised person remains a significant challenge, stemming from a lack of culturally specific frameworks to define stigma constructs and guide the development and validation of such measures for various populations. For researchers aiming to explore stigma, the review provides considerations as to how the measurement of stigma can be approached, based on the current state of the literature.

In studies assessing the stigma experiences of people with disabilities, a high level of stigma is associated with people with disabilities, which impacts on quality of life, depression, anxiety and, self-esteem (Molero et al., 2019; Mousley & Chaudoir, 2018). As such, an individual's experience of stigma is an important factor to consider in clinical practice when working with people with disabilities presenting with mental health concerns. However, due to the paucity of data regarding the reliability and validity of stigma measures, clinicians hoping to assess the impact of stigma quantitatively should be cautious when selecting a measure for use and interpreting results. Close attention should be paid to how the measure has been validated, for example, the characteristics of participants included in the study, any adaptations authors have made to an existing measure, and the setting in which the study was conducted. Importantly, clinicians should assess the face validity of the measure and whether it is suitable for their intended use. When measures are applied in clinical settings to assess stigma, they should be used in conjunction with other sources of clinical information.

Future directions

Culturally specific stigma frameworks defining stigma constructs would be beneficial to guide the development of stigma scales suited to exploring the four constructs of stigma at the level of the person with a disability. Prospective research should focus on the statistical testing of the psychometric properties of stigma measures, to improve the accuracy of scales for people with different types of disabilities. Such tools are needed to better understand the extent and impact of stigma experiences in people with disabilities, and design of stigma reduction strategies.

Conclusion

Using standardised quality criteria for psychometric testing, this review provides an overview and critical appraisal of measures that can be completed by people with disabilities to assess disability stigma. Systematic searches identified 34 measures, of which 31 were quality appraised. Although several scales have been used with people with disabilities, for most there was a lack of evidence regarding their psychometric quality, creating significant challenges in selecting a suitable measure to assess stigma. Where the focus of the study was validating a measure, most of the properties assessed were rated as good. However, the majority of measures had been used as outcome measurement tools without thorough appraisal of their quality. For these, the ratings were mixed, suggesting that the scales used may not be reliable for the population and setting in which they were applied. Of all the measures included, the Perceived Stigma of Intellectual Disability scale received the best ratings, although data were available from only two studies. Overall, there is a need for further development and validation of stigma scales for people with disabilities, particularly, for those measuring anticipated or self- stigma.

References

Allen, S., & Gilbert, P. (1995). A social comparison scale: psychometric properties and relationship to psychopathology. *Personality and Individual Differences, 19,* 293-302.

Allen, M. S., Iliescu, D., & Greiff, S. (2022). Single item measures in psychological science: A call to action. *European Journal of Psychological Assessment, 38*(1), 1–5. https://doi.org/10.1027/1015-5759/a000699

Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012). Self stigma in people with intellectual disabilities and courtesy stigma in family carers: a systematic review. *Research in developmental disabilities, 33*(6), 2122–2140. https://doi.org/10.1016/j.ridd.2012.06.013

Ali, A., King, M., Strydom, A., & Hassiotis, A. (2016). Self-reported stigma and its association with socio-demographic factors and physical disability in people with intellectual disabilities: results from a cross-sectional study in England. *Social Psychiatry & Psychiatric Epidemiology*, *51*(3), 465-474.

Ali, A., Kock, E., Molteno, C., Mfiki, N., King, M., & Strydom, A. (2015). Ethnicity and self-reported experiences of stigma in adults with intellectual disability in Cape Town, South Africa. *Journal of intellectual disability research, 59*(6), 530-540.

Ali, A., Strydom, A., Hassiotis, A., Williams, R., & King, M. (2008). A measure of perceived stigma in people with intellectual disability. *British Journal of Psychiatry*, *193*(5), 410-415.

Bachmann, C. J., Hofer, J., Kamp-Becker, I., Kupper, C., Poustka, L., Roepke, S., Roessner, V., Stroth, S., Wolff, N., & Hoffmann, F. (2019). Internalised stigma in adults with autism: A German multi-center survey. *Psychiatry Research*, *276*, 94-99.

Berger, B. E., Ferrans, C. E., & Lashley, F. R. (2001). Measuring stigma in people with HIV: psychometric assessment of the HIV stigma scale. *Research in nursing & health, 24*(6), 518–529. https://doi.org/10.1002/nur.10011

Bergman, A., McNabb, K., & Farley, J. E. (2021). A systematic review and psychometric appraisal of instruments measuring tuberculosis stigma in Sub-Saharan Africa. *Stigma and Health*. Advance online publication. https://doi.org/10.1037/sah0000328

Bettlach, C. R., Gibson, E., Daines, J. M., Payne, E. R., Vuong, L. N., Merrill, C. M., & Pet, M. A. (2022). The stigma of digital amputation: a survey of amputees with analysis of risk factors. *Journal of Hand Surgery: European Volume*, *47*(5), 461-468.

Boateng, G. O., Neilands, T. B., Frongillo, E. A., Melgar-Quiñonez, H. R., & Young, S. L. (2018). Best Practices for Developing and Validating Scales for Health, Social, and Behavioral Research: A Primer. *Frontiers in public health, 6*, 149. https://doi.org/10.3389/fpubh.2018.00149

Boyd, J. E., Adler, E. P., Otilingam, P. G., & Peters, T. (2014). Internalized Stigma of Mental Illness (ISMI) scale: a multinational review. *Comprehensive psychiatry, 55*(1), 221–231. https://doi.org/10.1016/j.comppsych.2013.06.005

Brohan, E., Clement, S., Rose, D., Sartorius, N., Slade, M., & Thornicroft, G. (2013). Development and psychometric evaluation of the Discrimination and Stigma Scale (DISC). *Psychiatry research, 208*(1), 33–40. https://doi.org/10.1016/j.psychres.2013.03.007

Brohan, E., Slade, M., Clement, S., & Thornicroft, G. (2010). Experiences of mental illness stigma, prejudice and discrimination: a review of measures. *BMC health services research, 10*(80). https://doi.org/10.1186/1472-6963-10-80

Brown, R. L. (2015). Perceived Stigma Among People With Chronic Health Conditions: The Influence of Age, Stressor Exposure, and Psychosocial Resources. *Research on Aging, 37*(4), 335–360. https://doi.org/10.1177/0164027514533133

Bury, S. M., Jellett, R., Haschek, A., Wenzel, M., Hedley, D., & Spoor, J. R. (2022). Understanding language preference: Autism knowledge, experience of stigma and autism identity. *Autism*. Advance online publication. https://doi.org/10.1177/13623613221142383

Cella, D., Lai, J. S., Nowinski, C. J., Victorson, D., Peterman, A., Miller, D., Bethoux, F., Heinemann, A., Rubin, S., Cavazos, J. E., Reder, A. T., Sufit, R., Simuni, T., Holmes, G. L., Siderowf, A., Wojna, V., Bode, R., McKinney, N., Podrabsky, T., Wortman, K., & Moy, C. (2012). Neuro-QOL: brief measures of health-related quality of life for clinical research in neurology. *Neurology, 78*(23), 1860–1867. https://doi.org/10.1212/WNL.0b013e318258f744

Centers for Disease Control and Prevention. (2023, March 30). *Facts About Developmental Disabilities*. Centers for Disease Control and Prevention. https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html

Chen, C. H. (2021). The roles of psychosocial developmental crisis and self-stigma in mental health among college students with disabilities. *International Journal of Disability, Development and Education*, *68*(2), 287-302.

Chung, E. Y., & Lam, G. (2018). Validation of two scales for measuring participation and perceived stigma in Chinese community-based rehabilitation programs. *Health & Quality of Life Outcomes*, *16*(1), 105.

Conover, K. J., & Israel, T. (2019). Microaggressions and social support among sexual minorities with physical disabilities. *Rehabilitation Psychology*, *64*(2), 167-178.

Conover, K. J., Israel, T., & Nylund-Gibson, K. (2017). Development and validation of the Ableist Microaggressions Scale. *The Counseling Psychologist*, *45*(4), 570-599.

Convention on the Rights of Persons with Disabilities. (2006). *United Nations Convention on the Rights of Persons with Disabilities*.

https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf

Corrigan, P. W., Michaels, P. J., Vega, E., Gause, M., Watson, A. C., & Rüsch, N. (2012). Self-stigma of mental illness scale-short form: reliability and validity. *Psychiatry research, 199*(1), 65–69. https://doi.org/10.1016/j.psychres.2012.04.009

Dagnan, D., & Waring, M. (2004). Linking stigma to psychological distress: Testing a social-cognitive model of the experience of people with intellectual disabilities. *Clinical Psychology and Psychotherapy, 11*(4), 247-254.

Equality Act 2010, c. 6. Available at: https://www.legislation.gov.uk/ukpga/2010/15/section/6

Fernandes, P. T., Salgado, P. C., Noronha, A. L., Sander, J. W., & Li, L. M. (2007). Stigma Scale of Epilepsy: validation process. *Arquivos de neuro-psiquiatria, 65*(1), 35–42. https://doi.org/10.1590/s0004-282x2007001000006

Fiske, S. T., Cuddy, A. J., Glick, P., & Xu, J. (2002). A model of (often mixed) stereotype content: competence and warmth respectively follow from perceived status and competition. *Journal of personality and social psychology, 82*(6), 878–902.

Fox, A. B., Earnshaw, V. A., Taverna, E. C., & Vogt, D. (2018). Conceptualizing and Measuring Mental Illness Stigma: The Mental Illness Stigma Framework and Critical

Review of Measures. *Stigma and health, 3*(4), 348–376. https://doi.org/10.1037/sah0000104

Ginty, A. T. (2013). Psychometric Properties. In M. D. Gellman & J. R. Turner (Eds.), *Encyclopedia of Behavioral Medicine* (pp. 1563–1564*)*. Springer.

Gomez, J. P., & Trierweiler, S. J. (1999). Exploring cross-group discrimination: Measuring the dimensions of inferiorization. *Journal of Applied Social Psychology*, *29*(9), 1900-1926.

Gonzalez-Bernal, J. J., Eiguren-Munitis, L., Gonzalez-Santos, J., Santamaria-Pelaez, M., Soto-Camara, R., & Rodriguez-Fernandez, P. (2021). Effectiveness of Community Occupational Therapy Intervention in, with and from the Community in People with Disabilities in Azrou (Morocco). *International Journal of Environmental Research & Public Health*, *18*(11), 24.

Green, S. E. (2007). Components of perceived stigma and perceptions of well-being among university students with and without disability experience. *Health Sociology Review*, *16*(3-4), 328-340.

Groce, N., & McGeown, J. (2013). *Witchcraft, wealth and disability: Reinterpretation of a folk belief in contemporary urban Africa*. Leonard Cheshire Disability and Inclusive Development Centre, UCL. https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3398227

Herrick, S. J., Lu, W., & Bullock, D. (2022). Postsecondary Students With Disabilities: Predictors of Adaptation to College. *Journal of College Student Retention: Research, Theory & Practice, 24*(2), 603–624. https://doi.org/10.1177/1521025120941011

Heydarian, N. M., Castro, Y., & Morera, O. F. (2022). A brief report examining the stereotype content model with blind Americans. *Rehabilitation Psychology*, *67*(2), 231-234.

Ji, Y., Rana, C., Shi, C., & Zhong, Y. (2019). Self-Esteem Mediates the Relationships Between Social Support, Subjective Well-Being, and Perceived Discrimination in Chinese People With Physical Disability. *Frontiers in Psychology*, *10*, 2230.

Johnston, M., & Graves, D. (2008). Towards guidelines for evaluation of measures: an introduction with application to spinal cord injury. *Journal of Spinal Cord Medicine, 31,* 13-26.

King, M., Dinos, S., Shaw, J., Watson, R., Stevens, S., Passetti, F., Weich, S., & Serfaty, M. (2007). The Stigma Scale: development of a standardised measure of the stigma of mental illness. *The British journal of psychiatry, 190*, 248–254. https://doi.org/10.1192/bjp.bp.106.024638

Kock, E., Molteno, C., Mfiki, N., Kidd, M., Ali, A., King, M., & Strydom, A. (2012). Cross-cultural validation of a measure of felt stigma in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *25*(1), 11-19.

Kong, L., Gao, Z., Xu, N., Shao, S., Ma, H., He, Q., Zhang, D., Xu, H., & Qu, H. (2020). The relation between self-stigma and loneliness in visually impaired college students: Self-acceptance as mediator. *Disability and Health Journal*, 14(2), 101054. https://doi.org/10.1016/j.dhjo.2020.101054

Kowalski, R. M., & Peipert, A. (2019). Public- and self-stigma attached to physical versus psychological disabilities. *Stigma and Health*, *4*(2), 136-142.

Kwon, C. S., Jacoby, A., Ali, A., Austin, J., Birbeck, G. L., Braga, P., Cross, J. H., de Boer, H., Dua, T., Fernandes, P. T., Fiest, K. M., Goldstein, J., Haut, S., Lorenzetti, D., Mifsud, J., Moshe, S., Parko, K. L., Tripathi, M., Wiebe, S., & Jette, N. (2022). Systematic review of frequency of felt and enacted stigma in epilepsy and determining factors and attitudes toward persons living with epilepsy-Report from the International League Against Epilepsy Task Force on Stigma in Epilepsy. *Epilepsia, 63*(3), 573–597. https://doi.org/10.1111/epi.17135

LeBel, T. P. (2008). Perceptions of and Responses to Stigma. *Sociology Compass, 2*(2), 409-432.

Li, W. (2013*). Effects of perceived discrimination on social alienation of disabled and the psychological mechanism.* Master thesis, Ningbo University.

Li, M. M., & Yang, L. (2018). The effect of the hearing-impaired high school students' self stigma on their self-esteem: the moderating effect of group identity. *Chinese Journal of Special Education, 220*(10), 38-43.

Lin, X. Y., Fang, X. Y., Liu, Y., & Lan, J. (2009). The effect mechanism of stigma perception on mental health among migrant children in Beijing. *Acta Psychologica Sinica, 41*(10), 967-979.

Lindsay, S. (2011). Discrimination and other barriers to employment for teens and young adults with disabilities. *Disability and Rehabilitation*, *33*(15-16), 1340-1350. https://doi.org/10.3109/09638288.2010.531372

Link, B. G., Cullen, F. T., Struening, E., Shrout, P. E., & Dohrenwend, B. P. (1989). A Modified Labeling Theory Approach to Mental Disorders: An Empirical Assessment. *American Sociological Review, 54*(3), 400–423. https://doi.org/10.2307/2095613

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology, 27*, 363-85.

Livneh, H., Chan, F., & Kaya, C. (2014). Stigma related to physical and sensory disabilities. In P. W. Corrigan (Ed.), *The stigma of disease and disability: Understanding causes and overcoming injustices* (pp. 93–120). American Psychological Association.

Ma, G. Y., & Mak, W. W. (2022). Associations of perceived stigma, perceived environmental inaccessibility, and self-compassion among people with physical disability in Hong Kong. *Disability and Health Journal*, *15*(3). https://doi.org/10.1016/j.dhjo.2022.101274.

Mak, W. W., & Cheung, R. Y. (2010). Self-stigma among concealable minorities in Hong Kong: conceptualization and unified measurement. *The American journal of orthopsychiatry, 80*(2), 267–281. https://doi.org/10.1111/j.1939-0025.2010.01030.x

McDonald, T. (2017). Discriminative and criterion validity of the Autism Spectrum Identity Scale (ASIS). *Journal of Autism and Developmental Disorders*, *47*(10), 3018-3028.

MENCAP. (2023, March 30). *Learning disability explained*. MENCAP. https://www.mencap.org.uk/learning-disability-explained

Milacic-Vidojevic, I., Colic, M., Toskovic, O., & Dragojevic, N. (2020). People with physical disability in Serbia: Relationship between internalized stigma, experienced and anticipated discrimination, and empowerment. *Scandinavian Journal of Psychology*, *61*(2), 290-296.

Milačić-Vidojević, I., Tošković, O., Dragojević, N., & Čolić, M. (2017). Experienced and Anticipated Discrimination in Persons with Physical Disabilities in Serbia. *European Journal of Interdisciplinary Studies, 7,* 65-74.

Mills, M. L. (2017). Invisible disabilities, visible Service Dogs: The discrimination of Service Dog handlers. *Disability & Society*, *32*(5), 635-656.

Molero, F., Recio, P., García-Ael, C., Fuster, M. J., & Sanjuán, P. (2013). Measuring Dimensions of Perceived Discrimination in Five Stigmatized Groups. *Social Indicators Research, 114*(3), 901–914.

Molero, F., Recio, P., Garcia-Ael, C., & Perez-Garin, D. (2019). Consequences of perceived personal and group discrimination against people with physical disabilities. *Rehabilitation Psychology*, *64*(2), 212-220.

Mokkink, L. B., de Vet, H. C. W., Prinsen, C. A. C., Patrick, D. L., Alonso, J., Bouter, L. M., & Terwee, C. B. (2018). COSMIN Risk of Bias checklist for systematic reviews of Patient-Reported Outcome Measures. *Quality of life research, 27*(5), 1171–1179. https://doi.org/10.1007/s11136-017-1765-4

Mousley, V. L., & Chaudoir, S. R. (2018). Deaf stigma: Links between stigma and well-being among deaf emerging adults. *Journal of Deaf Studies and Deaf Education*, *23*(4), 341-350.

Mushtaq, M., Anjum, A., Jameel, R., Iqbal, M. N., Shahid, A. A., & Dastgir, M. H. A. (2020). STIGMA of disability, social phobia and self-esteem in adolescents with physical disability. *Journal of Postgraduate Medical Institute, 34*(2), 98-103.

Nyblade L. C. (2006). Measuring HIV stigma: existing knowledge and gaps. *Psychology, health & medicine, 11*(3), 335–345. https://doi.org/10.1080/13548500600595178

Park, T., Reilly-Spong, M., & Gross, C. R. (2013). Mindfulness: A systematic review of instruments to measure an emergent patient reported outcome (PRO). *Quality of Life Research, 22*(10).

Paterson, L., McKenzie, K., & Lindsay, B. (2012). Stigma, social comparison and self-esteem in adults with an intellectual disability. *Journal of applied research in intellectual disabilities, 25*(2), 166-176.

Pérez-Garín, D., Recio, P., & Molero, F. (2021). Consequences of perceived personal and group discrimination against people with hearing and visual impairments. *18*(17), 9064. https://doi.org/10.3390/ijerph18179064

Petrovski, P., & Gleeson, G. (1997). The relationship between job satisfaction and psychological health in people with an intellectual disability in competitive employment. *Journal of Intellectual and Developmental Disability*, *22*(3), 199-211.

Pinel, E. C. (1999). Stigma consciousness: The psychological legacy of social stereotypes. *Journal of Personality and Social Psychology, 76*(1), 114 – 128.

Prinsen, C. A. C., Mokkink, L. B., Bouter, L. M., Alonso, J., Patrick, D. L., de Vet, H. C. W., & Terwee, C. B. (2018). COSMIN guideline for systematic reviews of patient-reported outcome measures. *Quality of life research, 27*(5), 1147–1157. https://doi.org/10.1007/s11136-018-1798-3

Privado, J., Carrasco, L., & Duran, R. (2019). Hearing loss: Stigma consciousness, quality of life and social identity. *The Spanish Journal of Psychology, 22,* E22. https://doi.org/10.1017/sjp.2019.15

Pyszkowska, A., & Stojek, M. M. (2022). Early Maladaptive Schemas and Self-Stigma in People with Physical Disabilities: The Role of Self-Compassion and Psychological Flexibility. *International Journal of Environmental Research & Public Health*, *19*(17), 31.

Quinn, D. M., & Chaudoir, S. R. (2009). Living with a concealable stigmatized identity: the impact of anticipated stigma, centrality, salience, and cultural stigma on psychological distress and health. *Journal of personality and social psychology, 97*(4), 634–651. https://doi.org/10.1037/a0015815

Ritsher, J. B., Otilingam, P. G., & Grajales, M. (2003). Internalized stigma of mental illness: psychometric properties of a new measure. *Psychiatry research, 121*(1), 31–49. https://doi.org/10.1016/j.psychres.2003.08.008

Rao, D., Choi, S. W., Victorson, D., Bode, R., Peterman, A., Heinemann, A., & Cella, D. (2009). Measuring Stigma across Neurological Conditions: The Development of the Stigma Scale for Chronic Illness (SSCI). *Quality of Life Research, 18*(5), 585–595.

Rohwerder, B. (2018). *Disability stigma in developing countries*. Institute of Development Studies.

https://assets.publishing.service.gov.uk/media/5b18fe3240f0b634aec30791/Disability_stigma_in_developing_countries.pdf

Schalock, R. L., Luckasson, R., & Tassé, M. J. (2021). An Overview of Intellectual Disability: Definition, Diagnosis, Classification, and Systems of Supports (12th ed.). *American journal on intellectual and developmental disabilities, 126(*6), 439–442. https://doi.org/10.1352/1944-7558-126.6.439

Semeah, L. M., Beamish, J. O., Schember, T. O., & Cook, L. H. (2019). The rental housing needs and experiences of veterans with disabilities. *Administration & Society*, *51*(2), 299-324.

Shakarchi, A. F., Assi, L., Ehrlich, J. R., Deal, J. A., Reed, N. S., & Swenor, B. K. (2020). Dual Sensory Impairment and Perceived Everyday Discrimination in the United States. *JAMA Ophthalmology*, *138*(12), 1227-1233.

Silván-Ferrero, P. R., Molero, F., & Nouvilas-Pallejà, E. (2020). Psychological Quality of Life in People with Physical Disability: The Effect of Internalized Stigma, Collective Action and Resilience. *International Journal of Environmental Research and Public Health, 17*(5), 1802.

Snyder, L. A., Carmichael, J. S., Blackwell, L. V., Cleveland, J. N., & Thornton, G. C., III. (2010). Perceptions of discrimination and justice among employees with disabilities. *Employee Responsibilities and Rights Journal*, *22*(1), 5-19.

Spencer, S. J. (1993). *The effect of stereotype vulnerability on women's math performance*. Unpublished doctoral dissertation, University of Michigan, Ann Arbor.

Stangl, A. L., Earnshaw, V. A., Logie, C. H. Van Brakel, W., Simbayi, L. C., Barré, I., & Dovidio, J. F. (2019). The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Medicine, 17*(31). https://doi.org/10.1186/s12916-019-1271-3

Stevelink, S., Wu, I. C., Voorend, C. G. N., & van Brakel, W. H. (2012). The psychometric assessment of internalised stigma instruments: a systematic review. *Stigma, Research and Action, 2*(2), 100-118

Stewart, A. L., Thrasher, A. D., Goldberg, J., & Shea, J. A. (2012). A framework for understanding modifications to measures for diverse populations. *Journal of aging and health, 24*(6), 992–1017. https://doi.org/10.1177/0898264312440321

Szivos, S. E. (1991). Social comparisons with siblings made by adolescents with a learning difficulty. *Journal of Community & Applied Social Psychology*, *1*(3), 201-212. https://doi.org/10.1002/casp.2450010303

Szivos-Bach, S. E. (1993). Social comparisons, stigma and mainstreaming: The self esteem of young adults with a mild mental handicap. *Mental Handicap Research*, *6*(3), 217-236.

Terwee, C. B., Prinsen, C. A. C., Chiarotto, A., Westerman, M. J., Patrick, D. L., Alonso, J., Bouter, L. M., de Vet, H. C. W., & Mokkink, L. B. (2018). COSMIN methodology for evaluating the content validity of patient-reported outcome measures: a Delphi study. *Quality of life research, 27*(5), 1159–1170. https://doi.org/10.1007/s11136-018-1829-0

Thornicroft, G., Brohan, E., Rose, D., Sartorius, N., Leese, M., & INDIGO Study Group (2009). Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey. *Lancet, 373*(9661), 408–415. https://doi.org/10.1016/S0140-6736(08)61817-6

Trammell J. K. (2009). Postsecondary students and disability stigma: Development of the Postsecondary Students Survey of Disability-Related Stigma (PSSDS). *Journal of Postsecondary Education and Disability, 22,* 106–116.

United Nations High Commissioner for Refugees. (2016). *UNHCR Age, Gender and Diversity – Accountability Report 2015.* http://www.unhcr.org/protection/women/5769092c7/unhcr-age-gender-diversityaccountability-report-2015.html

Van Brakel W. H. (2006). Measuring health-related stigma--a literature review. *Psychology, health & medicine, 11*(3), 307–334. https://doi.org/10.1080/13548500600595160

Van Brakel, W. H., Anderson, A. M., Mutatkar, R. K., Bakirtzief, Z., Nicholls, P. G., Raju, M. S., & Das-Pattanayak, R. K. (2006). The Participation Scale: measuring a key concept in public health. *Disability and rehabilitation, 28*(4), 193–203. https://doi.org/10.1080/09638280500192785

Van Rie, A., Sengupta, S., Pungrassami, P., Balthip, Q., Choonuan, S., Kasetjaroen, Y., Strauss, R. P., & Chongsuvivatwong, V. (2008). Measuring stigma associated with tuberculosis and HIV/AIDS in southern Thailand: exploratory and confirmatory factor analyses of two new scales. *Tropical medicine & international health, 13*(1), 21–30. https://doi.org/10.1111/j.1365-3156.2007.01971.x

Van Widenfelt, B. M., Treffers, P. D., de Beurs, E., Siebelink, B. M., & Koudijs, E. (2005). Translation and cross-cultural adaptation of assessment instruments used in psychological research with children and families. *Clinical child and family psychology review, 8*(2), 135–147. https://doi.org/10.1007/s10567-005-4752-1

Weiss, M. G., Doongaji, D. R., Siddhartha, S., Wypij, D., Pathare, S., Bhatawdekar, M., Bhave, A., Sheth, A., & Fernandes, R. (1992). The Explanatory Model Interview Catalogue (EMIC). Contribution to cross-cultural research methods from a study of leprosy and mental health. *The British journal of psychiatry, 160*, 819–830. https://doi.org/10.1192/bjp.160.6.819

Werner S. (2015). Stigma in the Area of Intellectual Disabilities: Examining a Conceptual Model of Public Stigma. *American journal on intellectual and developmental disabilities, 120*(5), 460–475. https://doi.org/10.1352/1944-7558-120.5.460

Werner, S., Corrigan, P., Ditchman, N., & Sokol, K. (2012). Stigma and intellectual disability: a review of related measures and future directions. *Research in developmental disabilities, 33*(2), 748–765. https://doi.org/10.1016/j.ridd.2011.10.009

Williams, D. R., Yu, Y., Jackson, J. S., & Anderson, N. B. (1997). Racial Differences in Physical and Mental Health: Socioeconomic Status, Stress, and Discrimination. *Journal of Health Psychology, 2*(3), 335-351.

World Health Organisation. (2023, March 17). *Disability.* WHO. https://www.who.int/news-room/fact-sheets/detail/disability-and-health

Zhang, L., Li, W., Liu, B., & Xie, W. (2014). Self-esteem as mediator and moderator of the relationship between stigma perception and social alienation of Chinese adults with disability. *Disability & Health Journal*, *7*(1), 119-123.

Zhang, X. Y. (2018). The Relationship between Hearing-Impaired College Students' Perceived Discrimination and Self-Esteem: The moderating role of Self-Compensation. *Chinese Journal of Special Education, 11*(8), https://doi.org/10.3969/j.issn.1007-3728.2015.11.014

Zheng, J., Hong, M., Zhang, S., & Dzyakov, D. G. (2022). Perceived stigma and self-identity among hearing impaired students: A brief report. *32*(3), 294-297.

Part 2: Empirical Paper

“I want to say that disabled people also want to live as human beings”: Stigma Experiences of Women with Disabilities in Pakistan

Abstract

Aims: Women with disabilities face the intersectional inequalities of disability and gender-based stigma (Convention on the Rights of Persons with Disabilities [CRPD], 2016). The experience of stigma within this group varies significantly and is often dependent on type, visibility, and severity of disability (Division for Social Policy and Development [DSPD], 2016; Rohwerder, 2018), and other factors like age and rural vs urban residence. This study was conducted in collaboration with the United Nations Development Programme (UNDP) and United Nations (UN) Women in Pakistan. The aim was to use the Women with Disabilities Stigma Inventory (WDSI), a new self-report stigma measure, to understand the factors that influence the stigma experienced by women with disabilities in Pakistan.

Method: Participants were recruited via local organisations for people with disabilities (OPDs). Data collectors were trained to administer the survey. 93 women with disabilities in the Balochistan and Sindh provinces completed the WDSI via interview. Interviews took place at participants' homes or at local community centres.

Results: Findings suggest that women with disabilities in Pakistan experience significant levels of stigma, frequently being denied services and participation in their communities, and experiencing abuse and gender-based violence. Type of limitation in functioning predicted experiences of exclusion and marginalisation and abuse. Being part of an ethnic minority vs majority group predicted experiences of exclusion and marginalisation.

Conclusions: As stigma is a construct shaped by culture, stigmatising beliefs about women with disabilities are likely to be deep rooted. Women with disabilities perceived that their stigma experiences were influenced by both gender and disability. As such, stigma interventions must be specific to how these two identities interact in

Pakistan. For the greatest impact, interventions should follow a multilevel model of combating stigma at the intrapersonal, familial, interpersonal, and structural levels (Werner & Scior, 2016).

Introduction

Stigma and disability

Stigma is a social construct, contingent on cultural and societal beliefs that inform prejudice stereotypes and separate, devalue and discriminate against an individual or group based on perceived differences (Link & Phelan, 2001). As such, no characteristic is inherently stigmatising (Goffman, 1963). Instead, stigma depends on the existence of power that dictates which identities are dominant and valued, and those that are perceived to disrupt societal and cultural norms and, thus, rejected (Link & Phelan, 2014).

People with disabilities are a stigmatised group, which results in the exclusion of, and discrimination against, them (Bond, 2017). A review of stigma in low- and middle-income countries (LMICs) found that a lack of understanding and misconceptions about the causes and nature of disabilities were key drivers of the stigma experienced by people with disabilities, and stigma was reinforced by segregation and discriminatory legislation and policies (Rohwerder, 2018). There are physical, social, economic, cultural, and legal barriers that prevent people with disabilities having fair access to education, employment, housing, and disability-specific health and social care support (Handicap International, 2015). As such, people with disabilities are disproportionately affected by natural disasters, economic crises, and political unrest (Bista & Sharma, 2019; Cornelsen, 2012; Dowling, 2016). They are at greater risk of experiencing poverty, unemployment, poor housing, social isolation, bullying and abuse (Hussain et al., 2022; Rickard & Donkin, 2018; Scior et al., 2016; World Health Organisation [WHO], 2011). Further, disability stigma threatens a person's quality of life and exercise of their fundamental human rights (Hendriks, 2007; Gauthier De Beco, 2020).

Context of Pakistan

Pakistan is a collectivist society, whereby living interdependently within networks and adhering to a shared values system is prioritised in order to ensure group harmony. Historically, the dominant understanding of disability has been rooted in a medical model that views disabilities as impairments that should be 'fixed'. For example, intellectual disabilities (IDs) are believed to be a result of illness or poverty (Mirza et al., 2019).

In parallel, there is a culture of pity and sympathy towards people with disabilities as they are perceived as symbols of good fortune (Ahmed et al., 2012). This encourages a charitable response rather than a rights-based approach that recognises people with disabilities in policies and strategies. In 2020, the Rights of Persons with Disability Act was passed in parliament, making it illegal to discriminate against people on the basis of disability (Kizilbash, 2020; Sightsavers, 2020). This was an imperative step in Pakistan adhering to the rights stated by the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), which it ratified in 2011. Further, the judgement directs a move from the medical model of disabilities to a social model, requiring societal changes to remove existing discriminatory barriers and allow for the equal participation and inclusion of people of disabilities. Prior to this, people with disabilities were unrepresented in powerful contexts, like parliament, meaning they were forgotten in the design of community services and state initiatives (British Council, 2014).

Islam is the most common religious faith in Pakistan and plays a significant part in people's lives (Sarkar, 2014). Religious and theological narratives about disabilities persist and lead to stigma and marginalisation, and a preference for religious and spiritual coping methods. In contrast to the aforementioned idea that disabilities represent good fortune, culturally informed religious narratives shape the belief that disabilities are a curse, test from God, or a punishment for parents' sins (Ravindran & Myers, 2011; Singal et al., 2011). As such, families are often afraid of facing discrimination and hide their relatives with disabilities from the community (Furrukh & Anjum, 2020). Additionally, due to a lack of community support, the responsibility for educating and caring for people with disabilities resides within families, which can place significant pressure on them (Ahmed et al., 2012; Arif et al., 2008).

Misinformation about disabilities is common. In a study examining attitudes towards epilepsy in Pakistan, epilepsy was thought to be infectious and cured through spiritual methods (Shafiq et al., 2007). Moreover, a lack of understanding about epilepsy appeared to lead to prejudice attitudes. For example, most respondents reported not wanting their child to marry someone with epilepsy, and some felt that people with epilepsy could not receive an education, perform activities of daily living, or contribute effectively to society. Similarly, stigma was found to be associated with dementia as it was seen to impact on engagement with daily prayers, and participants were unaware that dementia exempts them from certain religious obligations (Willis et al., 2020).

Overall, these perspectives have contributed to the segregation of people with disabilities, meaning that they remain an invisible and unrepresented group (Bryant et al., 2011) with limited opportunities for employment and integration into communities

(Hammad & Singal, 2014). Accordingly, low exposure to people with disabilities perpetuates existing beliefs and is associated with greater prejudice and discrimination (Ahmad & Koncsol, 2022). Several initiatives have been set out in Pakistan, with a key focus of supporting the rights of people with disabilities. For example, Pakistan has developed frameworks and legislation to support the inclusive education of people with disabilities (United Nations Children's Fund [UNICEF], 2021). Although there are still barriers, such as providing adequate support to enable children with disabilities to access education, it is hoped that changes like these will improve the landscape of opportunities for people with disabilities.

Gender-based violence in Pakistan

A patriarchal belief system dictates societal norms in Pakistan, influencing the experiences of women and increasing their economic and social dependence on family members and partners, and thus their vulnerability to discrimination and abuse (Khan & Hussain, 2008). Women hold less power than men and remain unrepresented in many sectors (Ali et al., 2011; UNICEF, 2006). As such, health inequalities are widespread and women's rights, for example to inherit property, live autonomously, or work in a paid job (Ahmad et al., 2016; Madhani, 2007), are restricted. Gender roles dictate that men are an economic asset with the responsibility of living with their family and supporting their parents in old age (Human Rights Watch, 2018). As such, son preference is prevalent, and literacy rates are lower amongst women as many families choose to only send their sons to higher education (Saeed, 2015). Further, there are less schools available for girls when compared to boys and many parents remove their daughters from school when they approach puberty, sometimes due to fears that they will engage in romantic relationships or be vulnerable to sexual violence (Human Rights Watch, 2018). A woman's value can be placed in marriage, reproduction and becoming a homemaker. Arranged marriages account for 95% of marriages in Pakistan (Allendorf & Ghimire, 2013; Gabriela, 2014), following which women are expected to join, and contribute to, their husband's family home. Women experience stigma and discrimination when they are perceived to not meet societal expectations, such as to have children (Hassan et al., 2020; Papreen et al., 2000)

Gender-based violence is highly prevalent in Pakistan, with one in three women reporting lifetime experiences of physical or sexual violence (National Institute of Population Studies, 2019). In terms of intimate partner violence (IPV), a systematic review by Ali et al. (2014), reported rates of physical IPV, such as slapping or pushing, between 28% and 35% across six eligible studies. For example, nearly one third of a random sample of 23,430 women from Punjab, Sindh, Balochistan, and Northwest Frontier Province who the completed the National Household Survey via interview reported experiencing physical violence (Andersson et al., 2010). The prevalence of forced sex or sexual coercion was reported in six studies and ranged between 1% and 77%, and in 11 studies between 48% and 84% of the women surveyed reported psychological abuse. The lowest prevalence of sexual abuse was reported in a sample of pregnant women who were interviewed and completed a questionnaire from the WHO Domestic Violence Module (Zareen et al., 2009). The same questionnaire was used with 500 married women presenting to four hospital sites in Karachi and 21% reported sexual abuse, whilst 50% had experienced psychological abuse during their marriage (Kapadia et al., 2010). Interestingly, the highest rates of sexual abuse were reported by a sample of 70 men, interviewed whilst accompanying patients to a hospital, of whom 77% said they had engaged in non-consensual sex with their wives (Shaikh, 2000).

Societies dominated by patriarchal ideologies are more likely to tolerate gender-based violence and abuse (Ahmad et al., 2004), particularly sexual abuse (Chandra et al., 2003), which makes it difficult for women to disclose abuse, seek support, or leave an abusive relationship (Andersson et al., 2010). It is believed that, as a sign of commitment, a woman should be sexually available to her husband, meaning that forced sex is often not considered abuse or violence and many women who experience sexual abuse remain silent (Madhani et al., 2017).

Gender inequalities that devalue the lives of women also have implications for how women are treated across health facilities and during childbirth (Jewkes & Penn-Kekana, 2015), with women frequently experiencing maltreatment (Abuya et al., 2015; Freedman & Kruk, 2014; Hameed et al., 2021).

Several initiatives have been recommended to promote gender equality and reduce gender-based violence in Pakistan (Centre for Peace and Development Initiatives, 2011), and over the last two decades legislation has been passed to protect women's rights, such as the Sindh Domestic Violence Act and the Protection Against Harassment of Women at the Workplace Act (Samo, 2023). Moreover, the Minister for Planning, Development and Special Initiatives recently launched a citizen's guide to prevent gender-based violence, which emphasises the inclusion of women in the development of Pakistan (Pakistan Today, 2023). This includes an Innovation Fund Program that will provide funding to female entrepreneurs. Furthermore, UNICEF have organised programmes to promote the engagement of girls in school. Initiatives include a community mobilisation strategy that resulted in approximately 900,000 more girls attending primary school (UNICEF, 2018), a gender-sensitive parenting package to promote responsive caregiving to young girls (UNICEF, 2019), and a campaign to empower women and girls and promote positive menstrual hygiene (UNICEF, 2018).

Stigma and intersectionality

Intersectional stigma refers to the intensified prejudice and discrimination experienced due to an interaction with other forms of stigma related to a person's identity, including their race, gender, and sexuality (Bowleg, 2012).

Women with disabilities are affected by multiple and intersecting forms of stigma. Reactions to disability are compounded by socially constructed gender norms, which vary dependent on other factors like ethnicity, socioeconomic status, and age. Internationally, women and girls with disabilities experience more stigma compared to men with disabilities and women without disabilities (CRPD, 2006). Women with disabilities are more likely to suffer domestic violence, sexual abuse, exploitation, mistreatment of their reproductive rights, neglect, and harassment (CRPD, 2016). They face barriers in most areas of life and frequently experience violations to their human rights and ability to exercise control over their own lives, especially in relation to equal opportunities in education, housing, employment, access to essential health services, political inclusion, and recognition within law. Women with disabilities are vulnerable to stigma, gender-based violence and sexual exploitation during conflicts and humanitarian emergencies as their specific needs are poorly understood (Handicap International, 2001; Rohwerder, 2001; United Nations Population Fund [UNFPA], 2018).

In Pakistan, women with disabilities live within complex systems where conservative family structures are bound to cultural norms (Jayachandran, 2015). They can be seen as a burden to their family with fewer opportunities for marriage (Gilani et al., 2009) due to the perception that disabilities prevent women from fulfilling gender roles, for example, to care for their husband and children (UNFPA, 2020). Women with disabilities experience violence frequently (National Institute of Population Studies and the International Classification of Functioning, Disability and Health, 2019). The expectation for women to be escorted whilst attending health facilities has been found to be particularly problematic, preventing women from seeking support (Hatherall et al., 2019).

Article 6 of the CRPD was created in response to the specific difficulties faced by women with disabilities, aiming to develop measures that recognise the rights and encourage the empowerment of women with disabilities (CRPD, 2016). Pakistan is one of 103 states partied to the CRPD and has agreed to prioritise strategies that to allow women to exercise their human rights.

Factors associated with stigma experiences

The experience of stigma within this group varies significantly and is context specific, often dependent on the type and visibility of disability (Division for Social Policy and Development [DSPD], 2016). Furthermore, research has found that the stigma experienced by people with disabilities can differ significantly depending on intersectionality with other forms of oppression and the particular social attitudes held by a person's community and family (Groce & McGeown, 2013), which are often influenced by socioeconomic, religious, cultural, and political factors.

As in all countries, culture plays a significant role in the understanding and acceptance of disabilities in Pakistan (Furrukh & Anjum, 2020). As stigma is a social construct, shaped by groups who hold more power than others, majority and minority ethnic groups are likely to have different experiences of stigma. Existing literature suggests that the extent to which disabilities are visible and perceived as barriers to fulfilling gender norms affects the level of stigma experienced. Thus, the visibility and type of disability a person has are important factors to consider. In Pakistan, greater stigma was found in relation to IDs compared to physical disabilities (Ansari, 2002) and mental health difficulties when compared to physical illnesses, due to the societal beliefs that mental health difficulties are a result of sorcery while physical illness is understood as a result of medical illness (Husain et al., 2020). Women with disabilities who are married, adhering to societal expectations, may experience less stigma than those who are single. In a Serbian study with people with physical disabilities, unmarried participants perceived greater discrimination (Milačić-Vidojević et al., 2017).

Geography influences the level of stigma experienced by people with disabilities. In Pakistan, individuals living in urban areas report less stigma than those in rural areas (Hamdani et al., 2014). Research suggests that this is related to knowledge, ‘modern’ ideas, and resources available for people with disabilities in more liberal, urban areas, which dispel many misconceptions about disabilities and encourage the community participation of people with disabilities (Minhas et al., 2015). Further, in a study investigating demographic variables that influence HIV-related stigma, age and province were found to predict experiences of stigma and discrimination (Dos Santos et al., 2014), with younger individuals and those from rural areas reporting more frequent stigma experiences. Similarly, in two studies examining the stigma experiences of participants with IDs, age (Ali et al., 2016) and ethnicity (Ali et al., 2015) were associated with stigma.

Additionally, the education, employment, and financial wellbeing of women in Pakistan is associated with empowerment and autonomy (Gilani et al., 2009; Jiwani et al., 2013; Neil & Domingo, 2015; Sarwar & Imran, 2019). Similarly, younger people in Pakistan have more empowering attitudes towards women (Batool & Jadoon, 2018).

Research with other stigmatised groups suggests that stigma resistance is related to higher self-empowerment (Yip & Chang, 2021) and lower self-stigma (O’Connor et al., 2018). As such, the factors of age, education, and employment, could be important in supporting women with disabilities to resist stigma and advocate for their rights.

Measurement of stigma

The Women with Disabilities Stigma Inventory (WDSI) is a newly developed self-report tool for women with disabilities (Scior et al., 2023). It was produced as part of a collaborative project between the United Nations Development Programme (UNDP), UN Women, and researchers from University College London (UCL), which aimed to design a measure to generate data on the stigma experiences of women with different types of disabilities globally. The measure was designed to be self-report, capturing the views and experiences of women with disabilities, which are rarely heard.

The project involved several phases of consultation with experts from local organisations for people with disabilities (OPDs) and women with disabilities from four countries, including Pakistan, to ensure that it was culturally relevant to the context in which it would be used. The measure’s subscales and items built on existing scales including the People Living with HIV Stigma Index 2.0 (Friedland et al., 2020), Abuse Assessment Screen-Disability (McFarlane et al., 2001), Safer and Stronger Program (Curry et al., 2009), Stigma Resistance Scale (Firmin et al., 2017), and the Questionnaire for Persons with Disabilities developed in Moldova (Ciocan, 2021).

After field testing, the measure underwent psychometric evaluation and was found to be a valid and reliable tool (Scior et al., 2023). It can be used to assess the stigma experiences of women with disabilities, including marginalisation, abuse, and gender-based violence, as well as stigma resistance, engagement with advocacy, and awareness of rights. The study detailed in this paper focuses on the implementation of the WDSI in Pakistan and exploration of the data collected.

Study aims

The need to challenge disability stigma and ensure that people with disabilities can participate equally in society is now widely recognised. For example, tackling stigma against people with disabilities globally was one of the four pillars of the 2018 Global Disability Summit (International Disability Alliance, 2018). Goal 10 of the 2030 Sustainable Development Agenda (UN, 2015) calls to end violence against women and girls with disabilities and for women and girls to have equal rights to social, economic, and political inclusion. Despite this, data on intersectional stigma and the realities of women with disabilities is minimal, particularly in relation to gender-based violence, and the lack of protection and rights of women with disabilities remains a global issue (ADD International, n.d.; Razzaq & Rathore, 2020; Turan et al., 2019). Further, there have been several legislative changes in Pakistan recently to support the rights of women with disabilities and adhere to the CRPD (Kizilbash, 2020; Pakistan Today, 2023; Sightsavers, 2020). However, there is no data to assess whether these changes are having a positive impact on the lives of women with disabilities. Where women with disabilities are the focus of research, studies are mostly small-scale and qualitative (UN Women, 2023).

Hearing from women with disabilities and understanding the impact of intersectionality will allow for a more comprehensive picture of the causes of stigma and gender-based violence, and the context in which it exists; necessary information for the design of targeted stigma-reduction strategies (Link & Phelan, 2001; UN Women, 2023)

The present study aimed to explore experiences of stigma, discrimination, and gender-based violence as reported by women with disabilities in Pakistan. Secondly, to determine how women's experiences of stigma differ on the basis of sociodemographic variables and limitations in functioning.

Methods

Participants

A power analysis, using the "G*Power3" computer program (Faul et al., 2007), was conducted with a desired power of 80% and alpha set at 5%. This indicated that to achieve a medium effect size ($F = 0.15$) in a multiple regression with six predictors, a minimum sample size of 98 was required. As a result of the prolonged flooding that impacted the areas where data were collected and the time constraints of the project, this sample size was not reached.

Data were collected from a total of 93 women with disabilities in November 2022. Participant demographics are summarised in Table 1. Of the 93 participants, 56% had mobility impairments, 19% had limitations that effected their vision, 9% had memory impairments, 8% had impaired hearing, 5% had communication impairments, and 30% had difficulties in self-care. Over three quarters (77%) of participants said that their limitations in functioning were visible to others, 63% reported using an assistive device and 77% required help from others to facilitate their daily life.

Just over half of the women interviewed had a disability registration card, and a third of whom had a card experienced difficulties seeking one. The disability registration card certifies someone's disability and is a pre-requisite for seeking disability-specific benefits from the federal and provincial governments in Pakistan.

Table 1

Participant Demographics

Variable	Category	N (%)
Age band	18-24	25 (27)
	25-34	39 (42)
	35-44	19 (20)
	45-54	2 (2)
	55-64	3 (3)
	65+	1 (1)
	Missing	4 (4)
Ethnicity	Balochi	13 (14)
	Gilgit Baltistan	3 (3)
	Kashmiri	1 (1)
	Muhajir/Refugee	9 (10)
	Pashtoon	15 (16)
	Punjabi	13 (14)
	Sindhi	27 (29)
	Missing	3 (3)
	Other (please specify)	9 (10)
Relationship status	Married	16 (17)
	Engaged	2 (2)
	Separated / Divorced	5 (5)
	Single	62 (67)
	Widowed	3 (3)
	Missing	3 (3)
	Other	2 (2)
Children	No	71 (76)
	Yes	19 (20)
	Missing	3 (3)
Education status	No formal education	30 (32)
	Primary/elementary school	15 (16)
	Secondary/high school	21 (23)
	Special needs school/Other	6 (7)
	Tertiary/university education	17 (18)
	Trade/vocational school	1 (1)
	Missing	3 (3)
Employment status	Employed	17 (18)
	Homemaker	10 (11)
	Student	20 (22)
	Unable to work	11 (12)
	Unemployed	25 (27)
	Voluntary work	5 (5)
	Missing	3 (3)
	Other	2 (2)
Location	Rural	36 (39)
	Urban	51 (55)
	Missing	6 (7)
Living situation	Independently	1 (1)
	Live with husband and children	12 (13)
	My immediate family (no husband)	67 (72)
	With in-laws and family	3 (3)
	With children (only)	4 (4)
	Missing	3 (3)
	Other	3 (3)
Minority group	No	82 (88)
	Internally displaced	3 (3)
	Racial minority	1 (1)
	Religious minority	3 (3)
	Missing	4 (4)

Recruitment

OPDs, with the support of UNDP, UN Women, and UCL researchers, facilitated the recruitment of women with disabilities for the study. Participants were recruited from the two largest provinces in Pakistan, Balochistan and Sindh, chosen as they are the most populous regions in Pakistan with both urban and rural areas. Additionally, the two provinces differ in terms of economic, social, and political characteristics, allowing for the inclusion of women with diverse demographic and cultural backgrounds.

Participants were women aged 18 and above with different types of disabilities, with capacity to consent to take part. The CRPD (2006) definition of disability was used, whereby people with disabilities are defined as "those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others." Due to ethical considerations, only women already known to OPDs took part in the study. The mixed sampling strategy was designed to include women with different types of disabilities and sociodemographic factors, to reflect the heterogeneity of this group within Pakistan.

Following devastating flooding in Pakistan that affected communities involved in the study, where possible the OPDs completed more outreach work to enable women with disabilities who could not travel to community centres to take part. The study was advertised by word of mouth by members of OPDs and enumerators, at community venues for people with disabilities or door to door by visiting towns and villages where women known to the OPDs lived. STEP, an OPD in Balochistan, used a snowball sampling approach, inviting women within their existing networks in and around Quetta to take part. They completed interviews in participants' homes. In Sindh, five villages were initially selected and three participants from each were randomly recruited to take part. HANDS collected data from women with disabilities in their homes and at their main centre in Hyderbad. Disabled Welfare Association (DWA) and NOWPDP randomly selected women with disabilities accessing their services and interviewed women from their base in Sujawal and Karachi.

Measures

The WDSI was used to measure experiences of stigma and gender-based violence. A detailed explanation of the development and psychometric evaluation of the measure is provided in a separate paper (Scior et al., 2023).

Table 2 provides an overview of the WDSI subscales and scoring. The Experiences of Exclusion and Marginalisation subscale (S3) of the WDSI is unidimensional and was found to be reliable ($\alpha = .84$) in a sample of 667 women with disabilities from Moldova, Pakistan, Palestine, and Samoa (Scior et al., 2023).

The Experiences of Abuse subscale (S4) has a unidimensional structure and reliably measures experiences of physical, psychological, financial, and emotional abuse ($\alpha = .85$). The six-item Responses to Stigma and Discrimination subscale (S6) is a reliable, unidimensional measure of stigma resistance and cognitive, emotional, and behavioural responses to stigma ($\alpha = .85$). The five advocacy items included in the Rights and Effecting Change subscale (S7) reliably measure experiences of advocating for the rights of women with disabilities ($\alpha = .72$).

Table 2

WDSI Subscales

Subscale	Number of items	Response options	Scoring (range of scores)	Measures used to inform subscale items
About You	8	NA	NA	People Living with HIV Stigma Index 2.0 (Friedland et al., 2020) Moldova Questionnaire for persons with disabilities (Ciocan, 2021)
Disability				
(a) Areas of limitations in functioning	5	4-point Likert scale from 'no difficulty' to 'cannot do at all'	1 = yes, disability present in this area of functioning: 'a lot of difficulty' or 'cannot do at all', or 0 = no disability in this area: 'a little difficulty' or 'no difficulty'	Washington Group Questionnaire (Washington Group on Disability Statistics, 2020)
(b) Further characteristics	4	'Yes' or 'no'	Score as 1 = yes or 0 = no/prefer not to say/don't know	
Experiences of Exclusion and Marginalisation	9	5-point Likert scale from 'never' to 'always'	Score each individual item as 0 = never/prefer not to say/ rarely, 1 = sometimes, 2 = often, 3 = always. Calculate the mean score for subscale score (0-3).	People Living with HIV Stigma Index 2.0 (Friedland et al., 2020)
Experiences of Abuse	8	5-point Likert scale from 'never' to 'always'	Score each individual item as 0 = never/prefer not to say/ rarely, 1 = sometimes, 2= often, 3 = always. Calculate the mean score for subscale score (0-3).	Abuse Assessment Screen-Disability (McFarlane et al., 2001) Safer and Stronger Program (Curry et al., 2009)
Experiences of Discrimination and Violence	6	'Yes' or 'no'	Score each individual item as 1= yes and 0= no/prefer not to say/don't know. Reverse score item 29. Calculate the sum of scores for subscale score (0-6).	Abuse Assessment Screen-Disability (McFarlane et al., 2001) Safer and Stronger Program (Curry et al., 2009)
Responses to Stigma and Discrimination	6	5-point Likert scale from 'never' to 'always'	Score each individual item as 0 = never/ rarely, 1 = sometimes, 2= often, 3 = always. Calculate the mean score for subscale score (0-3).	Stigma resistance scale (Firmin et al., 2017)
Rights and Effecting Change				
(a) Awareness of rights	11	3-point Likert scale from 'not at all aware' to 'very aware'	Score as 1= very aware, and 0= not at all aware/ a little aware. Calculate the sum of scores for awareness of rights score (0-11).	Moldova Questionnaire for persons with disabilities (Ciocan, 2021) People Living with HIV Stigma Index 2.0 (Friedland et al., 2020)
(b) Advocacy	5	5-point Likert scale from 'never' to 'always'	Score each individual item as 0 = never/ rarely, 1 = sometimes, 2= often, 3 = always. Calculate the mean score for advocacy score (0-3).	

Where applicable, throughout the measure, participants are asked to identify the perpetrator of stigmatising experiences and gender-based violence. Intersectionality is a framework most often applied in qualitative research and can be more difficult to interpret through quantitative methodologies (Bauer et al., 2021). To capture the impact of intersectionality, the WDSI asks participants to reflect on which parts of their identity they view as the reason that they have been stigmatised. Each subscale is completed with an open-ended question to provide information regarding their experiences of stigma not detailed within the scale items.

The measure was customised through discussions with UNDP, UN Women, OPDs and women with disabilities to meet local and cultural needs. For example, the term ‘partner or husband’ was replaced with ‘husband’, and additional questions were added about standing up for the rights of people with disabilities. The WDSI was translated from English to Urdu and back-translated by independent translators to check for semantic equivalence with the original English version. Adaptations were made to the items where concepts did not translate well. The measure was available in paper format or online using Qualtrics software. A copy of the WDSI and scoring guide used for the study can be found in Appendix C and Appendix D respectively.

Study design and procedures

The study presented in this thesis was part of a joint initiative with the UNDP, UN Women and UCL researchers (The Addressing Stigma and Discrimination experienced by Women with Disabilities [ASDWD] project), aiming to respond to the growing intersectional inequalities faced by women with disabilities. The ASDWD project was funded by the United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD). It was conducted in collaboration with UNDP and UN Women and OPDs in four partner countries: Palestine, Samoa, Moldova and Pakistan. In Pakistan, in addition to the UNDP and UN Women country teams, four OPDs, STEP, HANDS, DWA and NOWPDP, and women with disabilities linked to the OPDs were involved throughout the project. Details of those who contributed to the study in Pakistan are provided in Appendix E.

One outcome of the ASDWD project was the development and field testing of the WDSI in four partner countries. My UCL supervisors were contracted as research consultants for the project. Therefore, my supervisors had oversight of the wider project, and I joined them as part of my thesis, concentrating on the development and implementation of the WDSI in Pakistan. Initially, my supervisors completed a desk review of existing disability stigma measures, from which I worked with them to develop the WDSI. I completed the early preparatory work for the project, including applying for ethical approval and creating information sheets, consent forms and the WDSI guide for administrators, with input from my supervisors.

Throughout the project, regular meetings were held on Zoom between UCL researchers, UNDP, UN Women, OPDs and women with disabilities. These meetings were used to share information and advice. In addition, early versions of the WDSI and resources were regularly shared with country teams for their feedback. I joined the meetings between UCL researchers and the team in Pakistan and liaised with the country team to support them with the different stages of the project, such as conducing focus groups and providing feedback about the face and content validity of the WDSI from women with disabilities. As such, the methodology and resources described in this study were designed in collaboration with UNDP, UN Women, OPDs and women with disabilities in Pakistan. Although there were multiple stages involved in the development of the WDSI (outlined in the diagram of measure development shown in Appendix F), this thesis focuses on the results from the field testing of the version five of the WDSI in Pakistan.

Ethical approval was granted by UCL Research Ethics Committee. Approval for data collection in Pakistan was also granted by the Secretary of the Social Welfare Department (see Appendix G and Appendix H)

Enumerator Training

The study design was shaped by the methodology and perspective of participatory research, aiming to involve people with disabilities throughout. Thus, enumerators were 25 people with disabilities identified by the four OPDs. It was hoped that this would reduce power differentials between participants and data collectors, build capacity and research skills, and convey a positive message about the capabilities of women with disabilities.

Prior to data collection, all enumerators attended a one-and-a-half day training event held in person and via Zoom, led by UNDP, UN Women, and UCL researchers (the agenda and images from the training can be found in Appendix I). The training focussed on familiarising the enumerators with the WDSI and building their skills for administering the survey. This included an overview of the study aims, important ethical considerations like ensuring privacy and confidentiality during the interviews, building rapport with participants, and ensuring that the enumerators knew where to seek support should the interview be upsetting for them or the participants. To support and reinforce the training, trainers and enumerators were provided with two documents: a guidance for data collectors (a copy of which can be found in Appendix J) and an ethical standards guide (see Appendix K).

Administration of the WDSI

Interviews were conducted in a private room in participants' homes or at an OPD site (see Appendix L for images shared with participants' consent). Most were completed 1:1, however, five women with disabilities had hearing or speech impairments that prevented their verbal communication of responses due to the absence of an interpreter. These participants consented to the presence of a family member to respond on their behalf. The nature of the study was explained to participants verbally and via an information sheet (see Appendix M) which was available in accessible formats. Subsequently, a consent form was reviewed with all participants, and verbal consent was taken before the interview began (A copy of the consent form is included in the WDSI, as shown in Appendix C).

The WDSI was administered by interview and key terms were defined and explained by enumerators throughout. As discussed in the ethical guidelines and guidance for data collectors, enumerators were encouraged to make necessary adaptations to the administration of the interview to ensure that it was accessible to participants. For example, participants were able to have regular breaks.

To maintain confidentiality, no identifiable information was recorded and participants who completed the paper version of the WDSI were given a unique participant code. The majority of enumerators entered participant responses in real time onto Qualtrics software using mobile devices. In Sindh, enumerators used a paper copy of the WDSI due to internet connectivity issues and uploaded the data to Qualtrics following the interview. To ensure accuracy, the data were reviewed by a supervisor from one of the OPDs.

Following the interview, participants were provided with information on local services where they could seek support for the issues discussed during the interviews. Further, they were encouraged to give feedback on their experience of participating in the project, with the hope that this information would provide further context to their responses and important learnings about conducting research with women with disabilities in Pakistan. Similarly, a reflective space was provided for all enumerators on Zoom, and they were asked to complete an enumerator feedback survey, available in English and Urdu, on Qualtrics to capture their experiences of being part of the project and using the WDSI (a copy of the survey and results are provided in Appendix N, Appendix O and Appendix P respectively).

Results

A total of 93 participants completed the WDSI and were included in the analysis. The data were analysed using JASP version 0.16.

Experiences of exclusion and marginalisation

Experiences of exclusion and marginalisation were measured by S3 of the WDSI. Individual item scores suggest that stigma is commonly experienced by women with disabilities in Pakistan, see Table 3. For example, 52% of participants had been denied education, 43% had been discriminated against at work, 36% had not been allowed their own mobile phone, 43% had been excluded from social gatherings, 37% had been stopped from attending family events, and 47% said that people at least sometimes avoid contact with them.

Table 3

Frequencies of Experiences of Exclusion and Marginalisation

Item	N (%)				
	Always	Often	Sometimes	Rarely/Never	Prefer not to say/missing
Denied education	16 (17)	11 (12)	21 (23)	34 (37)	7 (8)
Denied employment	14 (15)	15 (16)	11 (12)	42 (45)	8 (9)
Denied computer access	12 (13)	4 (4)	11 (12)	56 (60)	7 (8)
Denied mobile phone	21 (23)	5 (5)	7 (8)	50 (54)	7 (8)
Excluded socially	15 (16)	6 (7)	19 (20)	46 (50)	4 (4)
Excluded by family	13 (14)	6 (7)	15 (16)	52 (56)	4 (4)
Denied healthcare	3 (3)	15 (16)	9 (10)	61 (66)	3 (3)
Denied access to public buildings	22 (24)	10 (11)	18 (19)	35 (38)	5 (5)
People avoid contact	9 (10)	16 (17)	19 (20)	39 (42)	7 (8)

Table 4

Perpetrator of Exclusion and Marginalisation

Perpetrator	N	%
Family members	47	51
Other	8	9
Colleagues or teachers	7	8
Prefer not to say	7	8
Community members (e.g., shop keepers, taxi drivers, religious leaders)	6	6
Not applicable (I have not been excluded or had services/assistance denied)	6	6
Public service providers (e.g., healthcare providers)	5	5
Friends or neighbours	4	4
Missing	3	3

Table 5

Perceived Reasons for Exclusion and Marginalisation

Frequency	Gender		Disability	
	N	%	N	%
Always	14	15	24	26
Often	13	14	22	24
Sometimes	20	22	18	19
Rarely	6	7	5	5
Never	33	36	18	19
Don't know	4	4	3	3
Missing	3	3	3	3

Most frequently, participants reported having been denied access to public services and buildings. Participants indicated that family members were the most likely perpetrators of exclusion and marginalisation (51%) (see Table 4). As described in Table 5, over half of the participants who had been excluded felt that it was because of their gender (51%), however, these experiences were most often attributed to the participant’s disability (69%).

A multivariate regression analysis was conducted to determine the extent to which experiences of exclusion could be predicted by sociodemographic variables. Independent variables entered into the model were those suggested by the research to be associated with stigma experiences: disability type (Ansari, 2002; DSPD, 2016; Furrukh & Anjum, 2020; Husain et al., 2020), age (Ali et al., 2006; Dos Santos et al., 2014), geographical location (Dos Santos et al., 2014; Hamdani et al., 2014), ethnicity (Ali et al., 2015; Groce & McGeown, 2013), relationship status (Milačić-Vidojević et al., 2017), and visibility of disability (DSPD, 2016).

For the purposes of the analyses, the variables were grouped. Disability type was categorised as visual (those who had limitations in functioning in the area of seeing), mobility (participants who indicated limitations in functioning in the area of walking), and multiple (limitations in multiple areas of functioning, such as seeing, walking, hearing, remembering or communicating as captured by the Washington Group Questions). Difficulties in self-care were treated as secondary if they appeared in concurrence with a limitation in another area of functioning. Hearing impairments or limitations in functioning in the area of remembering, communicating or self-care only were not entered as groupings due to the low number of participants in these categories. Age was categorised into three groups: 18-24, 25-34, 35+ (which included those who responded 35-44, 45-54, 55-64, and 65+). Geographical location was split into urban and rural (which included both semi-rural and rural), ethnicity was grouped as majority (Pashtoon, Punjabi, and Sindhi) and minority groups (Balochi, Pathan, Kashmiri, Gilgit, Baltistan, Chitrali, Muhajir [Urdu speaking Muslim migrants from India]), three categories were used for relationship status: single, in a relationship (to include both engaged and married), and separated (which captured those who are separated, divorced, or widowed), and visibility of disability was categorised as visible or concealable. Other responses were treated as missing data. The assumptions of normality, homoscedasticity and linearity were checked and met. A significant effect was found, $F(9, 53) = 2.04, p = .05$, and together the demographic variables explained

26% of the variance in exclusion and marginalisation scores. Two significant univariate effects were found. Disability type (*t* = 2.32, *p* = .02) and ethnicity (*t* = 2.65, *p* = .01) predicted the frequency of experiencing exclusion and marginalisation.

A one-way analysis of variance (ANOVA) was conducted to further explore the data. Levene's test showed that the variances for exclusion and marginalisation scores across disability types were equal, *F*(2,62) = 1.82, *p* = .17. There was a significant effect of disability type on exclusion and marginalisation scores, *F*(2, 62) = 3.56, *p* = .03. Post hoc testing using Bonferroni's correction revealed that having limitations in multiple areas of functioning did not affect the frequency of exclusion or marginalisation when compared to having difficulties walking (*t* = 2.34, *p* = .07) or visual impairments (*t*= 2.34, *p* = .07), although generally exclusion and marginalisation scores were higher for participants with limitations in multiple areas of functioning (*M* = 1.3, *SD* = 0.8) compared to participants with difficulties walking (*M*= 0.8, *SD* = 2.9) or visual impairments (*M* = 0.7, *SD* = 1.9) . There were no significant differences in scores between those with visual impairments or difficulties walking (*t* = 0.65, *p* = 1.00).

To examine the influence of ethnicity on scores, further analyses were conducted. A Shapiro-Wilk test was significant and suggested a deviation from normality (*W* = .88, *p* < .00). Based on this, a Mann-Whitney test was used. Whilst participants from an ethnic minority reported more frequent experiences of exclusion and marginalisation, no significant differences were found in exclusion and marginalisation scores between participants from an ethnic minority (*Mdn* = 0.8) compared to the majority ethnic group (*Mdn* = 0.6) (*U* = 750, *p* = .10).

Experiences of abuse

As shown in Table 6, in relation to people they are close to, 56% participants reported verbal abuse, 30% had experienced physical abuse, and 31% had been forced to stay at home or in a room alone. Nearly two thirds (60%) of participants had been teased by people they are close to. Family members were often the perpetrator of abuse, rather than friends or close acquaintances (Table 7). However, many participants chose not to indicate who the perpetrator of the abuse was (17%) or did not answer the question (29%). Fewer participants reported verbal abuse (40%) and physical abuse (12%) from people they do not know very well. When abuse was reported, most often the perpetrators were community members, for example shop keepers or taxi drivers (17%). Half of the participants (50%) felt that they had been abused because of their gender, and 71% perceived that the abuse had been a result of their disability (see Table 8).

Table 6

Frequencies of Experiences of Abuse

Item	N (%)				
	Always	**Often**	**Sometimes**	**Rarely/Never**	**Prefer not to say/missing**
Teased by people you are close to	10 (11)	22 (24)	23 (25)	31 (33)	4 (4)
Verbal abuse from people you are close to	12 (13)	15 (16)	25 (27)	34 (37)	4 (4)
Physical abuse from people you are close to	5 (5)	11 (12)	12 (13)	56 (60)	6 (6)
People you are close to have stolen or destroyed your property	2 (2)	3 (3)	15 (16)	59 (64)	11 (12)
Forced to stay home alone	5 (5)	8 (9)	16 (17)	56 (60)	5 (5)
Verbal abuse from strangers	3 (3)	13 (14)	21 (23)	48 (52)	5 (5)
Physical abuse from strangers	4 (4)	6 (7)	10 (11)	64 (69)	6 (6)
Strangers have stolen or destroyed your property	1 (1)	2 (2)	9 (10)	69 (74)	9 (10)

Table 7

Perpetrator of Abuse

Perpetrator	N	%
Family members	44	47
Community members (e.g. shop keepers, taxi drivers, religious leaders)	16	17
Friends/close acquaintances	7	8
Prefer not to say	16	17

Table 8

Perceived Reasons for Abuse

Frequency	Gender		Disability	
	N	%	N	%
Always	12	13	24	26
Often	14	15	23	25
Sometimes	20	22	19	20
Rarely	8	9	10	11
Never	33	36	14	15
Don't know	3	3	0	0
Missing	3	3	3	3

A second multivariate regression analysis was conducted to investigate which demographic variables predicted experiences of abuse. The same six demographic variables (disability type, age, geographical location, ethnicity, relationship status, and visibility of disability) were entered into the model. The assumptions of normality, homoscedasticity and linearity were confirmed. The model did not predict abuse scores, $F(9, 53) = 1.95$, $p = .06$. However, disability type ($t = 2.35$, $p = .02$) made a significant contribution to the model.

A one-way ANOVA was completed to assess the relationship between disability type and experiences of abuse. Levene's test showed that the variances for experiences of abuse scores across disability types were equal, $F(2,62) = 2.98$, $p = .06$. There was no significant effect of disability type on abuse scores, $F(2, 62) = 2.53$, $p = .08$. Although, on average, participants with limitations in multiple areas of functioning reported more frequent experiences of abuse (M = 1.0, SD = 0.8), compared to those with visual impairments (M = 0.5, SD = 0.5) and difficulties walking (M = 0.6, SD = 0.6).

Gender-based violence

Summed scores for S5 of the WDSI were used to evaluate the frequency of gender-based violence. Reported occurrence of gender-based violence was low compared to levels recorded in previous studies (see Table 9). Almost 10% reported sexual abuse and/or being harassed or intimidated by phone or social media, and 4% had been forced to marry. Few participants (2%) had been denied access to sexual or reproductive health services. Experiences of discrimination in consideration for marriage were frequent, with 42% of women having not been considered for marriage. Of those who responded 'yes' to any of the questions in S5, reporting gender-based violence, 45% had never told anyone and only 33% had spoken to someone about their experiences.

Table 9

Frequencies of Experiences of Gender-based Violence

Item	N (%)				
	Yes	No	Prefer not to say	Don't know	Missing
Harassed by phone or social media	9 (10)	76 (82)	2 (2)	3 (3)	3 (3)
Sexual abuse	9 (10)	75 (81)	4 (4)	2 (2)	3 (3)
Denied reproductive services	2 (2)	71 (76)	10 (11)	7 (8)	3 (3)
Been considered for marriage	43 (46)	39 (42)	4 (4)	0 (0)	7 (8)
Forced marriage	4 (4)	81 (87)	5 (5)	0 (0)	3 (3)

Stigma resistance

Item scores for the Responses to Stigma and Discrimination subscale are summarised in Table 10. On average, women resisted stigma at least sometimes (*M* = 1.4, *SD* = 0.8). Most participants reported that they know that they have many strengths

(77%), do not feel defined by their disability (78%) and are able to challenge any negative thoughts about themselves (74%).

Table 14

Frequencies of Stigma Resistance

Item	N (%)				
	Always	Often	Sometimes	Rarely/Never	Missing
Positive view of self	18 (19)	26 (28)	17 (18)	27 (29)	5 (5)
Know that prejudice is wrong	9 (10)	20 (22)	24 (26)	36 (39)	4 (4)
Confront prejudice	12 (13)	23 (25)	23 (25)	31 (33)	4 (4)
Know you have strengths	35 (38)	22 (24)	14 (15)	19 (20)	3 (3)
Disability does not define you	23 (25)	22 (24)	27 (29)	18 (19)	3 (3)
Challenge negative thoughts	25 (27)	25 (27)	19 (20)	20 (22)	4 (4)

A multivariate regression, with the variables of disability type, age, education, employment, and geographical location entered into the model, was carried out to determine the extent to which stigma resistance is predicted by demographic variables. The variables of age, education and employment have been shown to correlate with empowerment in Pakistan (Batool & Jadoon, 2018; Gilani et al., 2009; Jiwani et al., 2013; Neil & Domingo, 2015; Sarwar & Imran, 2019), and could be related to stigma resistance, as stigma resistance is related to higher self-empowerment (Yip & Chang, 2021) and lower self-stigma (O'Connor et al., 2018).

Education was grouped as no/little formal education (to include those with no formal education and those who had completed primary school), high school and vocational school, and higher education. Employment was categorised as in work (included participants in paid full-time work as an employee, in paid part-time work as an employee, working full-time but not as an employee (self-employed or business owner), doing voluntary unpaid work outside of the home), not in work (those who are a homemaker, unemployed, unable to work), and students. The assumptions of normality, homoscedasticity and linearity were met. No significant effect was found,

$F(9, 48) = 1.67$, $p = .12$, although together the demographic variables explained 24% of the variance in stigma resistance scores. No significant univariate effects were found, indicating that no single variable predicted stigma resistance.

Rights and advocacy

With the exception of awareness of the right to political participation (28%), approximately half of the women interviewed were aware of their human rights, for example to equality and non-discrimination (51%), education and work (55%), and access to sexual and reproductive health and rights services (50%), see Table 11. However, as shown in Table 12, most participants had not stood up for their rights, for example 65% had never participated in a campaign or advocacy group promoting the rights of people with disabilities, and 54% had never challenged or educated someone who was treating them or other people unfairly because of a disability. Family members frequently supported the participants to stand up for their rights (64%), whereas only 32% had been helped by community members or organisations. It was felt that rights-based organisations and services were difficult to access.

Several of the women interviewed shared that they would like more opportunities to understand and implement their rights and suggested that structural changes were needed to support their independence. For example, women highlighted the need for more education and employment opportunities, accessible services, and societal changes that would allow women greater freedom.

Table 15

Awareness of Rights

Item	N (%)		
	Aware	Not aware	Missing
Equality and non-discrimination	47 (51)	41 (44)	5 (5)
Protection from violence, abuse and exploitation	46 (50)	40 (43)	7 (8)
Education and work	51 (55)	35 (38)	7 (8)
Live with dignity within my family and the community	55 (59)	31 (33)	7 (8)
Privacy and a personal life	51 (55)	35 (38)	7 (8)
Access to justice and legal rights	42 (45)	44 (47)	7 (8)
Political participation	26 (28)	60 (65)	7 (8)
Financial rights	41 (44)	45 (48)	7 (8)
Health, recovery and development	51 (55)	35 (38)	7 (8)
Access to sexual and reproductive health and rights services	46 (50)	40 (43)	7 (8)
Access to prevention, protection and response services	40 (43)	46 (50)	7 (8)

Table 16

Frequencies of Advocacy

Item	N (%)				
	Always	Often	Sometimes	Rarely/Never	Missing
Family helped stand up for rights	22 (24)	15 (16)	22 (24)	28 (30)	3 (3)
Organisations helped stand up for rights	5 (5)	12 (13)	13 (14)	57(61)	3 (3)
Easy to access leaders about rights based issues	2 (2)	0 (0)	15 (16)	70 (75)	3 (3)
Educated others about rights	2 (2)	13 (14)	20 (22)	50 (54)	4 (4)
Participated in campaigns and advocacy groups	2 (2)	9 (10)	14 (15)	60 (65)	4 (4)

Responses to open ended question

Many of the participants expressed additional comments at the end of the interview, describing their stigma experiences and hopes for change. Two participants emphasised the limitations that stigma and discrimination have on their lives stating that other people's attitudes or their family members have "*forced them to stay at home*". Strikingly, one participant said, "*I want to say that disabled people also want to live as human beings*". There were hopes for "*more liberty and freedom*" to "*roam around independently*" and to be able to get a job and "*stand on my own feet and not need anyone*". Finally, participants highlighted difficulties in speaking out about their stigma experiences, with one woman sharing that "t*here are many things that I do not want to tell*".

Discussion

The aim of this study was to use the WDSI, a new self-report stigma measure, to explore experiences of stigma and gender-based violence reported by women with disabilities in Pakistan. Moreover, the study sought to examine what sociodemographic variables may be associated with stigma and stigma resistance.

Of the 93 participants who took part in the study, most were single women living in their family home. Many had never been considered for marriage, implying prejudiced attitudes towards the group of women interviewed as 86% of women over the age of 25 in Pakistan are married (National Institute of Population Studies, 2019). Few of the women interviewed had completed high school or further education, and a high number were unemployed. The proportion of participants who had never been to school was higher than the average number of women reported to have never been to school across Pakistan (World Bank, 2018). Similarly, to Hammad and Singal's (2014) findings, this suggests that there are limited opportunities and support for women with disabilities to advance their education and find employment, linked to their position within society. This is likely to perpetuate the existing difficulties women have in making decisions and living autonomously (Ahmad et al., 2016; Madhani, 2007). Further exploration of the influence of social determinants on outcomes such as health, education and social support would be helpful to explore the inequalities that women with disabilities face and the changes needed to support their rights.

Stigma experiences

In Pakistan, women with disabilities experience stigma, both in terms of exclusion and abuse. They experience oppression and denial of their rights, for example regarding access to education and work. The data suggest that the lives of the women are restricted, with few having access to their own mobile phone or computer. A lack of access to digital resources and information may perpetuate women's reliance on their families and limit their independence. Indeed, around 37% of the Pakistani population had access to the Internet in 2022 (DataReportal, 2022), and despite governmental efforts to improve digital inclusion, little attention has been paid to diverse groups and as such, many groups, including women with disabilities remain digitally unconnected (Jamil, 2021).

Similarly, many women could not access public services or buildings and reported that people avoid contact with them, suggesting that significant prejudice continues to exist at the community and institutional levels. Experiences of discrimination were frequent, with many women being excluded from social gatherings and family events. Family members were most often those excluding women with disabilities and denying them equal opportunities. This is consistent with previous qualitative research with mothers of children with disabilities conducted in the same two provinces of this study (Balochistan and Sindh), where mothers reported that their family members would avoid their child, beat them, and make fun of them, and that disability is generally not accepted in the community (Qayyum et al., 2013)

Verbal abuse and humiliation from family members were the most common types of abuse reported. Additionally, nearly a third of women had sometimes been forced to stay at home or in a room alone. As highlighted by previous research (Andersson et al., 2010; Madhani et al., 2017), women found it difficult to speak about their experiences of abuse and, in many instances, did not want to disclose the perpetrator. As such, the data which showed that family members were often the perpetrators of abuse must be interpreted with caution.

Disability seemed the greatest source of stigma, although stigma experiences were also attributed to gender. In an analysis of the demographic variables that predicted experiences of stigma, in terms of exclusion and abuse, six demographic variables accounted for 26% of the variance in exclusion and marginalisation scores, but the same variables did not significantly predict abuse scores. Disability type and ethnicity were most significant in predicting the frequency of experiencing exclusion and marginalisation, and disability type was the only factor affecting the likelihood of abuse. This finding gives some support to the existing literature, suggesting that attitudes and discriminatory behaviours towards people with disabilities differ by type of disability (Ansari, 2002; Furrukh & Anjum, 2020; Husain et al., 2020) and belonging to ethnic majority vs minority group (Ali et al., 2015; Groce & McGeown, 2013).

However, in contrast to previous findings (Husain et al., 2020), differences between disability groups were not significant in relation to the frequency of experiences of exclusion, marginalisation, and abuse. In this study, participants often did not report any limitations in their functioning or did not respond to the Washington Group Questions used to categorise disabilities. Similarly, the number of participants in some disability categories were relatively low. Thus, the sample included in the analyses was small, reducing the statistical power and likelihood of detecting a true effect.

Similarly, ethnicity predicted experiences of exclusion and marginalisation. This finding gives some support to the intersectionality framework, indicating that stigma experiences are dependent on power and intersecting identities (Groce & McGeown, 2013). However, the frequency of stigma experiences did not differ dependent when comparing minority vs majority groups. The non-significant findings could have resulted because the broader ethnic groups used for the analyses were not specific enough to detect the cultural, socioeconomic, and political differences between specific ethnic groups.

No other demographic variables were significantly associated with experiences of stigma which contradicts previous research, particularly literature that suggests concealable disabilities are less stigmatised, an association for which there is significant support (DSPD, 2016; Rohwerder, 2018). Again, this could be because of the small sample size, particularly as there were a low number of women who reported concealable disabilities, compared to those with visible disabilities. Geographical location did not impact on stigma experiences, conflicting with the idea that living in an urban area, where there is more provision for people with disabilities and where ideas about the rights of women and disability and are generally more liberal, reduces stigma and discrimination towards people with disabilities (Minhas et al., 2015; Hamdani et al., 2014). This could be because the women in this study were already known to OPDs, connected to services supporting the rights of women with disabilities, and thus, reducing the division between rural and urban areas.

Overall, there is currently a lack of acceptance of women with disabilities and an absence of services and infrastructure to meet their needs. This is consistent with previous research in Pakistan where women reported poor access to public healthcare services (Ahmad, 2013), and that special education centres in urban areas were inaccessible for poorer families in urban areas and were absent in rural areas (UNFPA and Women Enabled International, 2021). Where services and opportunities do exist, attitudinal barriers are preventing women from accessing them. Instead, women with disabilities are often rejected, verbally and physically abused, and hidden due to the stigma associated with their disabilities. The literature emphasises the importance of group harmony and shared values in collectivist societies, suggesting that experiences of marginalisation are influenced by societal misconceptions about disabilities that conflict with cultural and gender norms (Jayachandran, 2015). A multifaceted approach is needed to improve the lives of women with disabilities. They should be included in policies and strategies, improving the physical infrastructure and available services able to meet the specific needs of women with disabilities, allowing them to become more integrated into communities and exercise their rights. Similarly, stigma interventions should target the attitudes of family members and community members, focussing on the strengths and capabilities of women with disabilities to reduce the discrimination and abuse women experience at present. As stigma experiences were more frequently associated to disability, close attention should be paid to how interventions dispel myths and provide education about different types of disabilities.

Gender-based violence

Women with disabilities reported significant levels of gender-based violence, including sexual abuse and harassment via phone or social media, with nearly half of the women interviewed stating that they had never told anyone about their experiences. However, the levels of gender-based violence, particularly sexual abuse, reported were lower compared to those found in previous studies (Ali et al., 2015). Just under 10% of participants reported sexual abuse, compared to 21% of 500 married women recruited at hospital sites providing support to low-income groups in Karachi, who completed the WHO Domestic Violence module (Kapadia et al., 2010). This could be due to biases in the sample, meaning that experiences of gender-based violence were lower in those interviewed, or the women interviewed may have experienced gender-based violence and maltreatment but not perceive this as abusive. The women included in Kapadia et al.'s (2010) study did not have disabilities, were from low socioeconomic status households, and were all married. These differences in participant characteristics could contribute to the conflicting findings, requiring further exploration of how intersectional identities manifest. Alternatively, the study setting and format of the interviews may have made it challenging for women to share their experiences, which should be taken into account in the design of future studies. For example, some participants were interviewed at home and, although in a private room, may not have felt free to speak about their experiences due to fears of being overheard. Disclosing experiences of gender-based violence can cause difficult feelings of shame and powerlessness (Ortiz-Barreda et al., 2014). For many, the interviews would have been the first time they had been asked about their potential experiences of violence, which, despite careful attention to ethical issues and thorough training of data collectors, could have been overwhelming and may have led some women to avoid discussing this. Similarly, women with disabilities are disempowered within a society where group harmony is prioritised. As such, the negative consequences of speaking out about these experiences, for example further rejection and abuse, could be significant.

Stigma resistance

Stigma resistance in women with disabilities is relatively undocumented in Pakistan. Findings from this study are encouraging, suggesting that women are able to focus on their strengths to reduce the impact of stigma. However, women could be better supported to stand up to prejudiced attitudes. The number of women who stated that they consistently knew that prejudiced attitudes were wrong was relatively low. Almost a third of participants had never stood up to prejudiced attitudes or viewed prejudices as wrong. This suggests that women are experiencing internalised stigma related to their disabilities. Consequently, the women may not feel empowered to stand up to stigma, instead avoiding community settings due to the prejudices and discrimination that exist.

Taken together, the variables of disability type, age, education, employment, and geographical location explained 14% of the variance in stigma resistance scores. However, no single variable predicted stigma resistance, suggesting that stigma resistance was consistent between groups and support should be provided to women from all backgrounds to help them to understand a stand up to stigma. Previous research with women in Pakistan has found that age, education, and employment predict empowerment (Gilani et al., 2009; Jiwani et al., 2013; Neil & Domingo, 2015; Sarwar & Imran, 2019). Stigma resistance and empowerment may be unrelated constructs, explaining the inconsistent findings; alternatively, the small sample size may have been barrier in detecting the variables that affect stigma resistance. Concurrently, the study focussed on women already known to OPDs. The biases in the sampling strategy may nullify the influence of factors like education or geographic location.

Rights and advocacy

Concerningly, nearly half of the women interviewed were not aware of their rights across 11 different areas and most had not exercised their rights. Although women reported that their family members were supportive, data suggests that services and organisations supporting women to understand and implement their rights are difficult to access. If women with disabilities are not valued by their communities and institutions, or recognised within laws, it would be difficult for them to exercise their rights even if their knowledge and awareness of their rights increased. As such, a rights-based approach must be taken at all levels, aiming to change attitudes towards women with disabilities and their inclusion in society. The women interviewed provided valuable ideas regarding the structural changes required to support their independence. For example, women highlighted the need for more education and employment opportunities, accessible services, and societal changes that would allow women greater freedom. This implies that dispelling many of the misconceptions about women with disabilities cited within the literature is crucial (Hassan et al., 2020; Papreen et al., 2000).

Limitations

This study was part of a pilot project, and the included sample may not be representative of the heterogeneity of women with disabilities in Pakistan, given that the sample only included women from two provinces and those already known to OPDs. Many women with disabilities in Pakistan who are likely to experience stigma but do not access the support of OPDs are not accounted for in the results. This sampling technique was chosen for ethical reasons, due to the nature of questions included in the interview and because women with disabilities in Pakistan are a relatively hidden group. However, it is likely that this approach introduced bias to the results and, as such, the levels of stigma reported may be an under or over-estimation. Similarly, the sampling strategy could have contributed to the lack of variance in sociodemographic variables and non-significant differences between groups. The effects of stigma are likely to perpetuate difficulties in reaching women with disabilities and involving them in support groups and research.

Further, despite efforts to include women with different types of disabilities, OPDs noted difficulties in recruiting women with particular needs. For example, women with hearing impairments were not recruited if they did not know sign language or were not able to read or write. Also, women with moderate to severe IDs, and women with multiple communication impairments were not included due to the sensitive nature of the project involving women's direct experiences of discrimination and gender-based violence and the format of the data collection as an interview.

Furthermore, the data may not accurately reflect the experiences of women in Pakistan. Enumerators reported a sense that women were not able to share their stories openly (see Appendix P for enumerator feedback report), particularly in relation to violence and abuse. This could have contributed to the non-significant findings, and experiences of stigma and gender-based violence may be more frequent than reflected by the results. In future, more provisional work should be done with women with disabilities, for example, by meeting with them prior to an interview to allow a trusting relationship to build between data collectors and women with disabilities, so that women feel safe to share. In addition, many of the interviews were conducted in participants' homes to support the participation of women with disabilities in the project. However, this could have increased fears of being overheard. Careful consideration should be given to where interviews take place.

Due to the time-limited nature of the project and extensive flooding in Pakistan which prevented data collection and resulted in more outreach work, the sample size of the study was relatively small. As such, many of the groupings included in the analyses were made up of few participants which limited the exploration of the association between demographic variables and stigma and is likely to have contributed to the non-significant results. For example, in terms of disability type, very few participants had limitations in the areas of remembering, communicating, or hearing meaning that these groups could not be included separately in the analysis. Similarly, broader groupings had to be made, such as those for ethnicity, which reduced the specificity of the results. A larger sample size would have increased power and allowed for the testing of interaction effects and alternative statistical analyses, such as multilevel regressions, to better apply an intersectionality framework to a quantitative methodology (Bauer et al., 2021).

The Washington Group Questions were chosen to categorise disabilities as they are designed for use cross-nationally. There is no universally accepted definition of disability and to improve disability data collection the use of a standardised approach is recommended (WHO, 2011). Further, they are based on 2030 Sustainable Development Goals (UN, 2015) and UN CRPD policies, aiming to measure how limitations in different areas of functioning impacts on participation due to stigma at the community and institutional levels. However, capturing disabilities in this way brought challenges in disaggregating and interpreting the data. Therefore, conclusions about the influence of disability type are limited to whether individuals have limitations in one of six areas of functioning, or multiple areas of functioning. In future, it may be more helpful to categorise disabilities more specifically to understand how disability type effects stigma experiences.

In addition, the study design did not include a comparison group. Although throughout the discussion the results have been compared to other studies relating to the experiences of women in Pakistan, these studies did not employ the same methodology. The absence of a comparison group results in a lack of control over compounding factors like demand characteristics. Overall, this creates challenges in drawing meaningful conclusions about the stigma experiences of women with disabilities compared to other groups.

Finally, the study used a quantitative approach to explore stigma and provide data on the frequency of stigma experiences and gender-based violence. However, the conclusions that can be drawn about the causes of these experiences are limited. In future, the data should be complimented by qualitative enquiry to further explore the nuances in the data and understand the impact of intersectionality. For example, this could seek to explain the differences in stigma experiences dependent on disability type, and understand what women perceive to be the key barriers to their equal participation and causes of stigma. Additionally, the short quotes included in the results of this study are powerful in bringing the data to life and a qualitative approach is likely to support the key aims of this project, to give a voice to women with disabilities.

Clinical, research and policy implications

This study provides important information about the experiences of women with disabilities in Pakistan, interpreted through an understanding of how women with disabilities are viewed by their families and communities, and the institutional barriers that prevent them from exercising their rights. The study successfully used a new measure which was culturally adapted and co-designed with women with disabilities to measure multiple aspects of stigma, providing a holistic depiction of the impact of stigma on women with different types of disabilities.

Although, due to the relatively small sample size and sampling strategy, the results should be interpreted with caution, the study provides evidence that women with disabilities experience high levels of stigma, frequently being denied services and participation in their communities, and experiencing significant abuse and gender-based violence. Moreover, the data suggests that barriers exist which prevent women from realising their rights. Data regarding stigma resistance is hopeful, but more could be done to support women to recognise prejudices and stand up to stigma.

This data provides insights that can be used to inform interventions to reduce stigma and support the rights of women with disabilities in Pakistan, as highlighted by the CRPD (CRPD, 2016), 2018 Global Disability Summit (International Disability

Alliance, 2018) the 2030 Sustainable Development Agenda (UN, 2015). The recent changes in legislation in Pakistan, for example to protect the rights of people with disabilities (Kizilbash, 2020; Sightsavers, 2020), support inclusive education (UNICEF, 2021) and prevent gender-based violence (Pakistan Today, 2023) are encouraging. However, as stigma is construct shaped by culture, stigmatising beliefs about women with disabilities are likely to be deep rooted. Research has evidenced how difficult it can be to influence negative attitudes towards people disabilities and, even more so, behaviours (Septian & Hadi, 2021). The COM-B model (Hardeman et al., 2005) may be a useful framework to apply in designing stigma-reduction interventions. The model proposes that for behaviour to change, a person must have sufficient capability, opportunity, and motivation. For the greatest impact, interventions should follow a multilevel model of combating stigma at the intrapersonal, familial, interpersonal, and structural levels (Werner & Scior, 2016). Interventions that are socially, culturally and faith sensitive, ideally co-developed by women with disabilities, can be targeted at key decision makers across these levels, such heads of households, who often deny access to opportunities to women with disabilities and religious community figures who can guide people on the rights and treatment of persons with disabilities using religious text and scripture.

A systematic review by Sightsavers (2021) summarises existing interventions targeting disability stigma in sub-Saharan Africa and south Asia. Although only one study related to physical disabilities and most related to long-term health conditions, the authors concluded that most interventions were focussed at the familial and interpersonal levels, evaluating interventions based on education, training, and contact with people with disabilities. Additionally, the interventions were promising but methodologically flawed. A study in Kenya used workshops, aiming to change perceptions of disability and reduce stigmatising attitudes. Authors found that supernatural beliefs about disabilities reduced and provided some evidence that a change in attitudes reduced enacted stigma (Bauer et al., 2019). OPDs in Pakistan run several programmes to reduce stigma at the individual and structural levels, for example by training women with disabilities as peer counsellors, running leadership trainings, designing workshops to help people to understand how the definition of disability is socially constructed, and accessibility audits to remove the barriers to people with disabilities accessing community spaces (STEP, 2011; STEP 2012). The finding that women with disabilities in Pakistan were least aware of their right to political participation suggests that more work needs to be done in involving women with disabilities in key decision-making practices and policies. An example of an initiative in Pakistan is the Power to Persuade programme by the International Foundation for Electoral Systems (IFES) and STEP, which aimed to empower women with disabilities with the skills to influence policy (Election Access, 2021). STEP also supports people with disabilities to enrol in the electoral process and has created an Empowerment Café to share information with people with disabilities (STEP, 2012). Existing initiatives that are successful could be scaled-up and scaffolded by interventions at other levels.

Additionally, the results of this study have clinical implications. The findings suggest that stigma impacts on multiple aspects of women's lives. Although this study was not conducted in the UK and, therefore, the experience of stigma may present differently, the results emphasise the need to consider the impact of stigma when supporting people with disabilities; particularly how systemic, multi-level stigma may be contributing to the experiences of clients seen in mental health services in the UK. Clinicians should consider power and intersecting identities in order to deconstruct and understand an individual's experience of distress and how this may relate to stigma. Further, it is necessary that interventions that seek to relieve this distress and reduce stigma are designed to meet the individual's specific needs, accounting for intersecting identities and the specific context of culture.

The WDSI provides a standardised measure of stigma and gender-based violence experienced by women with disabilities in Pakistan. As many of the non-significant findings in this study could be explained due to the small sample size and sampling strategy, this study should be repeated with more women with disabilities from different backgrounds, to allow for further exploration of the impact of different sociodemographic variables on stigma. Subsequently, future research should concentrate on the implementation of targeted interventions to reduce stigma. Women with disabilities perceived that their experiences were influenced by both gender and disability. As such, interventions must be specific to how these two identities interact in Pakistan. The WDSI can be used to compare experiences before and after such aforementioned interventions, in addition to assessing trends in the experiences of women with disabilities in Pakistan across time to guide future policy decisions and research directions. In future, the WDSI could be validated in a UK setting and, eventually, be used by clinicians working in mental health services to quantitatively explore the experiences of women with disabilities. Given the existing clinical formulation and presenting difficulty of the client, different sections of the WDSI can be applied. For example, the stigma resistance subscale to understand the client's cognitive, emotional, and behavioural responses to stigma and whether these change through intervention.

As described above, the data provided in this study should be supplemented by qualitative data focussed on the causes of exclusion, abuse, gender-based violence, and awareness of rights. This would allow for the application of an intersectionality framework to understand how different identities interact and influence stigma.

The research has important ethical implications for future research exploring stigma and abuse with women with disabilities. Given the resources available on this project, two training sessions were provided to enumerators in Pakistan, in addition to the two written guides that provided ethical, practical, and emotional support for enumerators on collecting data sensitively. In the feedback session provided after data collection, enumerators noted that they would have liked some further support on coping with the emotional impact that some of the discussions elicited, both in the women with disabilities and themselves. In future, additional support and training should be provided before, during and following the interviews, so that participants, enumerators, and other stakeholders responsible for managing and collecting data are aware of the potentially distressing nature of discussions, how this can be responded to, and debriefs should be provided in the short and long-term following the interviews.

Moreover, as stigma is a complex construct, careful attention was paid to the language used throughout the measure, definitions were added throughout and UCL researchers worked with country teams to ensure cultural sensitivity. Despite this, enumerators felt that some participants may have struggled in understanding the questions, particularly those with cognitive and communication difficulties. As described in the methodology, this thesis focussed on the field testing of version five of the WDSI. Subsequently, the measure has been updated to reduce the complexity of the response scale, removing the ‘always’ option as, in discussion with the contributors to the project, it was felt that the difference between ‘always’ and ‘often’ was not clear or helpful. Further, it has been shortened to reduce the demands on both participants and enumerators in discussing sensitive topics. Further adaptations and versions of the measure should be developed and to ensure that it is accessible to women with different types of disabilities.

The study has several strengths, focussing on an area of research where existing literature is lacking and giving a voice to women with disabilities. It provides an example of collaborative and participatory research, whereby researchers worked with different organisations and women with disabilities were central to the design and implementation of the project. This was invaluable in providing context to the research and ensuring that the research was ethical.

References

ADD International. (n.d.). *Disability and Gender-Based Violence. ADD International's Approach. A Learning Paper.* https://add.org.uk/sites/default/files/Gender_Based_Violence_Learning_Paper.pdf

Abuya, T., Warren, C. E., Miller, N., Njuki, R., Ndwiga, C., & Maranga, A. (2015). Exploring the Prevalence of Disrespect and Abuse during Childbirth in Kenya. *PLOS ONE, 10*(4).

Ahmad, M. (2013). Health care access and barriers for the physically disabled in rural Punjab, Pakistan. *International Journal of Sociology and Social Policy, 33*(3), 246-260. https://doi.org/10.1108/01443331311308276

Ahmad, F., Riaz, S., Barata, P., & Stewart, D. E. (2004). Patriarchal beliefs and perceptions of abuse among South Asian immigrant women. *Violence Against Women, 10*, 262-282.

Ahmad, M., Batool, M., & Dziegielewski, S. F. (2016). State of Inheritance Rights: Women in a Rural District in Pakistan. *Journal of Social Service Research, 42*(5), 622-629.

Ahmad, S. S., & Koncsol, S. W. (2022). Cultural Factors Influencing Mental Health Stigma: Perceptions of Mental Illness (POMI) in Pakistani Emerging Adults. *Religions, 13*(5), 401. https://doi.org/10.3390/rel13050401

Ahmed, S., Bryant, L. D., Ahmed, M., Jafri, H., & Raashid, Y. (2013). Experiences of parents with a child with Down syndrome in Pakistan and their views on termination of pregnancy. *Journal of community genetics, 4*(1), 107–114. https://doi.org/10.1007/s12687-012-0124-y

Ali, A., King, M., Strydom, A., & Hassiotis, A. (2016). Self-reported stigma and its association with socio-demographic factors and physical disability in people with intellectual disabilities: results from a cross-sectional study in England. *Social Psychiatry & Psychiatric Epidemiology*, *51*(3), 465-474.

Ali, A., Kock, E., Molteno, C., Mfiki, N., King, M., & Strydom, A. (2015). Ethnicity and self-reported experiences of stigma in adults with intellectual disability in Cape Town, South Africa. *Journal of intellectual disability research, 59*(6), 530-540.

Ali, S. M. (1989). Does son preference matter? *Journal of Biosocial Sciences, 21*, 399–408.

Ali, T. S., Krantz, G., Gul, R., Asad, N., Johansson, E., & Mogren, I. (2011). Gender roles and their influence on life prospects for women in urban Karachi, Pakistan: a qualitative study. *Global health action, 4,* 7448. https://doi.org/10.3402/gha.v4i0.7448

Ali, P. A., Naylor, P. B., Croot, E., & O'Cathain, A. (2015). Intimate Partner Violence in Pakistan: A Systematic Review. *Trauma, Violence, & Abuse, 16*(3), 299–315. https://doi.org/10.1177/1524838014526065

Akram, N. (2018). Women's Empowerment in Pakistan: Its Dimensions and Determinants. *Social Indicators Research, 140,* 755–775.

Allendorf, K., & Ghimire, D. J. (2013). Determinants of marital quality in an arranged marriage society. *Social Science Research,* 42, 59–70.

Ansari, Z. (2002). Parental acceptance-rejection of disabled children in non-urban Pakistan. *North American Journal of Psychology, 4*(1), 121–128.

Arif, M. O., Fatmi, Z., Pardeep, B., Ali, T., Iqbal, H., Bangash, H. K., Pervaiz, R., Altaf, H., & Baba. J. A. (2008). Attitudes and perceptions about prenatal diagnosis and induced abortion among adults of Pakistani population. *Prenatal Diagnosis, 28*(11), 49–1155.

Batool, S. A., & Jadoon, A. K. (2018). Women's Empowerment and Associated Age-Related Factors. *Pakistan Journal of Social and Clinical Psychology, 16*(2), 52-56.

Bauer, C. R., Mbonani, L., & Charles, J. (2019). *Changing Cultural Perception on Disability through Empowerment of Families and Local Leaders*.

https://kupenda.org/wp-content/uploads/2019/09/Paper-How-Kupenda-Changes-Negative-Disability-Beliefs-and-Practices-.pdf

Bauer, G. R., Churchill, S. M., Mahendran, M., Walwyn, C., Lizotte, D., & Villa-Rueda, A. A. (2021). Intersectionality in quantitative research: A systematic review of its emergence and applications of theory and methods. *SSM – population health, 14*, 100798.

Bista, S. B., & Sharma, S. (2019). Violence against women and girls with disabilities during and after the 2015 Nepal earthquake: thematic analysis of qualitative data. *The Lancet, 7*. https://doi.org/10.1016/S2214-109X(19)30130-5

Bohren, M. A., Hunter, E. C., Munthe-Kaas, H. M., Souza, J., Vogel, J., & Gulmezoglu, A. (2014). Facilitators and barriers to facility-based delivery in low- and middle-income countries: a qualitative evidence synthesis. *Reproductive Health, 11*(71). https://doi.org/10.1186/1742-4755-11-71

Bond. (2017). *Stigma, disability and development*. https://www.bond.org.uk/wp-content/uploads/2022/03/stigma_disability_and_development.pdf

Bowleg, L. (2012). The problem with the phrase women and minorities: intersectionality – an important theoretical framework for public health. *American Journal of Public Health, 102*(7), 1267-1273.

British Council. (2014). *Moving from the margins: Mainstreaming persons with disabilities in Pakistan.* https://www.britishcouncil.org/sites/default/files/moving_from_the_margins_final.pdf

Bryant, L. D., Ahemed, S., Jafri, H., & Raashid, Y. (2011). 'All is done by Allah': understandings of Down syndrome and prenatal testing in Pakistan. *Social Science & Medicine, 72* (8), 1393-1399.

Centre for Peace and Development Initiatives. (2011). *Elimination of Violence against Women and increase Access to Gender Justice*. www.cpdi-pakistan.org/wp-content/uploads/2013/04/policy-brief-to-eliminate-violence.pdf

Chandra, P. S., Deepthivarma, S., Carey, M. T., Carey, K. B., & Shalinianant, M. P. (2003). A cry from the darkness: Women with severe mental illness in India reveal their experiences with sexual coercion. *Psychiatry: Interpersonal and Biological Processes, 66,* 323-334.

Ciftci, A. (2012). Mental Health Stigma in the Muslim Community. *Stigma, 7*(1). https://doi.org/10.3998/jmmh.10381607.0007.102

Ciocan, L. (2021). *Baseline study on social services for People with Disabilities and children from vulnerable groups*. Public Health Department of the Sotos Foundation.

Convention on the Rights of Persons with Disabilities. (2006). *United Nations Convention on the Rights of Persons with Disabilities*. https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf

Convention on the Rights of Persons with Disabilities. (2016). *Report of the Special Rapporteur on the rights of persons with disabilities.* https://www.refworld.org/docid/56c581e04.html

Cornelsen, K. (2012). Doubly Protected and Doubly Discriminated: The Paradox of Women with Disabilities After Conflict. *William & Mary Journal of Women and the Law, 19(*1), 105-136.

Corrigan, P., & Watson, A. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry, 1,* 6–20.

Corrigan, P., Kerr, A., & Knudsen, L. (2005). The stigma of mental illness: Explanatory models and methods for change. *Applied and preventative psychology, 11*,179-190.

Curry, M. A., Renker, P., Hughes, R. B., Robinson-Whelen, S., Oschwald, M., Swank, P., & Powers, L. E. (2009). Development of measures of abuse among women with disabilities and the characteristics of their perpetrators. *Violence Against Women, 15,* 1001-1025.

DataReportal. (2022, February 16). *Digital 2022: Pakistan*. DataReportal. https://datareportal.com/reports/digital-2022-pakistan

Dos Santos, M. M. L., Kruger, P., Mellors, S. E., Wolvaardt, G., & Van Der Ryst, E. (2014). An exploratory survey measuring stigma and discrimination experienced by people living with HIV/AIDS in South Africa: the People Living with HIV Stigma Index. *BMC Public Health, 14*, 80. https://doi.org/10.1186/1471-2458-14-80

Dowling, S. (2016). *Disability and unsafe migration: Data and policy, understanding the evidence (Global Migration Data Analysis Centre: Data Briefing Series, No. 7)*. IOM. https://publications.iom.int/system/files/pdf/gmdac_data_briefing_series_issue_7.pdf

Division for Social Policy and Development. (2016). *Toolkit on disability for Africa – Culture, beliefs and disability*. UN. https://www.un.org/esa/socdev/documents/disability/Toolkit/Intro-UN-CRPD.pdf

Election Access. (2021). *The Special Talent Exchange Program (STEP) Conducts National Policy Dialogues to Advocate for the Rights of Women with Disabilities in Pakistan*. Election Access. http://www.electionaccess.org/en/media/news/94/

Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis for the social, behavioral, and biomedical sciences. *Behavior Research Methods, 39*, 175-191

Firmin, R. L., Lysaker, P. H., McGrew, J. H., Minor, K. S., Luther, L., & Salyers, M. P. (2017). The Stigma Resistance Scale: A multi-sample validation of a new instrument to assess mental illness stigma resistance. *Psychiatry research, 258*, 37–43. https://doi.org/10.1016/j.psychres.2017.09.063

Freedman, L. P., & Kruk, M. E. (2014). Disrespect and abuse of women in childbirth: challenging the global quality and accountability agendas. *Lancet, 384*(9948), 42-44. https://doi.org/10.1016/S0140-6736(14)60859-X

Friedland, B. A., Gottert, A., Hows, J., Baral, S. D., Sprague, L., Nyblade, L., McClair, T. L., Anam, F., Geibel, S., Kentusi, U. T., Diof, D., Amenyeiwe, U., Mallouris, C., Pulerwitz, J., & PLHIV Stigma Index 2.0 Study Group. (2020). The people living with HIV stigma index 2.0: generating critical evidence for change worldwide. *Aids, 34*(1), S5-S18.

Furrukh, J., & Anjum, G. (2020). Coping with autism spectrum disorder (ASD) in Pakistan: A phenomenology of mothers who have children with ASD. *Cogent Psychology, 7*(1). https://doi.org/10.1080/23311908.2020.1728108

Gauthier de Beco. (2020). Intersectionality and disability in international human rights law. *The International Journal of Human Rights, 24*(5), 593-614. https://doi.org/10.1080/13642987.2019.1661241

Gilani, S. I., Ali, S., Mir, S. T., Mazhar, T., Iqbal, A., Ahmed, F., & Zareen, A. (2009). Use of alternative medicine for chronic hepatitis C: A hospital based study from Rawalpindi. *Medical Journal, 34,* 102-104.

Goffman, E. (1963). *Stigma, notes on the management of spoiled identity*. Prentice-Hall.

Groce, N., & McGeown, J. (2013). *Witchcraft, wealth and disability: Reinterpretation of a folk belief in contemporary urban Africa (Working paper series: No. 30)*. Leonard Cheshire Disability and Inclusive Development Centre, UCL.

Hamdani, S. U., Atif, N., Tariq, M., Minhas, F. A., Iqbal, Z., & Rahman, A. (2014). Family networks to improve outcomes in children with intellectual and developmental disorders: A qualitative study. *International Journal of Mental Health Systems, 8*, 1–8.

Hameed, W., Uddin, M., & Avan, B. I. (2021). Are underprivileged and less empowered women deprived of respectful maternity care: Inequities in childbirth experiences in public health facilities in Pakistan. *PLOS ONE 16*(4).

Hammad, T., & Singal, N. (2015). Education of women with disabilities in Pakistan: enhanced agency, unfulfilled aspirations. *International Journal of Inclusive Education, 19*(12), 1244-1264.

Handicap International. (2001). *Disability in humanitarian context: Views from affected people and field organisations*. https://reliefweb.int/report/world/disability-humanitarian-context-views-affected-people-and-field-organisations#:~:text=85%25%20of%20humanitarian%20actors%20responding,into%20account%20in%20humanitarian%20response.

Hardeman, W., Sutton, S., Griffin, S., Johnston, M., White, A., Wareham, N. J., & Kinmonth, A. L. (2005). A causal modelling approach to the development of theory-based behaviour change programmes for trial evaluation. *Health education research, 20*(6), 676–687. https://doi.org/10.1093/her/cyh022

Hassan, S., Khurshid, E., & Batool, S. (2015). Psychological distress experienced by women with primary infertility in Pakistan: Role of psychosocial and cultural factors. *NUST Journal of Social Sciences and Humanities, 28*(1), 56–72.

Hassan, S., Siddiqui, S., Friedman, B. D. (2020). Health Status and Quality of Life of Women Seeking Infertility Treatments in Baluchistan, Pakistan. *The British Journal of Social Work, 50*(5), 1401–1418. https://doi.org/10.1093/bjsw/bcz130

Hendriks, A. (2007). UN Convention on the Rights of Persons with Disabilities. European *Journal of Health Law, 14*, 273–280.

Human Rights Watch. (2018, November 12). *"Shall I Feed My Daughter, or Educate Her?" Barriers to Girls' Education in Pakistan*. Human Rights Watch. https://www.hrw.org/report/2018/11/13/shall-i-feed-my-daughter-or-educate-her/barriers-girls-education-pakistan

Husain, M., Zehra, S. Q., Umer, M., Kiran, T., Husain, M., Soomro, M., Dunne, R., Sultan, S., Chaudhry, I. S., Naeem, F., Chaudhry, N., & Husain, N. (2020). Stigma toward mental and physical illness: attitudes of healthcare professionals, healthcare students and the general public in Pakistan. *British Journal of Psychiatry Open*, *6*(5), 1-6.

Hussain, S., Alam, A., & Ullah, S. (2022). Challenges to Persons with Disabilities in Pakistan: A Review of Literature. *Journal of Social Sciences Review, 2*(3), 35-42.

International Disability Alliance UK Global Disability Summit. (2018). *Global Disability Summit: July 2018*. https://www.internationaldisabilityalliance.org/content/global-disability-summit-july-2018

Jamil, S. (2021). From digital divide to digital inclusion: Challenges for wide-ranging digitalization in Pakistan. *Telecommunications Policy, 45*(8). https://doi.org/10.1016/j.telpol.2021.102206.

Jayachandran, S. (2015). The roots of gender inequality in developing countries. *Annual Review of Economics, 7* (1), 63–88.

Jewkes, R., & Penn-Kekana, L. (2015). Mistreatment of Women in Childbirth: Time for Action on This Important Dimension of Violence against Women. *PLOS MED, 12*(6). https://doi.org/10.1371/journal.pmed.1001849

Jiwani, N. S., Gul, R. B., Ali, A., Salih, M., & Hanzala, M. (2013). Experiences and Perceptions of Patients Living With Hepatitis C in Karachi, Pakistan. *Journal of Transcultural Nursing, 24*(3), 297-304.

Kapadia, M. Z., Saleem, S., Karim, M. S. (2010). The hidden figure: Sexual intimate partner violence among Pakistani women. *European Journal of Public Health, 20,* 164–168.

Khan, A., & Hussain, R. (2008). Violence against women in Pakistan: Perceptions and experiences of domestic violence. *Asian Studies Review, 32*, 239-253.

Khan, M. J., Arooj, K., Arif, H., Nazir, N., & Nosheen, M. (2018). Attitude of Male and Female University Students Towards Gender Discrimination. *Pakistan Journal of Psychological Research, 33*(2), 429-436.

Kizilbash, M. (2020, December 8). *Pakistan and disability law – The dawn of a more inclusive society?* OxHRH Blog. https://ohrh.law.ox.ac.uk/pakistan-and-disability-law-the-dawn-of-a-more-inclusive-society/

Link, B. G., & Phelan, J. C. (2001). Conceptualizing Stigma. *Annual Review of Sociology, 27*(1), 363-385. https://doi.org/10.1146/annurev.soc.27.1.363

Link B. G., Phelan J. (2014). Stigma power. *Social Science & Medicine, 103*, 24–32.

Madhani, N. (2007). Career development in management at a Pakistani university: Is gender a factor? In R. Qureshi & J. F. A. Rarieya (Eds.), *Gender and education in Pakistan* (pp. 216–236). Oxford University Press.

Madhani, F. I., Karmaliani, R., Patel, C., Bann, C. M., McClure, E. M., Pasha, O., & Goldenberg, R. L. (2017). Women's Perceptions and Experiences of Domestic Violence: An Observational Study From Hyderabad, Pakistan. *Journal of Interpersonal Violence, 32*(1), 76-100.

McFarlane, J., Hughes, R. B., Nosek, M. A., Groff, J. Y., Swedlend, N., & Dolan Mullen, P. (2001). Abuse assessment screen-disability (AAS-D): measuring frequency, type, and perpetrator of abuse toward women with physical disabilities. *Journal of women's health & gender-based medicine, 10*(9), 861–866.

Milačić-Vidojević, I., Tošković, O., Dragojević, N., & Čolić, M. (2017). Experienced and Anticipated Discrimination in Persons with Physical Disabilities in Serbia. *European Journal of Interdisciplinary Studies, 7,* 65-74.

Minhas, A., Vajaratkar, V., Divan, G., Hamdani, S. U., Leadbitter, K., Taylor, C., & Cardoza, P. (2015). Parents' perspectives on care of children with autistic spectrum disorder in South Asia–Views from Pakistan and India. *International Review of Psychiatry, 27*(3), 247–256.

Mirza, I., Tareen, A., Davidson, L. L., & Rahman, A. (2009). Community management of intellectual disabilities in Pakistan: a mixed methods study. *Journal of Intellectual Disability Research, 53*(6), 559-570.

Misra, R., & Panigrahi, B. (1996). Effects of age on attitudes towards working women. *International Journal of Manpower, 17*(2), 3-17.

Naqvi, Z. F., & Shahnaz, L. (2002). How do women decide to work in Pakistan?. *The Pakistan Development Review, 41*(4), 495-513.

National Institute of Population Studies. (2019). *Pakistan demographic and health survey 2017-18*. https://dhsprogram.com/pubs/pdf/FR354/FR354.pdf

Neil, T.O., & Domingo, P. (2015). *The power to decide: women, decision-making and gender equality*. ODI. https://cdn.odi.org/media/documents/9848.pdf

National Institute of Population Studies and the International Classification of Functioning, Disability and Health. (2019). *Pakistan Demographic and Health Survey 2017-18*. https://evaw-global-database.unwomen.org/en/countries/asia/pakistan#1

New, P.W., Rathore, F. A., & Iftikhar, A. (2011). A report on disability and rehabilitation medicine in Pakistan: Past, present, and future directions. *Archives of Physical Medicine and Rehabilitation, 92*(1), 161–166.

O'Connor, L. K., Yanos, P. T., & Firmin, R. L. (2018). Correlates and Moderators of Stigma Resistance Among People with Severe Mental Illness. *Psychiatry Research, 270,* 198-204.

Ortiz-Barreda, G., Vives-Cases, C., Briones-Vozmediano, E., Goicolea, I., La Parra, D., Gil-González, D., & Felt, E. (2014). *Preventing and addressing intimate partner violence against migrant and ethnic minority women: The role of the health sector*. http://apps.who.int/iris/bitstream/10665/151969/1/WHO%20Intimate%20Partner%20Violence.pdf

Pakistan Today. (2023, March 9). *Ahsan launches citizen's guide to prevent gender based violence*. Pakistan Today. https://www.pakistantoday.com.pk/2023/03/09/ahsan-launches-citizens-guide-to-prevent-gender-based-violence/

Papreen, N., Sharma, A., Sabin, K., Begum, L., Ahsan, S. K., & Baqui, A. H. (2000). Living with infertility: Experiences among urban slum populations in Bangladesh. *Reproductive Health Matters, 8*(15), 33–44.

Qayyum, A., Lasi, S. Z., & Rafique, G. (2013). Perceptions of Primary Caregivers of Children with Disabilities in two Communities from Sindh and Balochistan, Pakistan. *Disability CBR & Inclusive Development, 24*(1), 130-142.

Razzaq, S., & Rathore, F. A. (2020). Disability in Pakistan: Past experiences, current situation and future directions. *The Journal of the Pakistan Medical Association, 70*(12), 2084–2085.

Ravindran, N., & Myers, B. J. (2011). Cultural influences on perceptions of health, illness, and disability: A review and focus on autism. *Journal of Child and Family Studies, 21*(2), 311–319.

Rickard, W., & Donkin, A. (2018). *A fair, supportive society.* https://www.instituteofhealthequity.org/resources-reports/a-fair-supportive-society-summary-report/a-fair-supportive-society-summary-report.pdf

Rohwerder, B. (2001). *Women and girls with disabilities in conflict and crises. Briefing by the Institute of Development Studies, commissioned by UK Department for International Development*. Institute of Development Studies. https://assets.publishing.service.gov.uk/media/5b9a458540f0b67866ffbd56/032-Women_and_girls_with_disabilities_in_crisis_and_conflict.pdf

Rohwerder, B. (2018). *Disability stigma in developing countries*. Institute of Development Studies. https://assets.publishing.service.gov.uk/media/5b18fe3240f0b634aec30791/Disability_stigma_in_developing_countries.pdf

Saeed, S. (2015). Toward an Explanation of Son Preference in Pakistan. *Social Development Issues, 37*(2), 17-36.

Samo, S. H. (2023, April 6). *Strategies to eliminate violence against women*. The Authentic Post. https://theauthenticpost.com/strategies-to-eliminate-violence-against-women/

Sarkar, S. (2014). Ethical issues relating to faith healing practices in South Asia: A medical perspective. *Journal of Clinical Research and Bioethics, 5*(4).

Sarwar, A., & Imran, M. K. (2019). Exploring Women's Multi-Level Career Prospects in Pakistan: Barriers, Interventions, and Outcomes. *Frontiers in Psychology, 10*. https://doi.org/10.3389/fpsyg.2019.01376

Scior, K., Hamid, A., Hastings, R., Werner, S., Belton, C., Laniyan, A., Patel, M., Groce, N., & Kett, M. (2016). Consigned to the margins: A call for global action to challenge intellectual disability stigma. *The Lancet Global Health, 4*(5), e294-e295.

Scior, K., Dixon, A., Delmain, H., Saunders, R., & Hamid, A. (2023). *The Women with Disabilities Stigma Inventory*. [Manuscript in preparation]. UCL Unit for Stigma Research, University College London.

Septian, E. R., & Hadi, E. N. (2021). Reducing Stigma of People with Disabilities: A Systematic Review. *Journal of Medical and Health Studies, 2(*2), 31–37. https://doi.org/10.32996/jmhs.2021.2.2.3

Shafiq, M., Tanwir, M., Tariq, A., Kasi, P. M., Zafar, M., Saleem, A., Rehman, R., Zaidi, S. Z., Taj, F., Khuwaja, A. A., Shaikh, K. S., & Khuwaja, A. K. (2007). Epilepsy: public knowledge and attitude in a slum area of Karachi, Pakistan. *Seizure, 16(*4), 330–337. https://doi.org/10.1016/j.seizure.2007.02.002

Shaikh, M. A. (2000). Domestic violence against women perspective from Pakistan. *Journal of Pakistan Medical Association, 50*, 312–314.

Sightsavers. (2020). *Pakistan's first-ever Disability Rights Act becomes law*. Sightsavers. https://tinyurl.com/ydw7394z

Sightsavers. (2021). *Disability-related stigma and discrimination in sub-Saharan Africa and south Asia: a systematic literature review*. Sightsavers. https://research.sightsavers.org/wp-content/uploads/2021/08/Sightsavers-systematic-review-into-stigma-and-disability-FINAL-UPDATED.pdf

Singal, N., Bhatti, F., & Malik, R. (2011). Counting the invisible: understanding the lives of young people with disabilities in Pakistan. *Disability and rehabilitation, 33* (11), 908-921.

Special Talent Exchange Programme. (2011). *STEP Newsletter 2011*. STEP. https://step.org.pk/wp-content/uploads/2019/08/STEP-Newsletter-2011.pdf

Special Talent Exchange Programme. (2012). *STEP Newsletter 2012*. STEP. https://step.org.pk/wp-content/uploads/2019/08/STEP-Newsletter-2012.pdf

Special Talent Exchange Programme & United Nations Population Fund. (2020). *Gender Based Violence and Women with Disabilities: Making the Invisible Visible*. UNFPA.

Turan, J. M., Elafros, M. A., Logie, C. H., Banik, S., Turan, B., Crockett, K. B., Pescosolido, B., & Murray, S. M. (2019). Challenges and opportunities in examining and addressing intersectional stigma and health. *BMC medicine, 17*(1), 7. https://doi.org/10.1186/s12916-018-1246-9

UN. (2015). *Goal 10: Reduce inequality within and among countries*. https://www.un.org/sustainabledevelopment/inequality/

UNFPA. (2018). *Women and Young Persons with Disabilities Guidelines for Providing Rights-Based and Gender-Responsive Services to Address Gender-Based Violence and Sexual and Reproductive Health and Rights*.

https://www.unfpa.org/sites/default/files/pub-pdf/UNFPA-WEI_Guidelines_Disability_GBV_SRHR_FINAL_19-11-18_0.pdf

UNFPA & Women Enabled International. (2021). *The impact of Covid-19 on women and girls with disabilities. A global assessment and case studies on sexual and reproductive health and rights, gender-based violence, and related rights*. www.unfpa.org/sites/default/files/pub-pdf/NEW_UNPRPD_UNFPA_WEI_-_The_Impact_of_COVID-19_on_Women_and_Girls_with_Disabilities.pdf

UNICEF. (2006). *The state of the world's children*. UNICEF Women and Children.

UNICEF. (2018). *Annual Report: Pakistan*. https://www.unicef.org/151akistan/media/2021/file/Annual%20Report%202018%20Revised%20Final.pdf

UNICEF. (2019). *Country Office Annual Report 2019: Pakistan*. https://www.unicef.org/media/90776/file/Pakistan-2019-COAR.pdf

UNICEF. (2021). *Disability-Inclusive Education Practices in Pakistan*. https://www.unicef.org/rosa/media/17011/file/Country%20Profile%20-%20Pakistan.pdf

UN Women. (2023). *"They call me by my name": A Synthesis Review of the United Nations Trust Fund to End Violence Against Women's Special Window on*

Ending Violence Against Women and Girls with Disabilities. https://untf.unwomen.org/sites/default/files/2023-03/A%20Synthesis%20of%20the%20UN%20Trust%20Fund_V6_compressed.pdf

Washington Group on Disability Statistics. (2020). *An Introduction to the Washington Group on Disability Statistics Question Sets*. https://www.washingtongroupdisability.com/fileadmin/uploads/wg/Documents/An_Introduction_to_the_WG_Questions_Sets__2_June_2020_.pdf

Werner, S., Scior, K. (2016). Interventions aimed at tackling intellectual disability stigma: What works and what still needs to be done. In Scior, K., Werner, S. (Eds.), *Stigma and intellectual disability: Stepping out from the margins*. Palgrave Macmillan.

Willis, R., Zaidi, A., Balouch, S., & Farina, N. (2020). Experiences of People With Dementia in Pakistan: Help-Seeking, Understanding, Stigma, and Religion. *The Gerontologist, 60*(1), 145–154. https://doi.org/10.1093/geront/gny143

World Bank. (2018). *Country at a Glance: Pakistan. Education Statistics*. https://datatopics.worldbank.org/education/country/pakistan

World Health Organization. (2000). *Violence against women*. http://www.who.int/mediacentre/factsheets/fs239/en/

World Health Organisation. (2011). *World Report on Disability*. WHO. https://www.who.int/teams/noncommunicable-diseases/sensory-functions-disability-and-rehabilitation/world-report-on-disability

Yip, C. C. H., & Chan, K. K. S. (2022). Stigma Resistance Among Sexual Minorities. *Sexuality Research and Social Policy, 19,* 647–655. https://doi.org/10.1007/s13178-021-00580-z

Zareen, N., Majid, N., Naqvi, S., Saboohi, S., Fatima, H. (2009). Effect of domestic violence on pregnancy outcome. *Journal of College of Physicians & Surgeons Pakistan, 19,* 291–296.

Part 3: Critical Appraisal

Introduction

This critical appraisal will focus primarily on the empirical paper, reflecting on the process of conducting research in partnership with international agencies, working on a project commissioned by the United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD). It will comprise of an exploration of my position as a Trainee Clinical Psychologist completing research within this context and working cross-culturally as a White-British researcher from a middle-class background. Moreover, it includes a discussion of the ethical issues raised during the project and learnings from this. Finally, I will return to the aims of the project (for it to be participatory, co-produced with people with disabilities and the organisations supporting them, and to implement a standardised measure that can assess the intersection between disability and gender-based stigma) and discuss the strengths and limitations of the methodology used, concluding with recommendations for future research and disseminations of the findings. The influence of power will be thought about throughout, particularly in relation to the inclusion of people with disabilities in research.

Context

The empirical research study that formed part two of this thesis was conducted as part of the Addressing Stigma and Discrimination experienced by Women with Disabilities (ASDWD) project funded by the UNPRPD. The UNPRPD is a collaborative body that brings together United Nations (UN) teams, governments, organisations for people with disabilities (OPDs) and members of the public to promote the Convention on the Rights of Persons with Disabilities (CRPD) and Sustainable Development Goals (SDGs) to safeguard the rights of people with disabilities (UN, 2015). Goal 10 of the 2030 SDGs calls to end violence against women and girls with disabilities and for women and girls to have equal rights to social, economic, and political inclusion.

The aims and timescale for the ASDWD project were set out by the UNPRPD. The main goal was to develop a new CRPD-compliant measure of the experiences of women with disabilities in relation to stigma and gender-based violence in Palestine, Pakistan, Samoa, and Moldova. This involved several steps to be completed over a year and a half, including conducting a review of existing disability stigma measures, and, in collaboration with teams in the four partner countries, drafting, customising, and piloting a new measure, and holding webinars to share the findings and reflect on the experience of being part of the project. My University College London (UCL) supervisors were contracted as research consultants for the project and oversaw each of these stages. My thesis concentrated on the piloting of the measure in Pakistan. In the participating countries, UN officers from the United Nations Development Programme (UNDP) and UN Women, local consultants employed by UNDP and UN Women, OPDs and people with disabilities formed country teams who worked in partnership with UCL researchers to implement the project.

Partnership working

The benefits of partnership working are well documented, for example in his book, Rebel Ideas, Matthew Syed (2020) discusses the power and importance of diverse teams in generating novel ideas. An important insight is that working with individuals from different backgrounds and disciplines exposes us to our blind spots and allows us to question our assumptions. With this, we are able to take insights from multiple people, develop and improve. This project would not have been successful without the diverse expertise and backgrounds of those involved.

Within the ASDWD project, working in partnership with several teams was highly valuable but also posed challenges, like those described by Lencioni (2002) and Atkinson et al. (2005) in their work examining the factors that facilitate multi-agency working. Firstly, a clear understanding of roles and responsibilities of individuals both within and across teams is important for successful partnerships. A significant amount of planning was completed before the start of the project and each team member's role and responsibilities were clearly stated in the project proposal agreed by the UNPRPD. This supported the accountability of each person who contributed to the project.

Communication and information sharing within and across teams are key factors in partnership working and, on reflection, were particular strengths of the project. As a Trainee Clinical Psychologist working alongside two Clinical Psychologists, the UCL research team regularly drew on systemic ideas to observe and reflect on the relational dynamics between partners, whilst in parallel considering our role. This way of thinking was helpful in promoting effective collaboration and directed our way of working with country teams. Primarily, our approach was shaped by social constructionist ideas and systems theory, recognising that realities are co-created and fluid, with each momentary interaction influencing the next. Also, that things are not linear but circular as all individuals in the system are interconnected and interact with each other (Shotter, 2012). It has been shown that recognising that results are a product of many elements and focussing on relational aspects of partnership working has a positive impact on collaboration and the quality of teamwork (Brazil, 2022).

In creating relationships, Bateson (1972) discusses 'warming the context', describing how people will feel more able to join the conversation if, first, the context is made more inviting. As such, we took a curious stance and spent time building relationships and understanding the backgrounds and expertise of everyone involved to recognise what they brought to the project. This was enabled by the co-creation of procedures and systems of communication. These included monthly Zoom meetings with the country teams, which were more frequent when necessary, email exchanges and a shared drive on Microsoft Teams. In addition, sharing of resources, information and past experiences completing research on sensitive topics with people with disabilities was explicitly encouraged. As such, key documents were regularly shared by the country teams which provided insights into our current understanding of the stigma experiences of women with disabilities in Pakistan, and the systems in which women live. Furthermore, recognising everyone's backgrounds allowed an understanding of differences in the languages and terminologies used. For example, UN colleagues were more familiar with terms like 'mission' rather than 'study' and the understanding of constructs like 'stigma' and 'disability' depended on culture. Open discussions ensured that the terminologies used were deconstructed, which allowed for the creation of a shared language that accounted for everyone's intended meaning. These aspects provided the crucial learnings needed to work collaboratively.

As researchers, often referred to as 'experts' and asked to direct meetings and the project more generally, we recognised that our contributions could sometimes hold more power in discussions with country teams. Some researchers pose that inequality of power in a system is unavoidable (Stacey, 2001), whilst others suggest that careful attention can be paid to relational processes to reduce power imbalances (Gergen et al., 2015). To achieve the latter, we had two main aims in interactions with country teams: to create relationships that valued all voices in the system and to facilitate an environment in meetings that allowed for ideas to be shared and built upon (Van Dijk

& Van Loon, 2015). Thus, avoiding 'doing to' and, as much as possible, ensuring that we were working alongside the rest of the system (Watson, 2012).

Concurrently, we were aware that we were part of the system, contributing to it. We thought carefully about our positioning and took a reflexive stance to appreciate both observing and being part of systemic processes. Through discussions and personal reflections, we tried to make visible how our own actions were influencing, and being influenced by the system (Chard, 2014). This included reflections on our own backgrounds, experiences, and training.

Shared aims and priorities have also been noted to effect how partnerships function. There were several shared aims for the project which will be discussed later in this critical appraisal whereas some challenges will be discussed here. Although the goals for the project were stated in the UNPRPD's project proposal, the suggested process for achieving these differed at times between partners. This was often a result of the organisational contexts and trainings from which individuals worked. In particular, differences were notable when discussing ethics for the project. UN country teams work as part of a global organisation and do not have the same ethical research bodies or processes as UCL researchers. Likewise, the UCL research team had a preference for the use of Qualtrics software to record responses to the WDSI as it has particular benefits in terms of confidentiality and data analysis. Although we mostly used a non-expert position, using reflexive questions to facilitate joint discussions, at times it felt important to share the expertise of the research team, using available resources that could support the aims of the project. Accordingly, we hoped to share our skills and experiences with the country teams using the spirit of integrated knowledge translation (IKT) and community-based participatory research (CBPR). These approaches both aim to co-create knowledge, achieve social change, and reduce the gap between knowledge from researchers and the context in which evidence can be applied (Jull et al., 2017). As such, an ethics resource was created, and training sessions were offered to country teams about ethics and the use of Qualtrics.

Also, in developing and customising the WDSI for use in Pakistan and the other partner countries, it became apparent that some of the aims stated by the UNPRPD would be difficult to implement. For example, it was hoped that the WDSI would gather specific detail regarding the gender-based violence experienced by women with disabilities. Similarly, the UNPRPD had hoped to collect data on the motivations for gender-based violence to inform national policies to address gender-based violence. However, the country team in Pakistan felt that asking women directly about some of these experiences, in particular asking women whether they had been sexually assaulted, would be culturally inappropriate. Additionally, country teams wanted to focus on collecting data at the individual level, directly from women with disabilities. However, research on motivations fits more closely with a qualitative approach which conflicted with the main aim of producing a measure able of quantifying stigma. UCL researchers had to balance a responsiveness to country teams, our own ethical accountability and the original project aims when developing the WDSI. Again, it was helpful to reflect on our own positioning and power within the system and carefully consider which direction to take and why. Here, we applied the notion of ‘centering the conversation’, to first understand the views of the country teams before carefully introducing concepts and ideas that were ‘different but not too different’ (Bateson, 1972) so to avoid a rupture in our relationship with country teams and the production of a measure that would cause distress to participants. Thus, in the example of asking about sexual assaults, by phrasing the question as “Has anyone made you engage in sexual activities when you did not want to?", the language was culturally appropriate, and we were still able to enquire about gender-based violence.

UCL researchers from academic backgrounds were more familiar with methodologies designed to gather rigorous evidence, whereas UN country teams complete project work, adhering to tight timeframes and producing set deliverables. Our expectations and identities are shaped by earlier experiences, and partnership working can disrupt our role identities (Daniels & Brooker, 2014). At times, the ambitious nature of the project placed significant pressure on the research team and their preferred thoughtful approach to conducting research. The UN style of working had several strengths which were crucial for the success of the project given the tight project timescales and limited funding, especially when responding to unforeseen events such as the severe flooding in Pakistan. The country teams worked impressively to problem-solve and utilise their existing resources.

Reflections on my positioning and working cross-culturally

I had hoped that my thesis would focus on people with disabilities after having worked in a service for children with intellectual disabilities. Here, I was witness to the stigma in systems and the lack of resources in place to support children and their families in England; they often felt forgotten, and I wanted to understand more about why.

When I joined the UNPRPD project, the aims and hopes had already been agreed. I felt excited and privileged to be part of a project working with UN agencies, but concurrently felt somewhat a lack of power within the system. The project seemed to be a good fit for what I hoped to research, but I remember feeling intimidated, overwhelmed by the scale of project, and unclear of my role. On reflection, I think this was due to my assumptions and associations with the UN; a global and powerful organisation with significant influence and media presence, the number of people involved, and because of my lack of agency in designing the study for my thesis. Additionally, within the UCL research team I was a Trainee Clinical Psychologist with much less experience than my supervisors. I was joining the project but did not have the same contractual obligations as the teams around me. Over time, the design and details of the project, as well as the focus of my thesis, became clearer and, as relationships with country teams and my supervisors built, I felt more comfortable in embracing the opportunity I had.

The primary UNPRPD goal was to design a standardised measure that could be used in different countries to generate and compare quantitative data about the stigma experienced by women with disabilities. As such, I felt positioned as a scientist practitioner, part of a project that was largely positivist in its approach, assuming that constructs are generalisable and there are observable, objective facts that can be quantified. In turn, my analyses used statistical inference to facilitate comparisons between groups. This methodology has several strengths, for example the data produced is clear and easy to communicate, emphasising the extent of stigma experienced by women with disabilities, which is important in provoking change. However, when designing the measure and analysing the results, I frequently noticed a draw to know more about the stories of the women who had shared their experiences of stigma, and understand the nuances in the data, especially in terms of culture and intersectionality. As a researcher and clinician, I identify with a social constructionist epistemology, whereby understanding is co-constructed through language (Barker, Pistrang & Elliott, 2016). This philosophy aligns with a qualitative methodology to understand feelings, values, and meanings. Moreover, the complex nature of stigma requires an exploration of the impact of culture, history, and social structures, without the constraint of pre-existing ideas or hypotheses. These approaches place individual experiences within wider familial, social, and political contexts, giving a rich understanding of constructs. Of particular significance, the depth of analysis enabled by qualitative approaches would allow the experiences of women with disabilities to come alive for the reader. I found the quotes recorded by enumerators, and some of the context provided by the country team in Pakistan particularly striking and impactful in understanding the terrible abuse women with disabilities experience, which is why I chose to include some of these quotes within my thesis, and one within the thesis title.

I was aware throughout the project that the research was being conducted in a country where I was not based and had limited prior knowledge of, yet significant emphasis was placed on the research team designing a measure for use in this context. Having not experienced the culture, I was conscious that I would not truly understand the experiences of women with disabilities in Pakistan, let alone how intersectionality or difference influences stigma. This experience made me reflect on my own identity and the power dynamics within the project. I identify as a middle-class, White-British, cis female, and in the context of this research, I was visibly accessing doctoral level education. There were some visible differences between myself and the members of the country teams, such as ethnicity, and invisible differences, including religion as I identify as atheist. There were also assumed and voiced differences between myself and the women with disabilities who completed the WDSI. Most notably, in terms of ability. In addition, many of the women had not received an education and lived in poverty.

I felt uncomfortable at times throughout the project and worried that I would be perceived as a 'White Saviour' enforcing my own values and views onto another, especially when I hold social privilege compared with women with disabilities who we heard are disempowered. Similarly, I worried about ‘taking from’ the communities in Pakistan who were responsible for collecting the data and the participants themselves for my own benefit, as their work was allowing me to complete my thesis. I reflected on my own biases, in that I had only experienced research in Western contexts, and the majority of publications I had read before this piece of research were published from Western countries with White, educated, industrialized, rich, and democratic (WEIRD) samples. As such, much of my understanding of stigma was informed from this perspective. I noticed that my own biases mirrored the cultural biases in psychological research more generally (Tindle, 2021). I was motivated to focus my research in the field of disabilities to use my power and voice as a researcher to give attention to voices that are often unheard. Additionally, I was brought up to value difference, and believe that cultural and religious factors are fundamental in understanding variabilities in behaviour. Being aware of my assumptions about how research is completed, I wanted to conduct the research in a considered manner, paying close attention to how my background has shaped my assumptions about research and the constructs of stigma and disabilities. Working cross-culturally, I spent time deconstructing my own ideas and learning how stigma and disabilities are understood in Pakistan. Individuals are embedded within cultures, and, as such, the experiences of women with disabilities in Pakistan are shaped by layers of societal values. In developing the WDSI, it was crucial to acknowledge that we cannot assume that meanings and, thus, the structure of instruments to measure constructs are equivalent across cultures (Byrne et al., 2009). Similarly, to reduce item biases the item content had to reflect understandings of stigma in Pakistan. Finally, to conduct the analysis in a reflexive manner, I tried to remain aware of my own biases and reactions to the data, aspiring to make sense of the experiences of women with disabilities within their cultural context.

Furthermore, conducting research in such a sensitive area, I was aware of the emotional impact on participants and enumerators of completing the WDSI, an experience that I did not have to bear. These reflections made me tentative in my approach, and I paid particular attention to the language being used both in conversations with country teams and within the WDSI items. I kept a reflective log to help me to think about how my own values and assumptions were influencing on my actions within the research. This helped me to maintain reflexivity and an awareness of my position within the project. I thought carefully about the impact of our decisions on women with disabilities who would complete the WDSI. On reflection, I think working outside my cultural knowledge had strengths as it allowed me to remain genuinely curious about the realities of women with disabilities without assuming sameness. It allowed me to lean into what was shared by the country teams and work collaboratively to design the project and the WDSI so it was culturally sensitive and suitable based on feedback from women with disabilities. Seeing the photos of data collection and listening to the stories shared by the country teams brought the study to life.

Ethical considerations

The nature of this project made me consider ethics from a different perspective. Through conducting research cross-culturally, I have learnt how ethical considerations must be viewed through the lens of the sociocultural context of the study setting. Issues like consent, prevention from harm, and confidentiality can only be understood within the specific values and belief systems of the participants, which are influenced by religious, political, and historical factors (Yick, 2007). What is considered ethical research will be perceived, understood, and applied differently in different countries (Rashad et al., 2004). Further, when participants are a marginalised group, such as women with disabilities, the impact of power dynamics should be made explicit. Ethical considerations become even more complex when conducting research on sensitive topics like discrimination and gender-based violence. A crucial aspect of our role was holding this in mind when considering how ethics can be applied in Pakistan, and raising questions about how to ensure confidentiality, informed consent, and the safety, including emotional safety, of participants. Facilitating a collaborative space with country teams to think about ethics together and how the principles could be embedded into the project was a strength of the work that we completed.

Many ethical principles depend on Western definitions and value orientations. For example, self-determination and making independent choices are central to autonomy and informed consent from an individualistic perspective. However, in collectivist cultures like Pakistan, the concept of self is embedded in mutual dependency and decisions can be deferred to another person or influenced by a group (Hanssen, 2004). Similarly, in societies with a patriarchal structure, a male authority figure within the family may be responsible for making decisions on behalf of other family members. Therefore, in contrast to a deontological perspective that would state that ethical codes are objective, the Western definition of autonomy and informed consent may not apply across countries.

Moreover, to give informed consent, the nature of a participant's involvement in the study and how their information will be used must be made explicit. It is also normal procedure for participants to be asked to sign an informed consent form as a prerequisite. However, when completing research with people with disabilities adaptations are needed to ensure that resources are accessible depending on a person's needs. In some areas in Pakistan the resources and procedures were not available to allow data to be collected from women with hearing impairments or intellectual disabilities (IDs). For example, in rural areas women with hearing impairments did not know sign language or were not able to read or write. This resulted in women with communication impairments or moderate to severe IDs being under-represented in the sample.

Ethical principles also include the notions of do no harm and beneficence. Beneficence implies that research should benefit others, which stems from the Western assumption that science benefits society (American Academy of Pediatrics Committee on Native American Child Health, & American Academy of Pediatrics Committee on Community Health Services, 2004). Harm can be both the immediate risks to participants, such as the psychological harm of being involved in research, and more subtle risks such as the implications of the research on a participant's relationships and power within their community. This was especially important to consider in this research given its focus on women's experiences of discrimination and gender-based violence. In Pakistan, country teams raised how important families are in reaching women with disabilities and involving them in research. However, concurrently, they acknowledged that if others knew that the women were involved in a project discussing taboo topics like abuse and sexual violence they could be further stigmatised and ostracised by their communities. As such, to minimise the risk of harm a considered approach was taken to only involve women with whom OPDs had existing relationships.

Further, both notions emphasise the fair treatment of participants and their communities, including balancing who is burdened by the research and who benefits most (Leaning, 2001). Here, women with disabilities and enumerators, who were also people with disabilities, were burdened the most in being asked to speak about distressing experiences. Ultimately, this must be evaluated against the potential benefits to people with disabilities, and the risks of harm should be mitigated as far as possible. In this study, women with disabilities were provided with information about where they could access support for any upsetting experiences raised during the interviews and enumerators were given the opportunity to debrief following the interviews. However, when asked for feedback, enumerators reported that more support would have been beneficial in preparing them to facilitate difficult conversations. Additionally, they requested a reflective space with other enumerators to process their experiences. Finally, how the research is disseminated and used to provoke positive changes for those who have been impacted the most by the project is key in determining whether the benefits of the project outweighs the risk of harm. This will be discussed later in this critical appraisal.

Project aims

One key aim for the research was for it to be participatory and co-produced with women with disabilities. For this to be achieved, women with disabilities had to be integral to the entirety of the research process, holding equal power in the research design, data collection and dissemination (McDonald & Stack, 2016). This is counter to non-participatory research where participants are simply sources of data and requires a shift from the traditional view that researchers are ‘experts’ to the idea that individuals have the right to be involved in research that concerns their own lives (Stalker, 1998).

The ladder of engagement and participation (Arnstein, 1969) provides a framework for assessing the extent to which research is truly participatory. Starting with informing, participation increases to consulting, involving, collaborating, and finally, devolving. As you move up the ladder through non-participatory and tokenistic actions to citizen power, populations that are the focus of the research are allocated more agency, power, and control. This research study falls into the category of 'collaborating', as people with disabilities were integral to the project, contributing to the design and customisation of the WDSI through focus groups, as suggested by Werner (2012), data collection, and feedback stages. Additionally, ethical issues were addressed in dialogue with women with disabilities. This is a significant achievement given the timeframe for the project. It is well documented that participatory research requires more time, resources, and effort (Northway et al., 2015); especially when conducting research with people with disabilities where there are challenges in developing partnerships that are adequately accessible and resourced (McDonald & Stack, 2016). In this research, the existing relationships that OPDs had with communities and women with disabilities were crucial. However, it did not meet the threshold for the category of 'devolving' as, ultimately, the agenda and research question for the project were set out by the UNPRPD. To move into this category, the research would have required further flexibility in procedures and existing ways of working.

Secondly, it was hoped that a standardised stigma measure could be developed to compare the experiences of women and support our understanding of how intersectionality effects stigma. This poses several questions and dilemmas. Primarily, it assumes that stigma is a generalisable construct, both across cultures and different disability types. However, by its very nature, stigma is culturally defined, suggesting that stigma measures should be produced and grounded in the setting where it will be applied. Additionally, the project highlighted that in Pakistan there is an absence of shared language for constructs like disability, stigma, and gender-based violence, particularly for translating these meanings into sign language. This creates an additional layer of complexity when trying to design and implement a global tool. To balance the requirement for customisation and standardisation, it was necessary to make small changes to the WDSI to ensure that it was culturally appropriate, however, we were careful not to make too many changes so not to change the item content and underlying structure of the measure. Similarly, as aforementioned, it was challenging to involve women with different types of disabilities. Additional work is needed to ensure that the measure is appropriate and accessible for women with different disability types.

Further, the research aims suppose that intersectionality can be assessed using quantitative approaches. The complex interactions of identities and how they effected stigma experiences could not be captured due to the limited sample size and statistical methods needed to sufficiently disaggregate the data (Bauer et al., 2021). Qualitative research is needed to complement quantitative approaches and explore the effect of multiple and intersecting forms of discrimination.

Recommendations and dissemination

Reliable stigma measures in the field of disabilities are lacking. The empirical paper of this thesis documents an ambitious project that aimed to develop and pilot a new self-report measure of disability stigma that is sensitive to the intersect of disability and gender. Findings and recommendations from the systematic review and empirical study suggest areas of future research that will benefit the wellbeing of people with disabilities.

It is hoped that the WDSI will continue to be used to gather evidence about the experiences of women with disabilities and evaluate the impact of stigma-reduction strategies and interventions. This research has emphasised the benefits of partnership working and co-producing research with women with disabilities. These relationships should be maintained and developed further. Where possible, the research topic should be co-created with women with disabilities to further increase the power held by the communities that the research will affect. Additionally, adaptations should be made to ensure that women with different disabilities and intersecting forms of discrimination are be included throughout the research process to ensure that their experiences are captured sufficiently.

Power often dictates whose voice is heard, where research is focussed, and who benefits from the outcomes. Arguably, the UNPRPD held the most power but those working on the ground in Pakistan and women with disabilities are likely to have been most effected by the project aims. Thus, it is important to consider who will benefit most from the outcomes of the project. In order for the research to be meaningful, the outcomes should be communicated to women with disabilities and key figures who have the power to make necessary changes. We hope to achieve publication with the country teams, which will contribute to the scarce literature in this area. Additionally, the results of this study will be disseminated to the country teams who were involved with the project through meetings and at conferences. The project has triggered conversations about the impact of stigma at multiple levels, including with OPDs and policy holders in Pakistan. A Policy Dialogue was recently held with key government figures, UN teams and OPDs in Pakistan, to discuss how to use the evidence gathered that shows that discrimination is ongoing. Recommendations include ensuring that women with disabilities are aware of their rights and have the opportunities and the skills to advocate for their rights. Concurrently, the necessary legislation must be in place, alongside changes in systemic factors including accessible education and employment and a shift in community and familial attitudes towards women with disabilities, to support their inclusion. The specific needs of women with disabilities must be accounted for within any stigma intervention, and the involvement of women with disabilities in the design of policies and interventions is crucial.

References

American Academy of Pediatrics Committee on Native American Child Health, & American Academy of Pediatrics Committee on Community Health Services. (2004). Ethical considerations in research with socially identifiable populations. *Pediatrics, 113*(1), 148–151.

Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of American Planning Association, 35*(4), 216-224.

Atkinson, M., Doherty, P., & Kinder, K. (2005). Multi-agency working: models, challenges and key factors for success. *Journal of Early Childhood Research, 3*(1), 7–17. https://doi.org/10.1177/1476718X05051344

Bateson, G. (1972). *Steps to an Ecology of Mind.* Paladin.

Brazil, V., McLean, D., Lowe, B., Kordich, L., Cullen, D., De Araujo, V., Eldridge, T., & Purdy, E. (2022). A relational approach to improving interprofessional teamwork in post-partum haemorrhage (PPH). *BMC health services research, 22*(1), 1108. https://doi.org/10.1186/s12913-022-08463-8

Byrne, B. M., Oakland, T., Leong, F. T. L., van de Vijver, F. J. R., Hambleton, R. K., Cheung, F. M., & Bartram, D. (2009). A critical analysis of cross-cultural research and testing practices: Implications for improved education and training in psychology. *Training and Education in Professional Psychology*, *3*(2), 94-105.

Chard, A. (2014). Orientations: Systemic Approaches to Research Practice. In G. Simon & A. Chard, *Systemic Inquiry* (pp. 32–40). Everything is Connected Press.

Daniels, J. & Brooker, J. (2014). Student Identity Development in Her Education: Implications for Graduate Attributes and Work Readiness. *Education Research, 56*(1), 65–76.

Gergen, K. J., Josselson, R., & Freeman, M. (2015). The promises of qualitative inquiry. *American Psychologist, 70*(1), 1–9. https://doi.org/10.1037/a0038597

Hanssen, I. (2004). An intercultural nursing perspective on autonomy. *Nursing Ethics, 11*(1), 28–41.

Jull, J., Giles, A. & Graham, I. D. (2017). Community-based participatory research and integrated knowledge translation: advancing the co-creation of knowledge. *Implementation Sciences, 12*(150). https://doi.org/10.1186/s13012-017-0696-3

Leaning, J. (2001). Ethics of research in refugee populations. *Lancet, 357*(9266), 1432–1433.

Lencioni, P. (2002). *The five dysfunctions of a team*. Jossey-Bass.

McDonald, K. E., & Stack, E. (2016). You say you want a revolution: An empirical study of community-based participatory research with people with developmental disabilities. *Disability and health journal, 9(*2), 201–207.

Northway, R., Howarth, J., & Evans, L. (2015). Participatory research, people with intellectual disabilities and ethical approval: making reasonable adjustments to enable participation. *Journal of clinical nursing, 24*(3-4), 573–581. https://doi.org/10.1111/jocn.12702

Rashad, A. M., Phipps, F. M., & Haith-Cooper, M. (2004). Obtaining Informed Consent in an Egyptian Research Study. *Nursing Ethics, 11*(4), 394-399.

Shotter, J. (2012). More than Cool Reason: 'Withness-thinking' or 'systemic thinking' and 'thinking about systems'. *International Journal of Collaborative Practices, 3*(1), 1-13.

Stalker, K. (1998). Some ethical and methodological issues in research with people with learning difficulties. *Disability and Society, 13*(1), 5-19.

Syed, M. (2020). *Rebel Ideas: The Power of Diverse Thinking*. John Murray Press.

Tindle, R. (2021). Improving the global reach of psychological research. *Discover Psychol*ogy, *1*(5). https://doi.org/10.1007/s44202-021-00004-4

UN. (2015). *Transforming our world: the 2030 Agenda for Sustainable Development*. https://documents-dds-ny.un.org/doc/UNDOC/GEN/N15/291/89/PDF/N1529189.pdf?OpenElement

Van Dijk, G. & Van Loon, R. (2015). Dialogical Leadership: Dialogue as Condition Zero. *Journal of Leadership, Accountability and Ethics, 12*(3), 62-75.

Watson, W. H. (2012). Family systems. In V. S. Ramachandran, *Encyclopedia of human behavior* (pp. 184–193). Elsevier Academic Press.

Werner, S. (2012). Individuals with Intellectual Disabilities: A Review of the Literature on Decision-Making since the Convention on the Rights of People with Disabilities (CRPD). *Public Health Rev 34*(14). https://doi.org/10.1007/BF03391682

Yick, A. G. (2007). Role of Culture and Context: Ethical Issues in Research with Asian Americans and Immigrants in Intimate Violence. *Journal of Family Violence, 22*, 277–285. https://doi.org/10.1007/s10896-007-9079-x

Appendices

Appendix A - Definitions of psychometric measurement properties, informed by the COSMIN user manual

Domain	Measurement Property	Definition
Reliability		The degree to which the measurement is free from error
	Internal Consistency	A measure of the correlations between items in the domain to assess whether the items all relate to the same construct. Internal consistency is usually measured using Cronbach's alpha.
	Measurement Error	Any systematic or random difference that cannot be attributed to true changes in the underlying detectable construct. A measure is said to be acceptable if the smallest detectable change (SDC) on the measure is less than the minimal important change (MIC).
	Reliability	The consistency of a measure and the proportion of variance that can be attributed to true differences between persons. Reliability is often assessed by intraclass correlation coefficients, Cohen's Kappa, or test-retest correlations.
Validity		The degree to which the measure reflects the construct(s) which it is designed to measure
	Content Validity	Includes face validity and evaluates whether the items are relevant and adequately reflect the construct for which they are designed to measure.
	Structural Validity	The extent to which scores on the measure are captured by its dimensionality, which is normally measured by calculating the proportion of the variance which is accounted for by the measure's factors.
	Hypothesis Testing	The degree to which scores on the measure confirm predictions about relationships with other measures and differences between groups. This is often reflected by correlations with other measures.
	Cross-cultural Validity	The capacity of the translated and adapted items to perform as the original items in measuring the same construct.
	Criterion Validity	The degree to which the measure correlated with an accepted 'gold standard'.
Responsiveness	Responsiveness	The ability of a measure to detect change over time, in accordance with expected hypotheses made about the relationships between changes in scores on the measure and changes in scores on other instruments.

Appendix B - Quality criteria for measurement properties from Park et al. (2013)

Property	**Rating**	**Quality Criteria**
Internal Consistency	+	(Sub)scale unidimensional and Cronbach's alpha(s)/*McDonald's omega* ≥ 0.70 for the scale or each subscale
	?	Dimensionality not known or Cronbach's alpha/*McDonald's omega* not determined
	-	Cronbach's alpha(s)/*McDonald's omega* < 0.70 for the scale or each subscale
Measurement Error	+	Minimal important change (MIC) > Smallest detectable change (SDC) OR MIC is outside of the Limits of Agreement (LoA)
	?	MIC not defined
	-	MIC < SDC OR MIC is equal to, or inside the LoA
Reliability	+	Intraclass correlation coefficient (ICC) or weighted Kappa ≥ 0.70 OR Pearson's r ≥ 0.80
	?	Neither ICC/weighted Kappa, nor Pearson's r determined
	-	ICC or weighted Kappa < 0.70 OR Pearson's r < 0.80
Content Validity	+	The target population considers all items in the questionnaire to be relevant AND considers the questionnaire to be complete
	?	No target population involvement OR no assessment of completeness or comprehensiveness
	-	The target population considers items in the questionnaire to be irrelevant OR considers the questionnaire to be incomplete
Structural Validity	+	Factors should explain at least 50 % of the variance OR Good or adequate fit by goodness-of-fit criteria for a confirmatory factors analysis (CFA) or exploratory factor analysis (EFA): Good or adequate fit = comparative fit index (CFI) ≥ 0.90, root mean square error of approximation (RMSEA) ≤ 0.08, standardized root mean square residual (SRMR) < 0.10
	?	Explained variance not mentioned OR Indeterminate fit criteria for a CFA or EFA: Indeterminate fit = the values of fit indexes ranged in between the adequate criteria and inadequate criteria
	-	Factors explain< 50 % of the variance OR Poor fit by goodness-of-fit criteria for a CFA or EFA: Poor fit = CFI ≤ 0.85, RMSEA ≥ 0.10, SRMR ≥ 0.10
Hypothesis testing	+	Correlation with an instrument measuring the same construct ≥ 0.50 OR at least 75 % of the results are in accordance with the hypotheses *about the stigma measure* AND correlation with related constructs is

		higher than with unrelated constructs OR no evidence of differential item functioning (DIF)
	?	Solely correlations determined with unrelated constructs OR ≥ 50 % but < 75 % of the results are in accordance with the hypotheses *about the stigma measure* OR possible DIF
	-	Correlation with an instrument measuring the same construct < 0.50 OR < 50 % of the results are in accordance with the hypotheses *about the stigma measure* OR correlation with related constructs is lower than with unrelated constructs OR notable evidence of DIF
Responsiveness	+	Correlation of changes with an instrument measuring change in the same construct ≥ 0.50 OR At least 75 % of the results are in accordance with the hypotheses *about the stigma measure* OR Area under the curve (AUC) ≥ 0.70 AND correlation of changes with related constructs is higher than with unrelated constructs
	?	Solely correlations determined with unrelated constructs
	-	Correlation of changes with an instrument measuring change in the same construct< 0.50 OR < 75 % of the results are in accordance with the hypotheses *about the stigma measure* OR AUC < 0.70 OR Correlation of changes with related constructs is lower than with unrelated constructs

The criteria have been adapted for the purpose of the review, as recommended by COSMIN authors

Appendix C – WDSI

Women with Disabilities Stigma Inventory

Pakistan version – Response options to questions marked with * have been customized for the specific country

Introduction

This is a survey about the experiences of women with disabilities in your country. The survey has been developed to find out more about the lives of women with disabilities. Before you start the survey, please read/listen to the information sheet and then consent to taking part.

Interviewer: you must give the interviewee the information sheet and allow her time to read it.
If she is unable to read, you must read it to her.

Consent Form

Thank you for your interest in taking part in this study. If you have any questions about the study, please ask the interviewer (or the person who told you about this study) before you decide whether to continue.

I confirm that:
I have read the Study Information Sheet OR someone has read it to me;
I understand the study and what it involves;
I understand that I can stop at any time and without giving a reason;
I understand that all the information I give will be kept confidential;
I understand that my anonymized information will be analyzed for the purposes of this project;
I understand that the UN partners at University College London will do further analyses with the anonymized information;
I agree to take part in this project.

I confirm that I agree to all of these statements and to taking part in this study.

○ Yes

Section 1 – About You

This section asks you some questions about yourself. For each question please select the option that best describes you.

1. How old are you?

○ 18 – 24

○ 25 – 34

○ 35 – 44

○ 45 – 54

○ 55 – 64

○ 65 +

2. What type of area do you live in?

○ Rural

○ Semi-rural

○ Urban

○ Other (please specify) ____

3. What is your ethnicity?*

○ Punjabi

○ Sindhi

○ Pathan

○ Balochi

○ Pashtoon

○ Kashmiri

○ Gilgit Baltistan

○ Chitrali

○ Muhajir/Refugee

○ Other (please specify) ____

4. What is your current relationship status?*

○ Single

○ Engaged

○ Married

○ Divorced

○ Separated

○ Widowed

○ Other (please specify)

4. Do you have children?

○ Yes

○ No (Skip to Q6)

4a. Do your children live with you?

○ Yes, all of the time

○ Yes, some of the time

○ No

5. Who do you live with?*

○ on my own

○ with my children only

○ with my husband (and children)

○ with my parents, siblings or extended family

○ with my husband's parents, siblings or extended family

○ Other, please specify ____

6. What is the highest level of education that you have completed?

○ No formal education

○ Primary/elementary school

○ High school/secondary school

○ Trade/vocational school

○ University/tertiary education

○ Other (please specify) ____

7. What is your current work status?

○ In paid full-time work as an employee

○ In paid part-time work as an employee

○ Working full-time but not as an employee (self-employed or business owner)

○ Doing voluntary unpaid work outside of the home

○ Homemaker

○ Student

○ Unemployed

○ Unable to work

○ Other (please specify) ____

8. Do you currently belong to, or have you ever been a member of, any of the following groups? Please select all that apply.

○ Refugee or asylum seeker

○ Migrant worker

○ Internally displaced person

○ Member of a religious minority

○ Member of a racial minority

○ I don't belong to any of these groups

Section 2 – Disability

In this section, you will be asked some questions about your difficulties or disability. For each question, please select one of the options.

9. Do you have:	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Don't know
a. difficulty seeing, even if wearing glasses?					
b. difficulty hearing (even if using a hearing aid)?					
c. difficulty walking or climbing steps?					
d. difficulty remembering or concentrating?					
e. difficulty with self-care, such as washing all over or dressing?					
f. using your usual language, do you have difficulty communicating, for example, understanding or being understood?					

	Yes	No	Don't know	Prefer not to say
10. Are any of your difficulties visible to other people?				
11. Do you need the assistance of assistive devices and/or equipment in order to facilitate your daily life? An 'assistive device' is something that helps a person to perform a particular task.				
12. Do you need help from others in order to facilitate your daily life?				
13. Do you have a disability identity card/certificate from the government?				
14. Did you face any difficulty in getting registration/ certification?				

Section 3 – About Experiences of Exclusion and Marginalization

This section asks about experiences of being excluded or denied access to places and activities. ‘Exclusion’ means leaving someone out. ‘Marginalization’ is to make a group of people less important based on a characteristic that they share. For each question, please select one of the options.

15. Have you:	Never	Rarely	Sometimes	Often	Always	Prefer not to say
a. been denied education or training opportunities? ‘Denied’ means to not be given something that you want or need.						
b. been denied employment, or lost a job or source of income?						
c. been denied access to computers or the internet?						
d. been denied your own personal mobile phone?						
e. been excluded or stopped from attending social gatherings or activities (parties, weddings, funerals)?						
f. been excluded or stopped from attending family activities (e.g. visiting relatives, family outings, holidays)?						
g. been denied access to healthcare services (e.g. doctor, hospital, dentist, maternity clinic)?						
h. been denied access to public services and buildings (e.g. markets, banks, community centers)?						
i. Have people avoided contact with you e.g. moved away, refused to speak to you, refused to serve you?						

16. Of the people who have excluded you, or denied services or assistance, whose actions have affected you the most?

○ Family members

○ Friends or neighbors

○ Colleagues or teachers

○ Community members (e.g. shop keepers, taxi drivers, religious leaders)

○ Public service providers (e.g. healthcare providers)

○ Other, please specify ____

○ Prefer not to say

○ Not applicable (I have not been excluded or had services/assistance denied)

17. How often do you think you were excluded or denied access <u>because you are a woman</u>?

○ Never

○ Rarely

○ Sometimes

○ Often

○ Always

○ Don't know

18. How often do you think you were excluded or denied access because of your disability?

○ Never

○ Rarely

○ Sometimes

○ Often

○ Always

○ Don’t know

19. Do you think you were excluded or denied services or assistance for another reason?

---

20. Have there been other experiences of being excluded or denied services or assistance not already mentioned?

Section 4 – About Experiences of Abuse

This section asks whether you have ever experienced different types of abuse. ‘Abuse’ is when someone causes a person harm or distress. For each question, please select one of the options.

21. Have you ever experienced the following from people that you are close to?

Have any of them	Never	Rarely	Sometimes	Often	Always	Prefer not to say
a. teased, laughed at or gossiped about you?						
b. verbally abused you (e.g., yelled at, insulted, or threatened you)?						
c. physically abused you (e.g., pushed, hit, or hurt you in other ways)?						
d. stolen or destroyed things that belong to you (e.g. money, property, mobile, share in inheritance, important equipment)?						
e. forced you to be in a room or house alone?						

21a. Of people that you are close to, whose actions have been most hurtful to you? Select all that apply.

○ Family members

○ Friends/close acquaintances

○ Other (please specify) ______________________________

○ Prefer not to say

○ Not applicable

22. How about people that you don’t know very well (e.g. strangers, service providers, taxi drivers, service providers, police, soldiers)?

Have any of them	Never	Rarely	Sometimes	Often	Always	Prefer not to say
a. verbally abused you?						
b. physically abused you?						
c. stolen or destroyed things that belong to you?						

22a. Of people that you don’t know very well, whose actions have been most hurtful to you? Select all that apply.

○ Colleagues

○ Community members (e.g. shop keepers, taxi drivers, religious leaders)

○ Public service providers (e.g. teachers, healthcare providers)

○ Other ____

○ Prefer not to say

○ Not applicable

23. How often do you think these bad things happened because you’re a woman?

○ Never

○ Rarely

○ Sometimes

○ Often

○ Always

○ Prefer not to say

24. How often do you think these bad things happened because of your disability?

○ Never

○ Rarely

○ Sometimes

○ Often

○ Always

○ Prefer not to say

25. Do you think these bad things happened for another reason?

Section 5 – About Experiences of Discrimination and Violence

This section asks whether you have ever experienced different types of discrimination or violence. ‘Discrimination’ means treating a person unfairly because of who they are or because they possess certain characteristics.

The questions may cause some bad memories and pain. We are asking about your experiences so that we can better prevent others to go through similar experiences. If you feel you would like to talk to someone, we can help you and refer you to someone who will support you. For each question, please select one of the options.

26. Has anyone harassed or intimidated you by phone or social media (e.g. by sending you intimate pictures or videos)? ‘Intimidate’ means to make someone fearful. ‘To harass’ means to put someone under pressure.

○ Yes

○ No (Skip to Q.27)

○ Don’t know (Skip to Q.27)

○ Prefer not to say (Skip to Q.27)

26a. If yes, who? Select all that apply.

○ Family member

○ Friend or close acquaintance

○ Colleague or manager

○ Stranger

○ Other ____

○ Prefer not to say

27. Has anyone made you engage in sexual activities (e.g. touching, kissing, sex) when you did not want to?

○ Yes

○ No (Skip to Q.28)

○ Don't know (Skip to Q.28)

○ Prefer not to say (Skip to Q.28)

27a. If yes, who? Select all that apply.

○ Family member

○ Friend or close acquaintance

○ Colleague or manager

○ Service provider

○ Stranger

○ Other ____

○ Prefer not to say

28. Have you been denied access to sexual or reproductive health services e.g. menstrual hygiene care, family planning services, contraception?

○ Yes

○ No

○ Don't know

○ Prefer not to say

29. Have you ever been considered for marriage?

- ○ Yes
- ○ No
- ○ Don’t know
- ○ Prefer not to say

30. Have you been forced to marry? ‘Forced’ means being made to do something you do not want to.

- ○ Yes
- ○ No
- ○ Don’t know
- ○ Prefer not to say

31. Have you ever had a medical procedure without your knowledge/agreement or that you did not want e.g. sterilization, abortion?

- ○ Yes
- ○ No
- ○ Don’t know
- ○ Prefer not to say

32. How often do you think these bad things happened because you’re a woman?

○ Never

○ Rarely

○ Sometimes

○ Often

○ Always

○ Prefer not to say

33. How often do you think these bad things happened because of your disability?

○ Never

○ Rarely

○ Sometimes

○ Often

○ Always

○ Prefer not to say

34. Do you think these bad things happened <u>for another reason?</u>

____

35. If you have experienced discrimination or abuse, have you told anyone about these things?

○ Yes (Go to Q26a)

○ No

○ Prefer not to say

○ Not applicable (I have not experienced discrimination or abuse)

35a. Did you receive any support?

○ Yes. From whom? ____

○ No

Section 6 – Responses to Stigma and Discrimination

This section asks about your feelings about yourself and things you may do when you experience stigma or discrimination. 'Discrimination' means treating a person unfairly because of who they are or because they possess certain characteristics. 'Stigma' means harmful attitudes, beliefs or acts against someone based on a certain characteristic.

36. To what extent do the following statements hold true for you?

	Never	Rarely	Sometimes	Often	Always
You can have a positive view of yourself even when others don't					
When you experience prejudice and/or discrimination, you know that it's wrong.					
Confronting prejudice and discrimination means doing what you want to do, no matter what others think about you.					
You know you have many strengths (despite your difficulties)					
You remind yourself that your difficulties do not define you					
You challenge negative thoughts about your difficulties					

Section 7 – Rights and Effecting Change

This section asks about different human rights and how aware you are of them. 'Human rights' are things that we all should be able to have or do.

37. How aware are you of your right to:

	Not at all aware	A little aware	Very aware
Equality and non-discrimination (equality means that everyone has the same opportunities)			
Protection from violence, abuse and exploitation (abuse is when someone causes you harm or distress)			
Education and work			
Live with dignity within my family and the community			
Privacy and a personal life (privacy is the right to be alone or have information about yourself kept secret)			
Access to justice and legal rights			
Political participation			
Financial rights, including the right to control your monies and salary			
Health, recovery and development			
Access to sexual and reproductive health and rights services			
Access to prevention, protection and response services			

38. Help with your rights:

	Never	Rarely	Sometimes	Often	Always
a. Have your family and/or friends helped you to stand up for your rights?					
b. Have community leaders and/or organizations helped you to stand up for your rights?					
c. Has it been easy to access community leaders, politicians or government officials to discuss rights-based issues?					
d. Have you had opportunity to challenge or educate someone who is treating you or other people unfairly because of a disability?					
e. Have you participated in campaigns, advocacy groups or meetings to improve the lives of people with disabilities?					

39. What opportunities would you like to have to find out more about your rights?

---

40. Are there other ways you have stood up for the rights of women or people with disabilities?

---

41. These final questions ask you about support available to women who experienced violence. In your opinion, to what extent are the following involved in supporting women with disabilities who have suffered or suffer from violence?
(*Section only included in Moldova survey during field testing)*

	To a great extent	A little	Not at all
Police			
Human rights organisations/women's rights organisations			
Medical institutions			
Social workers			
Paralegals			
Local public authority (e.g. mayor)			
Family/relatives			
Friends/neighbours			
Psychologists			
Priests/religious groups			
Others			

42. Where would you ask for help / support / assistance in case you or someone you know experience violence? Please select 3 in order of priority
(*Section only included in Moldova survey during field testing)*

	Priority 1	Priority 2	Priority 3
Police			
Human rights organisations/ women's rights organisations			
Medical institutons			
Social workers			
Paralegals			
Local public authority (e.g. mayor)			
Family/relatives			
Friends/neighbours			
Psychologists			
Priests/religious groups			
Others			

43. Before closing, is there anything else you would like to share about experiences of prejudice or discrimination, or your interactions within your family or community?

If you would like to access support, here are some organizations that you could access:

NOWPDP (for persons with hearing impairments/deaf persons)
www.nowpdp.org
info@nowpdp.org
+92 (21) 32294527-8 or +92 (333) 1354478
NOWPDP House Bungalow No.83/1 N I Line Saghir Hussain Shaheed Road, Saddar Karachi

Saaya Association of Persons with Disabilities h
http://www.saayaassociation.org
saayaassociation@hotmail.com
+92 (51) 4444493

Disabled Welfare Association
https://dwa-pk.org/

+92 (21) 32789037/9
Funhouse A1 Cc2 Apartment Opposite Block A/C, Housing Complex Near
Hashmani Eye Hospital, Jacub Line, Karachi

HANDS
https://hands.org.pk
+92 (21) 34532804 or +92-346-111-777-1
140-c, P.E.C.H.S Block 2 Block 2 PECHS, Karachi

National Forum for Women with Disabilities (NFWWD)
Info@step.org.pk
+92518435806
Flat 109, 1st Floor, Khudadad Heights, Main Margalla Road, Sector E-11, Islamabad

Other organizations can be accessed here:
https://www.ds-international.org/201akistan

Ministry of Human Rights- Complaint Cell
secretary@mohr.gov.pk
9th Floor, New Pak Secretariat (Kohsar Block) Sector F-5, Islamabad
+92 (51) 9216620

National Commission for Human Rights
http://nchr.org.pk/enComplaintsForm.aspx?id=49
+92 (51) 9216771 051-92167725th Floor Evacuee Trust Complex, Agha Khan Road, Islamabad
National Commission for Human Rights, Balochistan
Ms. Farkhanda Aurengzeb, Balochistan Office No 404/174-B, Lane 8, Jinnah Town Quetta

Appendix D – WDSI scoring guide

Women with Disabilities Stigma Inventory (WDSI) Scoring Guide

Section 1: About You
Responses to Q1-Q8 can be used as individual items to describe the sample, and as independent variables for analyses regarding the impact of different sociodemographic variables on experiences of stigma and gender-based violence.

Section 2: Disability
Responses to Q9-Q14 can be used as individual items to describe the sample, and as independent variables for analyses regarding the impact of different sociodemographic variables on experiences of stigma and gender-based violence.

Q9: Washington Group questions to detect different types of disabilities. Score as 1 = yes, disability present in this area of functioning: ‘a lot of difficulty’ or ‘cannot do at all’, or 0 = no disability in this area: ‘a little difficulty’ or ‘no difficulty’

Q10: Visibility of disability. Score as 1 = yes, disability visible, or 0 = no, and don’t know
Q11: Use of assistive devices. Score as 1 = yes, uses assistive devices, or 0 = no, and don’t know
Q12: Reliance on others. Score as 1 = yes, relies on others, or 0 = no, and don’t know
Q13: Disability identity card. Score as 1 = yes, has disability identity card, or 0 = no, and don’t know
Q14: Difficulties registering. Score as 1 = yes, has disability identity card, or 0 = no, and don’t know

Section 3: Experiences of Exclusion and Marginalization

1 factor, 9 items measuring experiences of exclusion and marginalization
Q15a: Denied education opportunities
Q15b: Denied employment
Q15c: Denied computer access
Q15d: Denied mobile
Q15e: Excluded socially
Q15f: Excluded family
Q15g: Denied healthcare
Q15h: Denied building access
Q15i: People avoiding contact

Score each individual item as Never/prefer not to say(0), Rarely (0), Sometimes (1), Often (2), Always(3) and calculate the mean for subscale score

Section 4: Experiences of Abuse

1 factor, 8 items measuring experiences of abuse
Q21a: Teased
Q21b: Verbal abuse (close rel.)
Q21c: Physical abuse (close rel.)
Q21d: Stolen from (close rel.)
Q21e: Left in house alone
Q22a: Verbal abuse (stranger)
Q22b: Physical abuse (stranger)
Q22c: Stolen from (stranger)

Score each individual item as Never/prefer not to say(0), Rarely (0), Sometimes (1), Often (2), Always(3) and calculate the mean for subscale score

Section 5: Experiences of Discrimination and Violence

Q26: Harassed by phone
Q27: Sexual abuse
Q28: Denied sexual health services
*Q29: Considered for marriage
Q30: Forced marriage
Q31: Forced medical procedure

Score each individual item as 1= yes and 0= no, prefer not to say, and don’t know and calculate the sum of scores for subscale score
*Reverse score item 47 so 1= no and 0= yes, prefer not to say, and don’t know

Section 6: Responses to Stigma and Discrimination

1 factor, 6 items measuring stigma resistance
Q36a: Positive view of self
Q36b: Know prejudice to be wrong
Q36c: Confronting prejudice
Q36d: Know that you have strengths
Q36e: Differences are not self-definition
Q36f: Challenge negative thoughts

Score each individual item as Never (0), Rarely (0), Sometimes (1), Often (2), Always(3) and calculate the mean for subscale score

Section 7: Awareness of Rights and Advocating for Rights of Women with Disabilities

Q37

A: Equality
B: Abuse
C: Education
D: Dignity
E: Privacy
F: Justice
G: Politics
H: Financial
I: Health
J: Sexual Health
K: Prevention

Score as 1= aware of rights, and 0= not at all aware, or a little aware and calculate the sum of scores for awareness of rights score

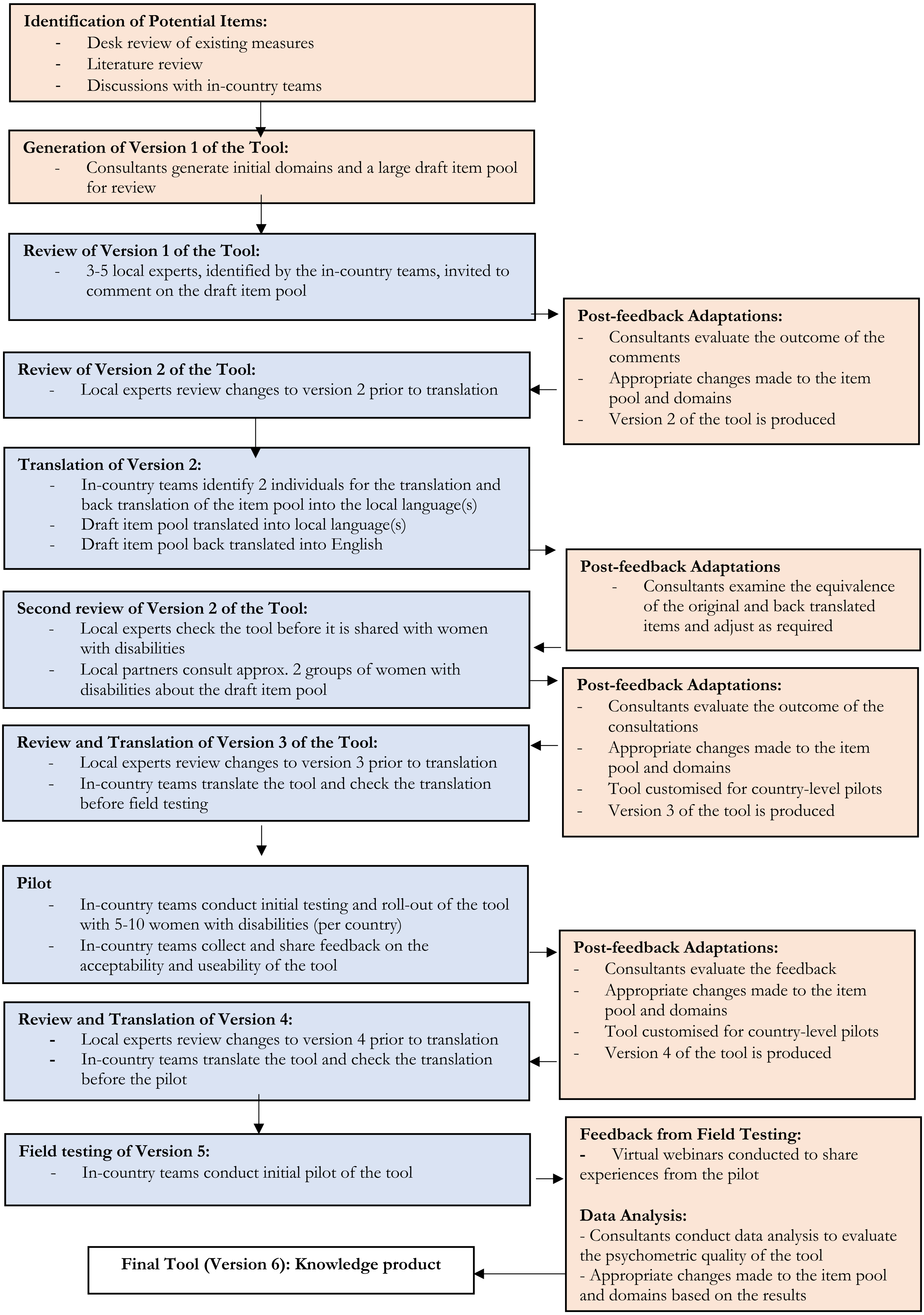
1 factor, 5 items to measure advocacy
Q38a: Close rel. standing up for rights
Q38b: Organisations standing up for rights
Q38c: Easy to access organisations
Q38d: Challenged unfair treatment
Q38e: Participated in disability support campaigns

Score each individual item as Never (0), Rarely (0), Sometimes (1), Often (2), Always(3) and calculate the mean for advocacy score

Appendix E – UN country team and OPD consultants involved in the project

- Ms Abia Akram, Project Director STEP & Founder National Forum of Women with Disability
- Ms Lema Jan, Project Officer Federal, Rights Based Development, Decentralization, Human Rights and Local Governance – Democratic Governance Unit, UNDP
- Mr Ali Qambar, National Specialist UNV and Social Inclusion Officer, Human Rights and Local Governance – Democratic Governance Unit, UNDP
- Ms Tayyaba Arshi, National Specialist UNV and Social Inclusion Officer, Human Rights and Local Governance – Democratic Governance Unit, UNDP
- Mr Abdul Ali, Deputy Director Development and in charge of the Persons with Disabilities portfolio, Social Welfare Department of Baluchistan
- Dr Sarwat Mirza – Senior Advisor at Health and Nutrition Development Society (HANDS) and National Coordinator of Community Based Inclusive Development Network (CBIDN).
- Saima Ali – President, Disabled Welfare Association (DWA)
- Fatima Jamil – Senior Program Manager, Network of Organizations of People with Disabilities (NOWPDP)
- Fareeha Ummar – Portfolio Manager, Women's Economic Empowerment & Sustainable Livelihoods, UN Women
- Anum Aftab – Consultant, Social Cohesion, UN Women
- Yann Cres – Human Rights and Local Governance – Democratic Governance Unit, UNDP
- Amar Hassan – Human Rights and Local Governance – Democratic Governance Unit, UNDP

Appendix F –WDSI Development Process



Identification of Potential Items:
- Desk review of existing measures
- Literature review
- Discussions with in-country teams

Generation of Version 1 of the Tool:
- Consultants generate initial domains and a large draft item pool for review

Review of Version 1 of the Tool:
- 3-5 local experts, identified by the in-country teams, invited to comment on the draft item pool

Post-feedback Adaptations:
- Consultants evaluate the outcome of the comments
- Appropriate changes made to the item pool and domains
- Version 2 of the tool is produced

Review of Version 2 of the Tool:
- Local experts review changes to version 2 prior to translation

Translation of Version 2:
- In-country teams identify 2 individuals for the translation and back translation of the item pool into the local language(s)
- Draft item pool translated into local language(s)
- Draft item pool back translated into English

Post-feedback Adaptations
- Consultants examine the equivalence of the original and back translated items and adjust as required

Second review of Version 2 of the Tool:
- Local experts check the tool before it is shared with women with disabilities
- Local partners consult approx. 2 groups of women with disabilities about the draft item pool

Post-feedback Adaptations:
- Consultants evaluate the outcome of the consultations
- Appropriate changes made to the item pool and domains
- Tool customised for country-level pilots
- Version 3 of the tool is produced

Review and Translation of Version 3 of the Tool:
- Local experts review changes to version 3 prior to translation
- In-country teams translate the tool and check the translation before field testing

Pilot
- In-country teams conduct initial testing and roll-out of the tool with 5-10 women with disabilities (per country)
- In-country teams collect and share feedback on the acceptability and useability of the tool

Post-feedback Adaptations:
- Consultants evaluate the feedback
- Appropriate changes made to the item pool and domains
- Tool customised for country-level pilots
- Version 4 of the tool is produced

Review and Translation of Version 4:
- Local experts review changes to version 4 prior to translation
- In-country teams translate the tool and check the translation before the pilot

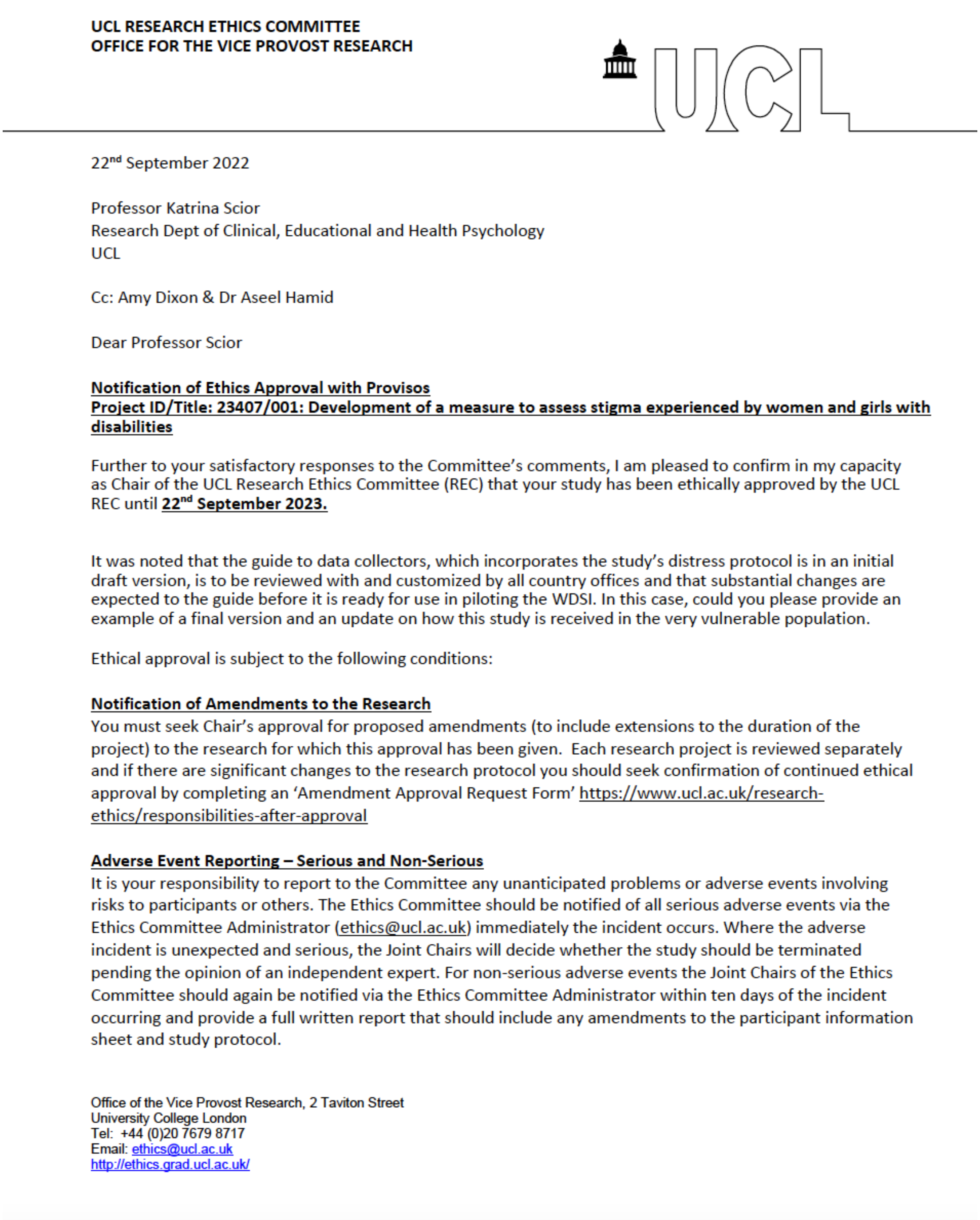
Field testing of Version 5:
- In-country teams conduct initial pilot of the tool

Feedback from Field Testing:
- Virtual webinars conducted to share experiences from the pilot

Data Analysis:
- Consultants conduct data analysis to evaluate the psychometric quality of the tool
- Appropriate changes made to the item pool and domains based on the results

Final Tool (Version 6): Knowledge product

Appendix G – UCL Research Ethics Committee approval



UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

22nd September 2022

Professor Katrina Scior
Research Dept of Clinical, Educational and Health Psychology
UCL

Cc: Amy Dixon & Dr Aseel Hamid

Dear Professor Scior

Notification of Ethics Approval with Provisos
Project ID/Title: 23407/001: Development of a measure to assess stigma experienced by women and girls with disabilities

Further to your satisfactory responses to the Committee's comments, 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 UCL REC until **22nd September 2023.**

It was noted that the guide to data collectors, which incorporates the study's distress protocol is in an initial draft version, is to be reviewed with and customized by all country offices and that substantial changes are expected to the guide before it is ready for use in piloting the WDSI. In this case, could you please provide an example of a final version and an update on how this study is received in the very vulnerable population.

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. 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 an 'Amendment Approval Request Form' https://www.ucl.ac.uk/research-ethics/responsibilities-after-approval

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol.

Office of the Vice Provost Research, 2 Taviton Street
University College London
Tel: +44 (0)20 7679 8717
Email: ethics@ucl.ac.uk
http://ethics.grad.ucl.ac.uk/

The Joint Chairs 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.

Final Report
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.
In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research;
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

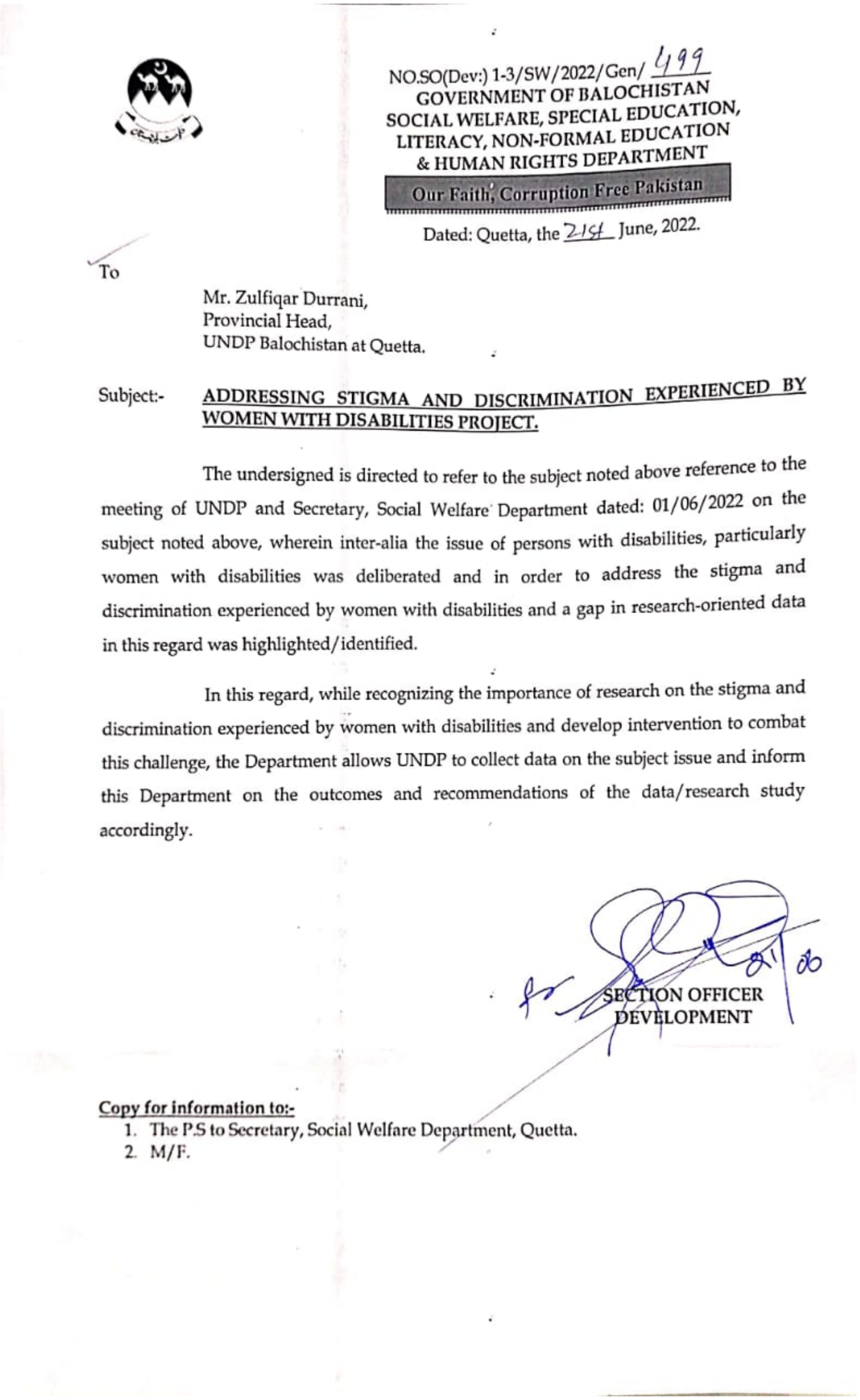
With best wishes for the research.

Yours sincerely

Lynn Ang

Professor Lynn Ang
Joint Chair, UCL Research Ethics Committee

Appendix H – Data collection approval letter



NO.SO(Dev:) 1-3/SW/2022/Gen/ 499
GOVERNMENT OF BALOCHISTAN
SOCIAL WELFARE, SPECIAL EDUCATION,
LITERACY, NON-FORMAL EDUCATION
& HUMAN RIGHTS DEPARTMENT

Our Faith, Corruption Free Pakistan

Dated: Quetta, the 21st June, 2022.

To

Mr. Zulfiqar Durrani,
Provincial Head,
UNDP Balochistan at Quetta.

Subject:- **ADDRESSING STIGMA AND DISCRIMINATION EXPERIENCED BY WOMEN WITH DISABILITIES PROJECT.**

The undersigned is directed to refer to the subject noted above reference to the meeting of UNDP and Secretary, Social Welfare Department dated: 01/06/2022 on the subject noted above, wherein inter-alia the issue of persons with disabilities, particularly women with disabilities was deliberated and in order to address the stigma and discrimination experienced by women with disabilities and a gap in research-oriented data in this regard was highlighted/identified.

In this regard, while recognizing the importance of research on the stigma and discrimination experienced by women with disabilities and develop intervention to combat this challenge, the Department allows UNDP to collect data on the subject issue and inform this Department on the outcomes and recommendations of the data/research study accordingly.

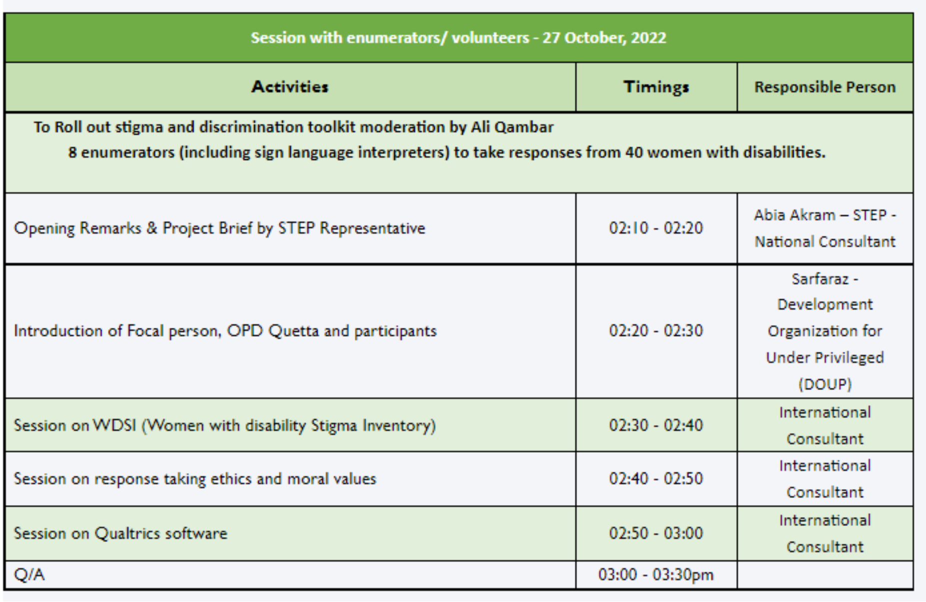
for 21/06

SECTION OFFICER
DEVELOPMENT

Copy for information to:-

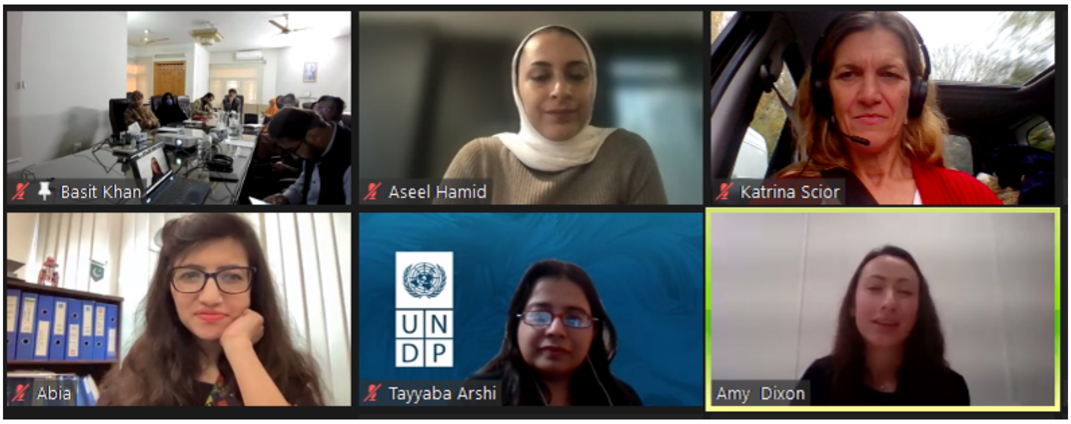
1. The P.S to Secretary, Social Welfare Department, Quetta.
2. M/F.

Appendix I – Images from enumerator training



Session with enumerators/ volunteers - 27 October, 2022

Activities	Timings	Responsible Person
To Roll out stigma and discrimination toolkit moderation by Ali Qambar 8 enumerators (including sign language interpreters) to take responses from 40 women with disabilities.		
Opening Remarks & Project Brief by STEP Representative	02:10 - 02:20	Abia Akram – STEP - National Consultant
Introduction of Focal person, OPD Quetta and participants	02:20 - 02:30	Sarfaraz - Development Organization for Under Privileged (DOUP)
Session on WDSI (Women with disability Stigma Inventory)	02:30 - 02:40	International Consultant
Session on response taking ethics and moral values	02:40 - 02:50	International Consultant
Session on Qualtrics software	02:50 - 03:00	International Consultant
Q/A	03:00 - 03:30pm	



Appendix J – Guidance for data collectors

Women with Disability Stigma Inventory (WDSI)

Guidance for data collectors

Prepared by Amy Dixon, Prof. Katrina Scior, and Dr Aseel Hamid, University College London

The WDSI has been developed as part of the Addressing Stigma and Discrimination experienced by Women with Disabilities (ASDWD) project by UNDP and UN-Women, funded by UN PRPD. The project aims to address key challenges in overcoming stigma and discrimination experienced by women and girls with disabilities. To date, our understanding of the experiences of women and girls with disabilities in relation to stigma (negative stereotyping, prejudice and discrimination) and its effects on their everyday lives is limited. The WDSI is a new tool which has been produced by UNDP, UN women, international research consultants and local partners to document stigma related experiences of women and girls with disabilities. It will now be field tested in four countries selected by the UN (Moldova, Pakistan, Palestine and Samoa). It is hoped that evidence generated using the tool will serve as baseline and could be used in future to assess the impact of interventions that seek to reduce stigma and discrimination faced by women and girls with disabilities.

This document is a guide for data collectors, providing information on how to administer the WDSI.

1. Glossary of Key Terms

Anonymous means no one will know you took part or that it was you who said certain things.

A **disability** is any condition that makes it more difficult for the person to do certain activities and interact fully with the world around them. A disability will have been around for at least 12 months and likely longer.

The WDSI is designed to be used by women with different types of disability. A person may have problems with:

1) **Seeing:** Includes people who have some difficulty seeing which impacts on their daily life. For example, they may be blind or unable be able to read or see signs properly (even when wearing glasses or contact lenses).

2) **Hearing:** Includes people who have some difficulty hearing which impacts on their daily life (even when wearing a hearing aid). They may be unable to hear with one ear or both. For example, they may be deaf or have difficulty hearing someone talking in a busy place.

3) **Mobility:** Includes people who, in the absence of assistive devices like a crutch or wheelchair, have difficulties moving which impacts on their daily life. For example, a physical disability that causes difficulties walking a short distance without a break, or going up and down stairs. It also includes people who cannot use their hands and fingers for holding tools, writing, etc., or to raise items at and above eye level.

4) **Remembering and Concentrating**: Includes people who, without the support of adaptations, have difficulties in memory, concentration, decision-making, understanding speech, reading, directions and using a map, making calculations, and reading.

5) **Communication:** Includes people who, without adaptations, have difficulties exchanging information and ideas with others through the use of speech.

A disability includes people who are Autistic, or those with an intellectual disability/mental disability or learning difficulty.

An **intellectual disability/mental disability** is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socializing or managing money – which affects someone for their whole life.

A **learning difficulty** does not affect someone's general intellect but means that someone may have difficulties processing information and learning in certain areas such as reading, writing, spelling.

Autism is a developmental disability which affects how people communicate and interact with the world and other people.

Discrimination means treating a person unfairly because of who they are or because they possess certain characteristics.

Consent means you agree of your own free will.

Stigma means harmful attitudes or acts against someone based on a certain characteristic.

Gender Based Violence means harmful acts directed at someone because of their gender.

Abuse is when someone causes a person harm or distress.

Exclusion means leaving someone out.

Marginalization is to make a group of people less important based on a characteristic that they share.

Forced means being made to do something when you do not want to.

Denied means to not give you something that you want or need.

Adaptations or adjustments mean that changes are made to make it easier for all people to visit places and use services.

Intimidate means to make someone fearful.

To **harass** means to put someone under pressure.

An **assistive device** is something that helps a person to perform a particular task.

Prejudice is when someone has a dislike for someone without knowing them well.

Human rights are things that we all should be able to have or do.

2. Role of the Interviewer

Interviewers will play a critical role in obtaining first-hand information from women with disabilities, and the way this is done is very important given the sensitivity of the topic of stigma. Before proposing a step-by-step guide on how to obtain informed consent and how to administer the Women with Disabilities Stigma Inventory (WDSI), we discuss some issues to take into consideration.

2.1 Sensitivity of research topic

Given that many of the questions include difficult topics such as discrimination, exclusion, and violence, it is key to ask questions in a sensitive and non-judgmental manner. Interviewers should role play reading these questions until they feel comfortable talking about them.

2.2 Privacy and safety

It is important, for the safety and security of respondents, to introduce the project as a study on addressing stigma and discrimination against women with disabilities. It is important to use this general description and to avoid making a specific reference to violence. We also recommend that all interviewers familiarize themselves with the **ASDWD Ethical Standards Guide** and the relevant links for further information.

2.3 Building rapport

Ensuring that participants feel comfortable from the outset is key. Interviewers can do this by ensuring that they greet participants warmly and pay close attention to interviewees' verbal and non-verbal communication. If interviewers sense reluctance from participants, they should try to make participants feel comfortable and emphasize that answers will be kept confidential, and that information will be grouped together to form a report and so will not be identifiable. They should also ensure that the interview moves at pace but is not overly rushed by asking the questions slowly and checking understanding, giving time to reflect.

3. Before the Interview

3.1 Inviting participants to take part in the study

- Share a copy of the information sheet with the potential participant and tell them more about the study. Read/ask the participant to read the information sheet.
- Ask if they would be interested in taking part in the study, letting them know that they can change their mind.
- Check that they meet the inclusion criteria. To meet the inclusion criteria, they must:
  - Be a woman or girl
  - Have a diagnosis of a disability or identify as having a disability in line with the UN CRPD definition of disability (those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others) – this will include people who have long-term difficulties seeing, hearing, communicating with others, understanding things, remembering and processing

        information, or problems with their mobility. Individuals may have an intellectual disability or be Autistic.
    - Have had this disability for at least 1 year
    - Currently live in Pakistan
    - Be above the legal age of consent
    - Have the capacity to consent to take part in the study (see section 4.3 below for details on assessing capacity)
- Find out the participant's preference for completing the WDSI.
- Would they prefer to complete the WDSI on paper or online?

Do they have any communication needs that require adaptations to complete the WDSI, e.g. a communication specialist, a carer to attend the interview with them, large font, text reader software, need for visual prompts?

- Are there any other adjustments that can be made to help them to take part, e.g. a preferred time of day, if they need regular breaks?
- Agree a confidential and private place to meet.
- Check how will they get there? Will they need any support? Who will be available to support them to get to the interview?
- Agree a date and time to meet (at least 24 hours after registering their interest in taking part in the study)
- N.B. it could be helpful to write this information down for the participant

3.2 What to check before the interview

- Is the place that you have agreed to meet private and a safe setting for the interviewee? Is it set up for the interview e.g., are chairs arranged, is there a drink available for participants?
- Do you have the materials required?

    - Device to complete the WDSI online or a paper copy of the WDSI
    - A copy of the information sheet in the participant's preferred format if completing the WDSI on paper (the online survey contains the information sheet)
    - A copy of the consent form in the participant's preferred format if completing the WDSI on paper (the online survey contains the consent form)
    - Information of available resources (to be given at the end of the interview **only** to respondents who feel happy and safe to take this information)
- Who is available to contact if you need support or queries arise during the meeting?
- Do you have a voice recorder if you are seeking verbal consent from the participant?
- Do you have visual prompts to help the participants answer the questions, e.g. a visual reminder of the response scales?

4. Obtaining Informed Consent

To participate in the study and complete the WDSI, all participants must provide informed consent. This means that following initial interest in the project, every participant has been supported to read/listen to and understand the information sheet provided. They will have had the opportunity to think about their decision (allowing at least 24 hours between showing interest and the scheduled interview). Then, when they arrive at the interview, and prior to starting the WDSI, they will review the information sheet and consent form. If they are completing the WDSI online this is provided within the online survey. If they have chosen to complete a paper copy of the WDSI, a paper version of the information sheet and consent form will be used. Participants should be supported to go through the consent form and either in writing or verbally confirm that they would like to take part, as follows:

4.1 Completing the WDSI online using Qualtrics:

1. Ensure that participants are in a private, confidential and safe space.
2. Remind the person what the study is about and ask them to read the information sheet/read the information sheet aloud.
3. Assess their capacity to consent before proceeding (please read 'Capacity to Consent' below).
4. Explain that you will now go through the consent form where they will read statements/you will read aloud statements about taking part in the study. Remind them that they should ask you any questions if they do not understand.
5. Ask the participant to select the 'yes' box at the bottom of the consent form if they agree with all of these statements and are happy to continue.

4.2 Completing a paper version of the WDSI:

1. Remind the person what the study is about and ask them to read the information sheet/read the information sheet aloud.
2. Assess their capacity to consent before proceeding (please read section 2.3 'Capacity to Consent' below).
3. Explain that you will now go through the consent form where they will read statements/you will read aloud statements about taking part in the study. Remind them that they should ask you any questions if they do not understand.
4. If the participant cannot read or write, in order to obtain verbal consent, please follow the steps below:
    a. Read each statement to the participant and ask if they agree. (Follow the capacity to consent guidance below if they say they do not agree or are unsure.)
    b. Say that you are now pressing record. Explain that if they state their name this will be recorded "so that we have confirmation that you have agreed to take part in our research" but that 215akist will know what it is they say in the rest of the interview.
    c. Ask the participant to say their name when they get to the bottom of the page
5. If the participant is giving written consent on paper, please follow the process below:
    a. Give the participant a pen and the consent form.
    b. Ask them to sign and date the form at the bottom or insert the date yourself if needed.

4.3 Capacity to Consent

To take part in the project, all participants must have capacity to consent to all parts of the project.

Capacity to consent to research is the ability of a potential participant to understand and process the information that is necessary to make an informed decision regarding project participation.

When assessing a person's capacity to consent to take part, you should consider the following questions: can the person

1. **Understand** the information relevant to the decision?
2. **Retain** that information?
3. **Weigh** up the information as part of the process of decision making?
4. **Communicate** their decision?

With regards to participation in this project specifically, the person should be able to process the following key information and should broadly understand the implications:

- What the project is about, i.e. understanding the experiences of women with disabilities
- They will complete a questionnaire about themselves and personal experiences they may have had, this involves being asked lots of questions, some questions might make them feel sad. The
- answers to these questions will be kept private and used to help find out more about the experiences of women with disabilities.

How information is presented to a person can determine whether they appear to have capacity, since everyone processes information in different ways. Some may need support to go through the information sheet a few times, others may need visual prompts. It is therefore important to try to support a person to understand the research if they express interest and motivation to take part.

If, after such supportive attempts, you feel that the person does not have capacity to consent to participate, they will not be able to participate in the study, i.e. complete the WDSI.

5. Administering the WDSI

Information for people with disabilities should be tailored to the individual and so it is important for interviewers to think about the individual's needs. Prior to the interview, a member of the data collection team should discuss with the participant their preferences and needs so the appropriate materials and environment for the interview can be prepared.

5.1 Before Starting

1. Have a participant ID ready to enter on the paper WDSI
2. When the participant arrives, greet them and show them to where the interview will take place.
3. Clearly introduce yourself and thank them for coming.

4. As the WDSI asks about sensitive experiences, interviewers should seek to engage in general conversation with the participant to help build a trusting relationship. This is very important due to the sensitivity of the questionnaire. Interviewers should introduce themselves and ask how the participant would like to be addressed, and further questions like, their journey to the meeting.
5. Ask if there is anything else that they would like you to know before starting the interview and respond to any suggestions.
6. Go through the participant information sheet and consent form together (see section above on obtaining informed consent). This should include reminding the participant:
    i. That they do not have to answer a question if they do not want to, but that it would be helpful if they could answer as many questions as they can. Agree how they will tell you if they don't want to answer a question.
    ii. Ask and agree how they will tell you if they need help or something explained.
    iii. There is no right or wrong answer, the questions are about them and how they feel.
    iv. Remind about confidentiality (that the answers will only be shared with the study team).
    v. Let them know that the interview could last up to an hour. Agree how the participant will let you know if they would like to take a break.

Where key terms like stigma, discrimination, disability are used for the first time, make sure that you have read out the definition of this term provided/check that they have read and understood these terms.

7. Ask if they have any questions and respond to any questions.

5.2 Responding to Participants

1. If at any point the participant's response is not clear, please check your understanding by asking the participant to repeat their answer, asking the question in a different way or reading aloud the response options.
2. Ensure neutrality throughout the interview to avoid participants tending to give you the answers they think you want to hear; do not hint towards one response or another and do not appear to disapprove of responses.
3. If a participant provides an irrelevant answer, do not interrupt but rather ask questions to redirect the discussion to the original questions.
4. If at any point throughout the interview you conclude that the participant does not understand the questions and/or response scale after all efforts have been made to support their understanding, sensitively discontinue administration of the WDSI and thank them for their time.
5. Some of the key questions may cause some participants to feel upset. If you notice that a participant is answering 'prefer not to say' for many of the questions, this may be a sign that they have had difficult experiences that they are not ready to speak about. It is important not to pressure participant's into answering these questions, which is why the 'prefer not to say' option is included, but it may be important to make sure at the end of the interview that the participant knows where she can seek further support (repeat this a few times to make sure that she can remember the information if she does not want the details of services in written format). After each section, you should check

how the participant is feeling by asking e.g., “are you OK to continue?”. If the participant becomes upset during a section, how you respond to this is dependent on how upset the participant appears (mild/ very upset).

4. If the participant appears to be mildly upset whilst completing the questionnaire, you should acknowledge and validate this. Listen to their concerns and give them time to respond. For example, you could say “I’m sorry, some of the questions can be upsetting”, then ask if they would like to take a break. If they do not want a break, or after having a break, ask “are you happy to continue or do you want to stop here?”. Remind the participant that they do not have to answer a question that they do not want to and about confidentiality.

6. If the participant appears very upset, you should acknowledge and validate this as described above, then suggest taking a break. After a short while, ask the participant “do you feel better now?” or “Is there anything I can do to help?”, or “is there someone else you would like to speak to?” If the participant does not respond to your attempts to settle them, and they continue to be very upset, contact your manager for advice. You should also remind the participant that you can provide them with information on further support and ask if they would like you to do this.

7. Whilst field testing the WDSI, it is important for us to find out about the experience of completing it. As such, whilst completing the interview, if you notice that particular questions or sections are difficult for participants to complete e.g., because they are upsetting or because they don’t understand the question, please note down the details of your observations.

5.3 Administering the Survey: Step by Step

It is important that the wording and the sequence of questions is kept the same. Do not skip any question in the survey and don’t assume a respondent’s answer.

1. Ask if they are ready to start the interview. OK, let’s start....

2. You will first need to enter the participant ID. You can explain to the participant that we add a number to each person’s survey so that we keep them confidential

3. About You Domain

Move to the ‘About You’ section, tell the participant: “The first questions are about you.” Proceed by reading the introduction to the About You section. Ask the questions in order and select the answer that best represents the participant’s response.

When the about me questions are completed, say- “Ok, we finished the first set of questions. The next questions will be a bit different, and I want to tell you how they work.” Then move to the Disability domain.

4. Disability Domain

Read the introduction to the Disability domain, including the definition of disability. Check the participant’s understanding of the term disability.

The WDSI uses the Washington Group Short Set (WG-SS) of questions to provide a framework to identify the type of disability that the participant has. The intention with the Short Set questions is to record, with the exception of seeing and hearing, difficulties people have with unaccommodated functioning **(without the use of assistive devices or assistance**).

The WG-SS wants to be able to identify difficulties in functioning that may put a person at risk of limited or restricted participation. That risk of restricted participation – in the absence of accommodations – is 'disability' as defined by the UN Convention on the Rights of Persons with Disability (CRPD).

The domains of seeing and hearing are handled differently. In many cultures, both glasses/lenses and, to a lesser extent, hearing aids are commonly used and in most cases the use of these devices, especially glasses, is able to correct the difficulty almost completely. For this reason, for the questions about seeing and hearing difficulties, a difficulty will only be identified if the participant says that they have difficulties seeing and hearing even when they are using glasses/lenses or a hearing aid. However, in places where glasses or hearing aids are not common, these clauses are removed.

The types of disability are defined as problems with:

1) **Seeing:** Includes people who have some difficulty seeing which impacts on their daily life. For example, they may be blind or unable be able to read or see signs properly (even when wearing glasses or contact lenses).

2) **Hearing:** Includes people who have some difficulty hearing which impacts on their daily life (even when wearing a hearing aid). They may be unable to hear with one ear or both. For example, they may be deaf or have difficulty hearing someone talking in a busy place.

3) **Mobility:** Includes people who, in the absence of assistive devices like a crutch or wheelchair, have difficulties moving which impacts on their daily life. For example, a physical disability that causes difficulties walking a short distance without a break, or going up and down stairs. It also includes people who cannot use their hands and fingers for holding tools, writing, etc., or to raise items at and above eye level.

4) **Remembering and Concentrating**: Includes people who, without the support of adaptations, have difficulties in memory, concentration, decision-making, understanding speech, reading, directions and using a map, making calculations, and reading.

5) **Communication:** Includes people who, without adaptations, have difficulties exchanging information and ideas with others through the use of speech.

Explain that these questions are different, and you will ask them about some common difficulties. The response options are different too and they can respond by saying: *No difficulty, Some difficulty, A lot of difficulty, Cannot do at all, Don't know, Prefer not to say.*

If a difficulty is identified in this section, you will ask the participant the follow up question of 'How long have you had this difficulty?'. Please then select either 'from

birth' or enter the age that the participant acquired this difficulty. It is OK if they cannot remember exactly.
Once you reach the question 'Are any of your difficulties visible to other people?' the response options change to *Yes, No, Don't know, Other (please specify), Prefer not to say*. Let the participant know that the next questions ask a bit more about their difficulties. Ask the question and select the answer that best represents the participant's response.

At the end of this section, there is an opportunity to collect the participant's feedback on how they are finding answering the questions so far. Introduce this by saying, "It would be helpful to have some feedback on how you are finding the interview so far...you can respond by saying fine, a bit poor, very poor". Ask, "How have you found answering the questions so far?" If they answer, 'a bit poor' or 'very poor' then ask the follow up question "Can you give any details?" and write down their response. Thank them for their feedback and let them know that they have finished that set of questions.

Move onto the About Experiences of Exclusion and Marginalisation domain.

5. About Experiences of Exclusion and Marginalisation

Read the introduction to the Experiences of Exclusion and Marginalisation domain, including the definitions of exclusion and marginalisation.
Explain that the response options are different in this section, and they can respond by saying: *Never, Rarely, Sometimes, Often, Always, Prefer not to say*. Ask the question and select the answer that best represents the participant's response.
If 'always', 'often' or 'sometimes' are chosen, you will ask a follow up question to see whether this is due to lack of opportunities or a lack of accessibility for women and girls with disabilities. Read the follow up question to the participant and select the option that best represents their response.

Following this, the questions ask *how often* the participant thinks that they have had these experiences because of some part of their identity. It could be helpful to remind them that they can respond by saying: *Never, Rarely, Sometimes, Often, Always, Prefer not to say*.
Let the participant know that they have finished the questions in this section, and move to the next section.

6. About Experiences of Abuse

Read the introduction to the Experiences of Abuse domain, including the definition of abuse. Emphasise that these questions ask if they **have ever** had certain experiences.
The first set of questions in this section relates to people that the participant is close to. Try to ensure that they understand who would come under this category. The response options are the same and they can respond by saying: *Never, Rarely, Sometimes, Often, Always, Prefer not to say.*

When you reach the question ‘Of people that you are close to, whose actions have been most hurtful to you?’, you can select multiple response options. Read the question. Then read the response options to the participant one by one and ask the participant to indicate whether or not the person/group has been hurtful to them. Select all of the people who they identify as being hurtful to them.

The second part this section asks about people that the participant does not know very well. Try to ensure that they understand who would come under this category. The response options are the same and they can respond by saying: *Never, Rarely, Sometimes, Often, Always, Prefer not to say*.

When you reach the question ‘Of people that you don’t know very well, whose actions have been most hurtful to you?’ you can select multiple response options. *R*ead the question. Then read the response options to the participant one by one and ask the participant to indicate whether or not the person/group has been hurtful to them. Select all of the people who they identify as being hurtful to them.

The final part of this section includes questions that ask about experiences of abuse *from anyone,* starting with the question ‘Has someone broken or prevented you from using a wheelchair, walking stick, respirator, or other assistive devices?’. Let the participant know that the questions have changed and are now asking whether anyone has ever done hurtful things to them. The response options are the same and they can respond by saying: *Never, Rarely, Sometimes, Often, Always, Prefer not to say*.

For this question and the next question (Has someone you depend on refused to help you with an important personal need), if the participant responds with sometimes, often or always, then you will ask a follow up question to ascertain who has acted in this way towards the participant. *R*ead the follow up question. Then read the response options to the participant one by one and ask the participant to indicate whether or not the person/group has done these things to them. Select all of the people who they identify .

Following this, the final questions in the section ask *how often* the participant thinks that they have had these experiences of abuse because of some part of their identity. It could be helpful to remind them that they can respond by saying: *Never, Rarely, Sometimes, Often, Always, Prefer not to say*.

At the end of this section, there is an opportunity to collect the participants feedback on how they have found the questions, *since they were last asked*. Introduce this by saying, “It would be helpful to have some more feedback on how you have found this section of the survey...you can respond by saying fine, a bit poor, very poor”. Ask, “How have you found answering these questions?” If they answer, a bit poor or very poor then ask the follow up question “Can you give any details?” and write down their response. Thank them for their feedback and let them know that they have finished that set of questions.

7. About Experiences of Discrimination and Violence

Read the introduction to the Experiences of Discrimination and Violence domain, including the definitions of discrimination and violence. Emphasise that these questions ask if they **have ever** had certain experiences.

Explain to the participant that for this section they can respond by saying *Yes, No, Don't know, Prefer not to say*.

If the participant answers yes to the questions 'Has anyone made you engage in sexual activities (touching, kissing, hugging, sex) when you did not want to?', 'Has anyone made you feel bad about your body?' or 'Have you been denied sexual and/or reproductive health services e.g. menstrual hygiene care, family planning services, contraception?' then you will ask a follow up question to ascertain who has acted in this way towards the participant. *R*ead the follow up question. Then read the response options to the participant one by one and ask the participant to indicate whether or not the person/group has done these things to them. Select all of the people who they identify.

Following this, the final questions in the section ask *how often* the participant thinks that they have had these experiences of discrimination and violence because of some part of their identity. Explain that they can respond by saying: *Never, Rarely, Sometimes, Often, Always, Prefer not to say*.

Let the participant know that they have finished the questions in this section, and move to the next section.

8. Impact of COVID-19

Read the introduction to the Impact of COVID-19 domain. Emphasise that these questions ask about their experiences **since the start of COVID-19.**

Explain to the participant that for this section they can respond by saying *Yes, No, Don't know, Prefer not to say*.

At the end of this section, there is an opportunity to collect the participants feedback on how they have found the questions, *since they were last asked*. Introduce this by saying, "It would be helpful to have some more feedback on how you have found this section of the survey...you can respond by saying fine, a bit poor, very poor". Ask, "How have you found answering these questions?" If they answer, a bit poor or very poor then ask the follow up question "Can you give any details?" and write down their response. Thank them for their feedback and let them know that they have finished that set of questions.

9. Responses to Stigma and Discrimination

Read the introduction to the Responses to Stigma and Discrimination domain, including the definitions of discrimination and stigma. Emphasise that they are being asked how they feel *in general* about the statements.

Explain to the participant that for this section they can respond by saying *Yes, No, Don't know, Prefer not to say*.
Let the participant know that they have finished the questions in this section, and move to the next section.

10. Rights and Effecting Change

Read the introduction to the Rights and Effecting Change domain, including the definition of human rights.
Proceed by reading each right one by one. For each, ask the participant to respond with *Not at all aware, Somewhat aware, Very aware*.

Once you have gone through all of the human rights, explain that the next questions ask them some more about their rights. Explain that they can respond by saying: *Never, Rarely, Sometimes, Often, Always, Prefer not to say*.
Let the participant know that they have finished the questions in this section, and move to the next section.

11. Other Personal Experiences

Explain that you are coming towards the end of the interview. Read the final question, allowing the participant to share anything else that they feel that they have not had the opportunity to.
At the end of the survey, there is a final opportunity to collect the participant's feedback on how they have found the survey. Introduce this by saying, "It would be helpful to have some more feedback on how you have found this section of the survey...you can respond by saying fine, a bit poor, very poor".
Ask, "How have you found answering these questions?" If they answer, 'a bit poor' or 'very poor' then ask the follow up question "Can you give any details?" and write down their response. Thank them for their feedback and let them know that they have finished that set of questions.
Please also ensure that you, the data collector, enter your feedback in the space provided.

5.4 End of Interview

- Let the participant know that you have come to the end of the interview. Thank them for their time and remind them that the answers they have given will remain confidential.
- Information of available resources should be given only to respondents who feel happy and safe to take this information. Repeat the information to the participant a few times to make sure that she can remember it if she would like to hear about available support but does not want the details of services in written format.
- Show them out and ensure that they have made arrangements to travel to where they are going after the interview.

- Before submitting the online survey or inputting the data from a paper survey, please ensure that any personal information (names, addresses, reference to places that could make the person identifiable etc.) is removed.
- When sending the survey to researchers online

Appendix K – Ethical standards guide

Ethical Standards Guide for the ‘Addressing Stigma and Discrimination experienced by Women with Disabilities’ (ASDWD) Project

Prepared by Dr Aseel Hamid, Prof. Katrina Scior and Amy Dixon, University College London

The ASDWD project’s aims, within the framework of the multi-country programmatic funding support from the UN Partnership on the Rights of Persons with Disabilities Multi-Partner Trust Fund (UNPRPD MPTF), are in line with the UN Convention on the Rights of Persons with Disabilities (CRPD): to identify persons with disabilities and barriers that hinder their effective participation (Article 31[2]), and to produce the most effective interventions indicated. It also seeks to increase the availability of high-quality, timely and reliable data disaggregated by, amongst other criteria, disability[1] and gender, in line with the 2030 Agenda for Sustainable Development Goals[2]. The ASDWD project and work undertaken to develop and test tools and interventions to address the project’s aims must observe certain standards relating to ethical issues and data protection. A human-rights based approach, incorporating the Do No Harm (DNH) principle, must guide the conceptualisation and implementation of the ASDWD project to minimise risk. Doing no harm requires researchers, interviewers and others involved in the work to use methods and approaches to minimise the risk of harm at three levels:

a) the target population, including women and girls with disabilities and their family members and respective OPDs, civil society, policy and decision makers and all others who provide data as part of their participation in this project
b) those collecting data from the target population
c) the organisations responsible for the implementation of this UNPRPD funded initiative jointly led by UNDP and UN Women.

Transparency of the coordination of the national rollout and accountability to all stakeholders (national and international) forms the basis of the Ethics Task and Finish Group (ETFG), which will involve global, regional, and national partners from UNPRPD, UNDP and UN Women. This guidance draws on previous guidance detailed in the reference list, including from the UN Evaluations Group (UNEG)[3], the UN Ethics Office[4] as well as accepted international ethical standards which all researchers and ethical committees are expected to comply with when engaged in health research[5] and research with people with disabilities[6].

Ethical Standards

Four key concepts outlined below should be upheld throughout the research and evaluation process:

1) **Informed consent**. All participants must be fully informed as to what is being asked of them, including the topics discussed, who is involved, how data they provide will be processed and stored, and potential risks and benefits so that they can make a fully informed decision about whether they wish to participate. A sample information sheet and consent form for the project on measuring stigma and discrimination towards women with disabilities is provided in Appendices 1 and 2. Countries can translate and adapt these for use in their relevant contexts and for interventions delivered as part of this project. It is recommended to obtain informed consent in a format that is accessible to the individual concerned, for example either a signed form or an audio recording of their verbally given consent as evidence of informed consent – see section on 'Accessibility' below for more information on capacity and accessibility. Informed consent also emphasises that participation in the project is voluntary. This should be clarified in preliminary discussions with local stakeholders, and should continue through the recruitment and consent process, into the data-collection procedures. It should be made clear to all women and girls with disabilities that they may decline to join the study altogether, that they may decline to answer specific questions in a survey or interview, and that they may withdraw from the study. It must also be affirmed that participation or declining participation in the study will not have any negative impact on continued access to services[7], particularly in cases where an organisation is supporting a study (e.g., United Nations, local Ministry, or local OPD or NGO) is also providing a service to women and girls with disabilities, to avoid issues of coercion and/or undue influence.

2) **Benefit not harm**. There is a risk of potential psychological distress arising from sensitive questions being asked while being engaged as a participant in the project. Risk of harm to participants arising from investigating stigma, discrimination, gender-based violence (GBV) and other sensitive experiences must be balanced with the potential benefit to the overall community and must be minimised wherever possible throughout. This will be done during the conceptualisation phase through the selection of appropriate questions and wording, as well as during the implementation phase, through ensuring privacy and confidentiality of respondents, training of data collectors on issues such as verbal and non-verbal communication (active listening, validating, non-judgemental stance) and ethical and safety principles and mechanisms and how to manage any distress observed during data collection. In addition, establishing the availability of appropriate support structures for women and girls with disabilities who may need them, i.e. to provide appropriate signposting and/or referrals to relevant support systems where available, or what to do when such supports and services may not be in existence[8,9]. Data collectors should also be protected from harm; throughout the planning and implementation process consideration should be given to their training and support needs as they may be hearing information that could be distressing to them. Mechanisms for ensuring these will be further discussed and agreed upon while supporting the training of data collectors in each participating country.

3) **Confidentiality**. All participants have the right for their participation to remain confidential in that only the data collectors (and persons they choose to inform,

e.g., perhaps the person from a DPO who informed them about the project or trusted carer who they wish to accompany them) will be aware who has participated. Appropriate measures must be put in place to make certain that the information participants have shared, and their identity are kept confidential. This is particularly important for personal and sensitive data about women and girls with disabilities who are often at increased risk of discrimination based on their disability and gender, and who may be disclosing sensitive information in relation to GBV. As such, recruitment via word of mouth and using organisations' existing networks and collaborations may be more appropriate than e.g., public advertising of information about the project to ensure the privacy of women and girls with disabilities. Additionally, to ensure privacy, women and girls with disabilities should have the option to disclose, or withhold, information about their personal characteristics. Questions about personal characteristics should be voluntary and a non-response option should be provided. Categorising responses to such questions can support confidentiality (e.g., asking for age in age bands rather than specific numbers)[10]. Ensuring confidentiality includes how the data are collected, e.g., making sure that the interview location is private, how the data are stored (for example with names and other identifiers removed), and how the data about women and girls with disabilities are shared[7]. Country offices must follow retention policy guidelines for their office for the safekeeping and/or disposition of all records and documents[7]. Any personal data should only be used for purposes of analysis and be aggregated in a way that does not allow for the identification of individuals, for example by aggregating the data via subgroups[1,7].

4) **Data Protection/Data Transfer**. Countries should comply with internationally accepted regulations and good practice standards in the collection, storage, analysis, and reporting of data. Data protection legislation and procedures may vary significantly across countries, but all country offices (Cos) and local stakeholders should ensure that[1]:
    a. Data are processed in a transparent, fair, and lawful manner
    b. Data are collected for explicit, specific, and legitimate purposes
    c. The processing of the data is necessary and limited to the legitimate stated purpose
    d. Data are adequate, relevant, accurate, up to date and fit for the purposes of data processing
    e. The confidentiality of data is protected with appropriate measures that prevent unauthorized access, destruction, use, modification, or disclosure
    f. Data processors are accountable for any breach of the above principles (and must report all data breaches within 24 hours to the respective country office)
    g. Data subjects (i.e., participants) are granted the right to receive information about the data being collected and stored, to rectify incorrect or outdated information and to request the deletion of data unlawfully stored.

UN Ethics Group Ethical Principles

This guide is in line with the UN Ethic Group's (2020) four ethical principles[3]:

1) **Integrity**, where truthfulness, professionalism and independence, impartiality and incorruptibility are followed to mitigate any conflicts of interest or bias. Ongoing reflective practice is encouraged.
2) **Accountability**
    a. *Transparency* of the coordination of the national rollout and accountability to all stakeholders (national and international) is key. Roles, responsibilities, and reporting relationships need to be made clear wherever partnerships or alliances exist with OPDs or Ministries, to minimise the risk of conflicts of interest.
    b. *Responsiveness* to the methodology of tool and interventions as questions or feedback arise and, given that addressing GBV is a goal of this project, referring individuals to appropriate channels where sexual exploitation, abuse or other misconduct is identified is key.
    c. *Taking responsibility* for reporting potential or actual harms observed through the appropriate channels
    d. *Justifying* and fairly and accurately reporting to stakeholders (including women and girls with disabilities) decisions, actions, and intentions through the coproduction of material and summary reports. As part of a human rights-based approach, emphasis is placed upon transparency in the use of data to ensure accountability in policy implementation and enhance the capacity of women and girls with disabilities to engage in policy design and implementation[1].
3) **Respect**
    a. *Respect for persons*, which relates to respecting the autonomy and self-determination of participants, and protecting those who lack autonomy, including by providing security from harm
    b. *Access to* the process and outputs by all relevant stakeholders by ensuring accessible versions of material and reports
    c. *Meaningful engagement and fair treatment* of all relevant stakeholders, particularly women and girls with disabilities, in the evaluation processes from design to dissemination, so they can actively inform the evaluation approach and products rather than being solely a subject of data collection.
    d. *Fair representation* of different voices and perspectives in evaluation through ensuring intersectionality is captured and making adaptations to materials wherever possible.
4) **Beneficence**
    a. *Explicit and ongoing consideration of risks and benefits* of taking part and considering longer-term consequences.
    b. *Maximising benefits* of the project at systemic (including institutional), organisational and programmatic levels.
    c. *Doing no harm* and not proceeding in situations where harms cannot be mitigated
    d. *Ensuring evaluation makes an overall positive contribution* to the wider community and to the mission of the United Nations.

Accessibility

Providing support to enable persons with disabilities to participate meaningfully includes measures relating to universal design and accessibility[11]. Universal design enables multiple formats for data collection and information giving, changing the setting or format to accommodate participants[17], e.g., by having questions and response options read out by the survey software use to do away with the need for literacy skills). An example of an information sheet in an accessible format (Easyread) is available in Appendix 3. Research materials will be further elaborated and adapted in collaboration with women and girls with disabilities. More detailed guidance on accessibility considerations for persons with intellectual disabilities is available in The Listen, Include, Respect International Guidelines for Inclusive Participation[18].

All adults should be assumed to have mental capacity (i.e., the ability to make a particular decision at a particular time) unless and until they are shown not to. Capacity depends on understanding and understanding depends on **effective communication and accessible information as well as cognitive abilities. Article 12 of the CRPD affirms that all adults with disabilities have full legal capacity (i.e., the ability to hold and exercise rights and duties) on an equal basis with others in all aspects of life. The CRPD Committee General Comment 1 denotes that under Article 12, perceived or actual deficits in mental capacity should not be used as justification for denying legal capacity[11]. Persons with disabilities should be provided with access to support to exercise capacity and decision making[11]. The UN General Assembly Special Rapporteur report on legal capacity[12] set out means of supported decision making (see paras 28-33). It also noted that women with disabilities are at particularly high risk of substitute decision making (where a substitute decision maker appointed by a third party takes decisions based on what he or she considers to be in the best interests of the person concerned, even if it goes against the will of the latter) owing to gender stereotypes and GBV. The GBV Disability Toolkit[13] outlines ways of determining informed consent with survivors and what to do in situations where it is difficult to ascertain this. Standard operating procedures are encouraged in each CO to determine this.**

The overall scope of the ASDWD project is focused on women and girls with disabilities. Of note though, laws concerning capacity and consent in many countries make different provisions for minors. As such, if girls with disabilities are to be involved in this project as participants, the evolving capacities of children with disabilities (see CRPD Article 3[h]) must be considered carefully as do local legal provisions regarding research with minors. Further ethical and methodological considerations are provided in the UNICEF working paper on the Involvement of Children with Disabilities in Evidence Generation and Use[14].

The active and meaningful participation of people with disabilities, through their representative organisations, it at the heart of the CRPD[15] – accordingly, people with disabilities should participate in the design of research, evaluation and policies[1]. The

UN Disability Inclusion Strategy (UNDIS) Guidelines on Consulting Persons with Disabilities[16] provide in-depth guidance on why, when and how best to engage women and girls with disabilities and their respective organisations; all stakeholders of the ASDWD project who will be engaging with women and girls with disabilities and OPDs should familiarise themselves with these.

Safety

Safeguarding measures need to be put in place to ensure the safety and privacy of both participants and data collectors. The focus of the survey should be kept to stigma and discrimination in information sheets and discussions with participants (i.e., not specifically mentioning GBV). Ensuring privacy and safety of the setting in which data collection takes place is key; this should be agreed upon with the participant. Some women and girls with disabilities may choose to have a trusted caregiver or family member present with them during their participation; participants should be asked in advance and in private regarding their preferred arrangement. If they do choose to have someone present[13], care should be taken to ensure that the research process does not interfere with the relationship between the participant and her supporter or carer[5]. More detailed guidance on safeguarding and the presence of other trusted persons will be discussed and agreed upon in the training of data collectors.

Signposting to appropriate resources

Cos are responsible for putting together the resources and organisations available to women and girls with disabilities who participate in ASDWD and disclose safeguarding issues. Those collecting data from women and girls with disabilities are responsible for offering information on available resources and supports to respondents who wish to and who feel safe in receiving this information – they should be provided with such information during training and have an opportunity to practice managing potential distress presented by a participant. The international consultants will support Cos in providing more specific guidance during the training of data collectors regarding instances where a need for referral to services may arise. This will consider how UN focal points can facilitate this in parallel with confidentiality and safety considerations.

Making ethical decisions

While keeping these frameworks and guidance in mind for ethical implementation, there may be times when stakeholders are faced with difficult decisions. For example, if a woman with a disability discloses information that highlights that she is currently at risk of harm of violence, sexual exploitation, or abuse. This poses an ethical dilemma as it may not be possible to honour confidentiality and serve the best interests of the survivor. The World Health Organisation provide ethical and safety recommendations for research involving violence against women, which all data managers should become familiar with[19]. All UN personnel, volunteers and individuals involved in recruitment and data collection must familiarise themselves with the Inter-Agency Standing Committee's Minimum Operating Standards for Protection from Sexual Exploitation and Abuse (PSEA)[20]. A six-step model outlined by the UN Ethics

Office[4] helps data collectors and managers to think through difficult scenarios such as these. In addition, as well as considering the unique individual, family, community, cultural and spiritual setting that the survivor is based in, data collectors and managers must familiarise themselves with relevant country- and organisation-specific guidance on supporting survivors of GBV and advice should be sought from local disability and GBV experts. It is good practice to establish standard operating procedures for confidentiality in each country office prior to data collection.

Next steps: approval prior to data collection

NOTE: ALL COUNTRY OFFICES AND OTHER STAKEHOLDERS WITH RESPONSIBILITY FOR DATA COLLECTION, STORAGE, ANALYSIS AND/OR ANALYSIS MUST ADHERE TO CONTENTS OF THIS SECTION

This document provides some overall guidance for the ethical implementation at all levels of the research, implementation, evaluation, and reporting cycle of the ASDWD project. Prior to collecting data for the piloting or field testing of tools and interventions, Cos must ensure that all stakeholders involved are conforming to the country's ethical and data protection requirements. Those overseeing data collection are responsible for gaining ethical approval. Where available, institutional/organisation level ethical approval must be gained prior to data collection for the field-testing stages and, where unavailable, a letter of approval from the relevant implementing bodies must be gained. Appendix 4 contains a sample letter of approval for reference.

It is also recommended that, prior to data collection, questions for data collectors and managers in each CO are posed. Examples of these questions will be provided by International Consultants for Cos and national consultants to adapt, and they would enable ongoing reflection and preparation for potential issues such as in privacy, confidentiality, informed consent and study implementation and they facilitate the identification of vulnerable groups and individuals.

REFERENCES

[1] General Assembly Human Rights Council /49/60: Statistics and data collection under article 31 of the Convention on the Rights of Persons with Disabilities – Report of the Office of the United Nations High Commissioner for Human Rights.

[2] General Assembly resolution 70/1 paragraph 18. Transforming our world: the 2030 Agenda for Sustainable Development.

[3] UNEG (2020) Ethical Guidelines for Evaluation

[4] UN Ethics Office (2017) Putting Ethics to Work: A Guide for UN Staff

[5] CIOMS (2016) International Ethical Guidelines for Health-Related Research Involving Humans

[6] National Disability Authority Ethical Guidance for Research with People with Disabilities

[7] Practitioners Guide on Ethical Conduct of Research on Child Marriage in Humanitarian Settings

[8] World Health Organization (2001), Putting Women First: Ethical and Safety Recommendations for Research on Domestic Violence against Women.

[9] UN Women Violence Against Women and Girls Data Collection during COVID-19

[10] OHCHR Guidance Note on Approach to Data

[11] CRPD Committee General Comment 1

[12] Report of the Special Rapporteur on the rights of persons with disabilities

[13] GBV Disability toolkit

[14] UNICEF Office of Research-Innocenti Working Paper on Exploring Critical Issues in the Ethical Involvement of Children with Disabilities in Evidence Generation and Use

[15] CRPD Committee General Comment 7

[16] UN Disability Inclusion Strategy (UNDIS) Guidelines on Consulting Persons with Disabilities

[17] Conducting Accessible Research: Including People with Disabilities in Health, Epidemiological and Outcomes Studies.

[18] The Listen, Include, Respect International Guidelines for Inclusive Participation

[19] WHO Ethical and safety recommendations for intervention research on violence against women

[20] Inter-Agency Standing Committee’s Minimum Operating Standards for Protection from Sexual Exploitation and Abuse (PSEA)

Appendix 1: Sample Information Sheet for Participants (to presented in an accessible format as per the requirement of the person with disability)

Development of a Tool to Assess Prejudice and Discrimination Experienced by Women and Girls with Disabilities

What is the project about?

We are part of a project (hereafter called a ‘study’) to find out more about the lives of women with disabilities in this country and other countries. This study is led by the United Nations, who want to know more about the experiences of women with disabilities. This is to help them decide how best to seek positive changes to improve the lives of women with disabilities and stop or at least reduce discrimination they often face.

Researchers working with the UN have developed a new survey/interview *(delete as appropriate)* to help us to understand more. You are being invited to take part in the study to find out more about prejudice, discrimination and other negative things that often happen to women and girls with disabilities. Before you decide whether to take part, it is important for you to understand what taking part involves. Please take time to read/listen to the following information carefully. Please ask the interviewer if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The purpose of collecting information from you is to try to understand your experiences of prejudice, discrimination and other negative things that often happen to women and girls with disabilities.

The questions can be asked in different local languages and in adapted formats to ensure that everyone understands the questions. Your interviewer will talk to you about which format you would like to complete the survey in. (if you are completing this survey on your own and you would like to do so in a different format, please ask the person who told you about the study.)

Your interviewer will go through the questions with you. This may take about an hour. First, you will be asked to answer some questions about yourself. Then you will be asked some questions about your disability, for example the length of time you have lived with your disability. Next, you will be asked questions about your disability and about any negative experiences and discrimination because of your disability or because you are a woman or girl.

While your interviewer will know what you tell them, all the information that is collected will be kept anonymous – that means no one will know you took part or that it was you who said certain things. If you complete the questions on your own, please do not give your name or any details that will tell people who you are.

Where can I take part?

A member of the study team will arrange a time and place suitable for you to complete the interview/questions. This can be done over the phone, the internet or in person, as you prefer.

Why have I been chosen?

We are hoping to hear from women and girls aged 18 and above, who live in Moldova/ Pakistan/ Palestine/ Samoa *(delete as appropriate)*, and who have some form of disability. You must be able to understand what it says in this Information sheet and consent (that means agree of your own free will) to taking part in the study.

Do I have to take part?

No. It is completely up to you to decide whether to take part or not; choosing not to take part will not disadvantage you in any way. If you do decide to take part, you are still free to stop at any time and without having to give a reason.

What are the benefits of taking part?

Taking part will help the United Nations and others to recognise negative experiences women and girls with disabilities may have and to understand how they affect them. It may also help to push for positive change and ensure women and girls with disabilities have equal rights.

What are the possible disadvantages and risks of taking part?

You will be asked questions about your disability and negative experiences you may have had. Some of the questions are very personal and some may make you feel uncomfortable and upset. Please let your interviewer know if you would like to pause or stop the interview at any time. They will listen and stop and will also make sure that you know where else to get support.

What happens to the information that I give?

All information you give will be treated as confidential and kept in line with data protection laws. This means the information you give will be well protected. Noone will be able to know that you took part or that it was you who said certain things.

What will happen to the results of the study?

The results of this study will be written up as a report. They will also be shared through talks at events such as conferences so that others can here about the lives of women and girls with disabilities and negative experiences and discrimination they often face. In the report no one will be able to identify any of the women or girls who took part.

Who is organising and paying for the study?

This study is organized and paid for by the United Nations Development Programme (UNDP) and UN Women and is funded by UN PRPD. The study has been approved by XXX *(please insert).*

Further information and Contact details

If you have any questions or would like further information, please feel free to contact

Name, Email, Phone Number. *(please insert)*

Thank you for taking the time to read this information sheet. Your help makes this study on an important cause possible

Appendix 2: Example Consent form (to be adapted as necessary for functional capacity)

Consent Form: The Development of a Measure to Assess the Stigma Experienced by Women and Girls with Disabilities

Please complete this form after you have read the Information Sheet OR the interviewer has read the Information Sheet to you and you have listened to the description of the study given by the interviewer.

Thank you for your interest in taking part in this project. If you have any questions about the project, please ask the interviewer before you decide whether to join in. You will be given a copy of this Consent Form to keep.

Participant's Statement

I: ………………………………………………………………………………. (please print name)

- agree that the project has been explained to me;
- have read the Information Sheet OR the interviewer has read it to me;
- understand the project and what it involves;
- understand that I will be asked questions about my experiences that could be upsetting and that I will be supported should I become distressed during the project;
- understand that if at any time I no longer want to take part in the project, I can tell the interviewer and withdraw immediately without giving a reason;
- understand that I can withdraw my data up to 4 weeks after the interview;
- consent to the processing of my anonymised information for the purposes of this project;
- understand that the information I give will be treated as strictly confidential and handled in accordance with the Data Protection Act 1998;
- agree to take part in this project.

By signing below, I am confirming that I understand and agree to all of these statements.

Name of participant	Date	Signature
Name of interviewer	Date	Signature

Appendix 3: An example of an adapted Information Sheet (Easyread)

Information About Our Research

Please read/listen to the following information.

Ask the interviewer if there is anything that is not clear or if you would like more information.

What is the research about?

We are doing research with the United Nations. Research means finding out about things.

We are doing research to find out more about the experiences of women with disabilities.

This is to help improve the lives of women with disabilities.

We have developed a new survey to help us to understand more.

You are invited to complete this survey as part of our research to see if the survey is useful and should be used in the future.

Before you decide whether to take part in the project, it is important for you to understand why it is being done and what it will involve.

What the research involves

Your interviewer will go through the survey with you.

This will take about 60 minutes.

Your interviewer will ask you questions about:

- you, like how old you are
- your experiences, like the length of time you have lived with your disability
- some experiences that you may have had because of your disability
- how you feel about your disability
- some experiences that you may have had because you are a female

Please tell your interviewer if there are any changes to the way that they communicate with you that could help you to complete the survey.

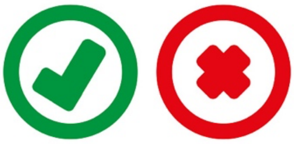
What we will do with your answers

Your answers will be confidential. This means that we don't share your answers with anyone. Only people involved in the research will see your answers.

We will not use your name in our report and only your interviewer will know that the answers come from you.

Choosing to take part in the research

You can choose if you want to take part in the research. It is up to you.



You can say no. If you say no, you will not be treated differently.

If you say yes, you will be asked to sign a consent form.
This consent form says that you agree to take part in the research.

Changing your decision

You can stop taking part in the research. You do not need to tell us why.

You can tell us to destroy any information that we have about you.

Things that might be difficult

You will be asked to answer questions about your disability and experiences.

This could be upsetting or make you feel sad. Please tell the person asking you questions about anything you find hard or sad. They will make sure you have someone to talk to.

You can take a break or stop the interview at any time.

Good things about taking part

Your answers will help us to understand your experiences.
They will help us to make the survey better.

What we find through the research might help women with disabilities.

How to make a complaint

If there is a problem, please talk to your interviewer about this.

You can contact:

We will do our very best to sort out the problem.

We will tell you when we think the problem has been fixed.

Appendix 4: sample approval letter

Research approval letter

[Date]

To: [CO contact person, CO address]

Dear [CO contact person],

RE: Addressing Stigma and Discrimination experienced by Women with Disabilities (ASDWD) Project

I am writing in response to the request for authorisation of data collection for the activities related to the project on **Addressing Stigma and Discrimination experienced by Women with Disabilities (ASDWD) Project**, a project run jointly by UNDP and UN Women and funded by UN PRPD.

After close review, I am glad to inform you that the [ethical committee/trustees/board members] at the [host organisation] has approved the data collection for this project in line with our ethics considerations. The [host organisation] recognises the importance of the project to describe the discrimination experienced by women with disabilities and the develop interventions to combat this.

Please keep the [host organisation] informed on the outcomes of the project. I look forward to the report and recommendations that will be generated from the study.

Best regards,

[Host organisation contact person]

Appendix L – Images from data collection

Appendix M – Information sheet used in Pakistan

Women with Disabilities Stigma Inventory: Information for Participants

What is the project about?

This project (hereafter called a ‘study’) seeks to find out more about the lives of women and girls with disabilities in this and other countries. A ‘disability’ is any condition that makes it more difficult for a person to do certain activities and interact fully with the world around them. It results from the interaction between personal limitations and negative attitudes and barriers that hinder the person’s full and effective participation in society on an equal basis with others. A disability will have been around for at least 12 months and likely longer – it’s not a short-term illness.

Before you decide whether to take part, it is important for you to understand what taking part involves. Please take time to read/listen to the following information carefully and to ask if anything is not clear, or if you would like more information.

What is the purpose of the study?

This study is led by the United Nations to help them decide how best to seek positive changes to improve the lives of women with disabilities. Discrimination means treating a person unfairly because of who they are or because they possess certain characteristics. Researchers at University College London, working with the United Nations, have developed a survey to help us to understand more about the experiences of women and girls with disabilities.

What is involved in taking part?

Completing the survey may take about 30 to 60 minutes. You can have a break any time – if you are completing the survey with an interviewer, just let them know you would like a break. First, you will be asked to answer some questions about yourself. Then you will be asked some questions about your disability. Next, you will be asked questions about experiences that you may have had because of your disability or because you are a woman or girl or because you are a woman/girl with disability.

Why have I been chosen?

We are hoping to hear from women and girls aged 18 and above, who live in Pakistan, and who have some form of disability. You must be able to understand what it says in this information sheet and consent (that means you agree of your own free will) to taking part in the study.

Do I have to take part?

No. It is completely up to you to decide whether to take part and choosing not to will not disadvantage you in any way. If you do decide to take part, you are free to stop at any time and without having to give a reason.

What are the benefits of taking part?
Taking part will help the United Nations and others to recognize negative experiences women and girls with disabilities may have and to understand how they affect them. It may also help to push for positive change and ensure women and girls with disabilities have equal rights. Rights are things that we all should be able to have or do.

What are the possible disadvantages and risks of taking part?
Some of the questions you will be asked are personal and some may make you feel uncomfortable and upset. Please let your interviewer know if you would like to pause or stop the interview at any time. They will stop and make sure that you know where else to get support.

What happens to the information that I give?
While your interviewer will know what you tell them, all the information that you give will be kept anonymous – that means no one will know you took part or that it was you who said certain things. If you complete the questions on your own, please do not give your name or any details that will tell people who you are. All information you give will be treated as confidential and kept in line with data protection laws. This means the information you give will be well protected. The anonymous information will also be shared with the researchers at University College London, who will do some more in-depth analysis. They will not be able to tell who took part in the study.

What will happen to the results of the study?
The results of this study will be written up as a report. They will also be shared through talks at events such as conferences so that others can hear about the lives of women and girls with disabilities and discrimination they often face. In the report no one will be able to identify any of the women or girls who took part.

Who is organizing the study?
This study is led by the United Nations Development Programme (UNDP) and UN Women and is funded by UN PRPD.

Further information and Contact details
If you have any questions or would like to make a complaint, please feel free to contact:

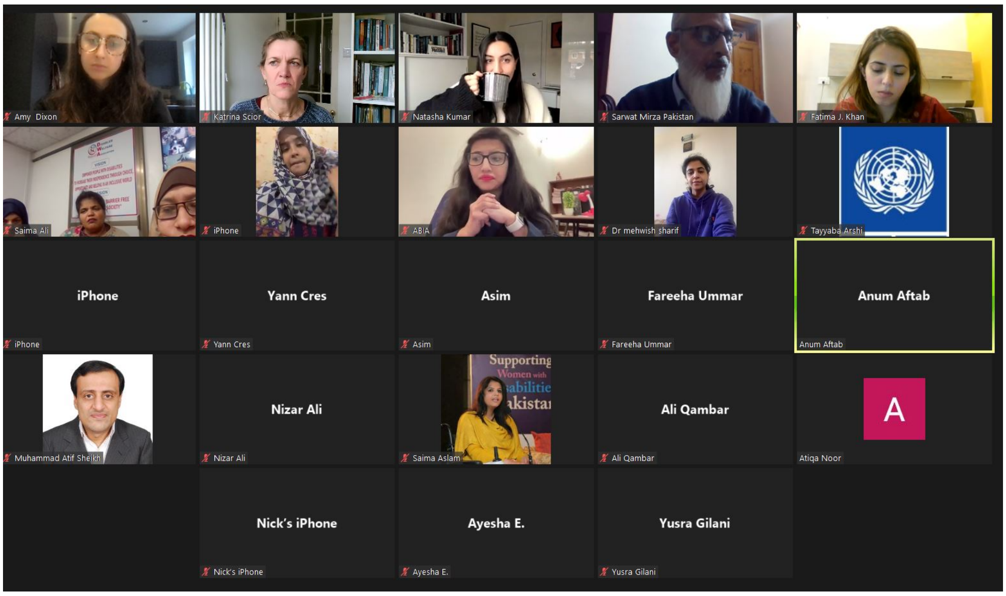
Lema Jan
Email: lema.jan@undp.org
Tel: +92-3409823655

Anum Aftab
Email: anum.aftab@unwomen.org

They will do their best to address your concerns.

Thank you for taking the time to read/listen to this information sheet.

Appendix N – Image from enumerator reflective space



Appendix O – Enumerator feedback survey

Enumerator Feedback

Thank you for being part of the project aiming to hear about the experiences of women with disabilities in your country using the Women with Disabilities Stigma Inventory (WDSI).

We would really like to hear about your experiences of being part of the project and using the WDSI. We hope that your feedback will enable important learning about using the WDSI and how to support enumerators.

This short survey should take you no longer than 15 minutes to complete. The answers will be shared with UN partners at University College London.

Please avoid using any names or other identifiable information in your answers, so that the information provided can remain anonymous.

Q1 How satisfied were you with the training you received before the interview(s)?

○ Extremely satisfied

○ Somewhat satisfied

○ Somewhat dissatisfied

○ Extremely dissatisfied

○ Prefer not to say

Q1a

Please answer this question if you answered Q1 Somewhat dissatisfied or Extremely dissatisfied

What aspects of the training were you unhappy with?

Q2 To what extent did the training cover the skills that you needed to interview respondents?

○ Completely

○ Mostly

○ Somewhat

○ Not at all

○ Prefer not to say

Q3 Did the training help you to think about ‘do no harm’, for example how to ensure that the interview was kept private and how to respond to any distress during the interview?

○ Yes

○ Somewhat

○ Not at all

○ Prefer not to say

Q4 Is there anything else that you would like to tell us about the training you received, or how future training could be improved?

Q5 How many interview(s) did you conduct?

Q6 Where were the interview(s) conducted? (e.g. in participants’ homes, in a community centre)

Q7 Was anyone else present during the interview(s)?

○ Yes, always – please specify who and why

○ Sometimes – please specify who and why

○ No, never

Q8 What was the **shortest time** the interview(s) took to complete?

○ 15-30 minutes

○ 31-45 minutes

○ 46-60 minutes

○ 61-75 minutes

○ 76-90 minutes

○ 91+ minutes

Q9 What was the **longest time** the interview took to complete?

○ 15-30 minutes

○ 31-45 minutes

○ 46-60 minutes

○ 61-75 minutes

○ 76-90 minutes

○ 91+ minutes

Q10 How long did the interview(s) take on average?

○ 15-30 minutes

○ 31-45 minutes

○ 46-60 minutes

○ 61-75 minutes

○ 76-90 minutes

○ 91+ minutes

Q11 Did you have to pause any interview(s) at any point?

○ Yes, I had to pause the interview(s) a lot – please state the main reason you had to pause

____

○ Yes, I had to pause the interview(s) at least once – please state the main reason you had to pause

____

○ No

Q12 Were you told anything highly sensitive or that surprised or even shocked you during the interview(s)?

○ Yes, a lot of things

○ Yes, a few things

○ No

Q12a

Please answer this question is you answered Q12 Yes, a lot of things or Yes, a few things

In broad terms, what did this relate to?

Q12 Did you experience any problems during the interview(s)?

Yes, a lot – please specify

Yes, a few – please specify

○ No

Q13 Was support available to you should you need it during an interview?

Yes – please specify what support was available

○ No

○ Unsure

Q14 Is there any support that you would have liked to have received that was not available during the interview(s)?

○ Yes – please specify

____

○ No

○ Unsure

Q15 Is there anything else you would like to share about your experience of conducting the interview(s)?

____

Q16 How did you feel immediately after the interview(s)?

____

Q17 Have you had a chance to talk to someone about the interview(s) and how the interview(s) left you feeling?

○ Yes

○ No

○ Unsure

Q18 How do you feel now about the interview and your role in the project?

____

Q19 Is there any support that you would have liked to have received that was not available after the interview(s)?

○ Yes – please specify

○ No

○ Unsure

Q20 If an opportunity was offered to meet with other enumerators to share your experiences and views about the interviews (and the project more generally), how likely would you be to attend?

○ Very likely

○ Somewhat likely

○ Unlikely

○ Unsure

Q20a

Display answer this question you answered Q20 as Very likely or Somewhat likely

Would you prefer to meet with a small group of enumerators from your organisation or all of the project enumerators (up to 13)?

○ A small group from my organisation

○ All project enumerators

○ Either

○ Unsure

Q21 Is there anything else that you would like to tell us about the interviews or your role in the project?

Thank you for taking the time to complete this survey

Appendix P – Enumerator survey results

UN Women and UNDP Pakistan Summary of Enumerator Feedback

Aim

An enumerator feedback survey was distributed to the 13 individuals (hereafter 'enumerators') who collected data using the Women with Disabilities Stigma Inventory (WDSI) on behalf of UN Women and UNDP, as part of the project on Addressing Stigma, Discrimination and Violence for Empowering Women with Disabilities (ASDWD). The aim was to understand more about enumerators' experiences of being part of the project and in particular using the WDSI with women with disabilities.

Enumerators for UN Women collected data from women with disabilities residing within the villages in rural areas of Sanghar or those accessing services from the HANDS Independent Living Centre in Hyderabad, Sindh Province. Enumerators for UNDP collected data from women with disabilities living in urban and rural areas in and around Quetta, Balochistan Province. All participants were already known to Civil Society Organisations (CSOs), such as the organisation STEP.

This report summarises the feedback from the eight enumerators who collected data on behalf of UN Women Pakistan, and the five enumerators who collected data on behalf of UNDP Pakistan.

Training

A one and a half day training was provided for enumerators prior to data collection. The training was focussed on familiarising the enumerators with the WDSI and building their skills for administering the survey. This included an overview of the project aims, ethical considerations like ensuring privacy and confidentiality during the interviews, building rapport with participants, and ensuring that the enumerators knew where to seek support should the interview be upsetting for the participants and/or enumerator.

The first set of questions asked enumerators for their feedback on the comprehensiveness of the training that they received before collecting data from women with disabilities.

Six enumerators from UN Women and one enumerator from UNDP were extremely satisfied with the training they received. Four were 'somewhat satisfied' with the training and none were dissatisfied. Enumerators reported that the training covered most of the skills that they needed to interview women with disabilities; see Figure 1.

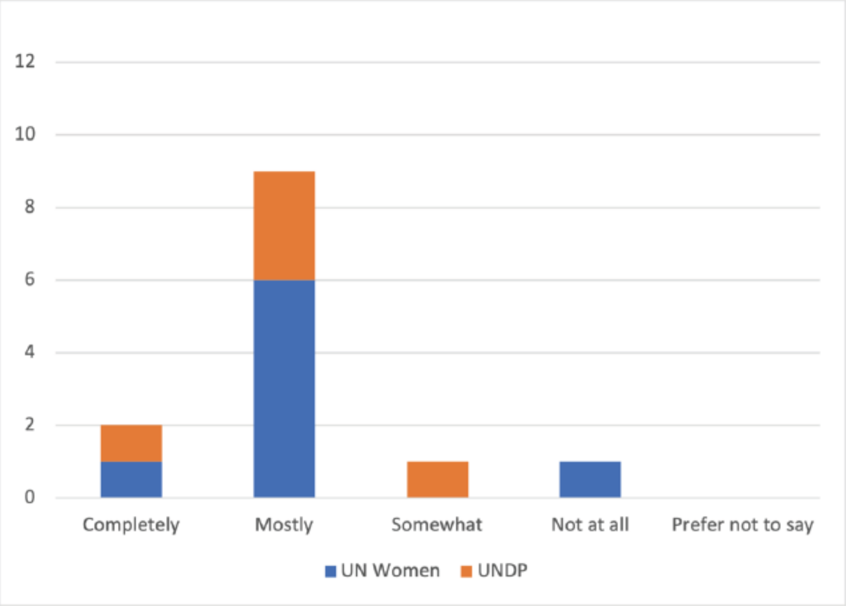


Figure 1
Responses to question: “To what extent did the training cover the skills that you needed to interview respondents?”

Finally, six of the eight enumerators from UN Women and three of the five enumerators from UNDP felt that the training helped them to think about the 'do no harm' principle, for example, how to ensure that the interview was kept private and how to respond to any distress during the interview. The remaining four enumerators thought that the training was somewhat helpful in supporting them to think about ethical considerations for the interviews.

Overall, the feedback about the training was very positive, with enumerators highlighting that they learnt about the realities of the lives of women with disabilities and their rights, and that the training helped prepare them to collect sensitive information from women with disabilities.

When asked what could be done to improve the training, several enumerators reported that they would have liked more training on how to build trust with interviewees to support them to share their stories more openly. One enumerator suggested that more practice focussed on interviewing skills could have been incorporated into the training. One enumerator felt that some of the terminology in Urdu was difficult to understand.

Administering the WDSI

The next set of questions asked enumerators about their experiences of administering the WDSI.

Three of the eight enumerators from UN Women and four of the five enumerators from UNDP reported that they had to pause an interview at least once. The reasons for this varied with two enumerators stating that they paused an interview because they were unsure how to proceed when they felt that a participant was avoiding answering the questions, particularly those relating to experiences of abuse. One enumerator paused an interview to ensure confidentiality because a third person had entered the room. Another enumerator paused an interview because the participant became very emotional.

As displayed in Figure 2, 10 out of the 13 enumerators were told highly sensitive information during the interviews, relating to gender-based violence, abuse and disability discrimination. Additionally, enumerators noted that what they heard about family members' behaviours towards women with disabilities at times was shocking to them.

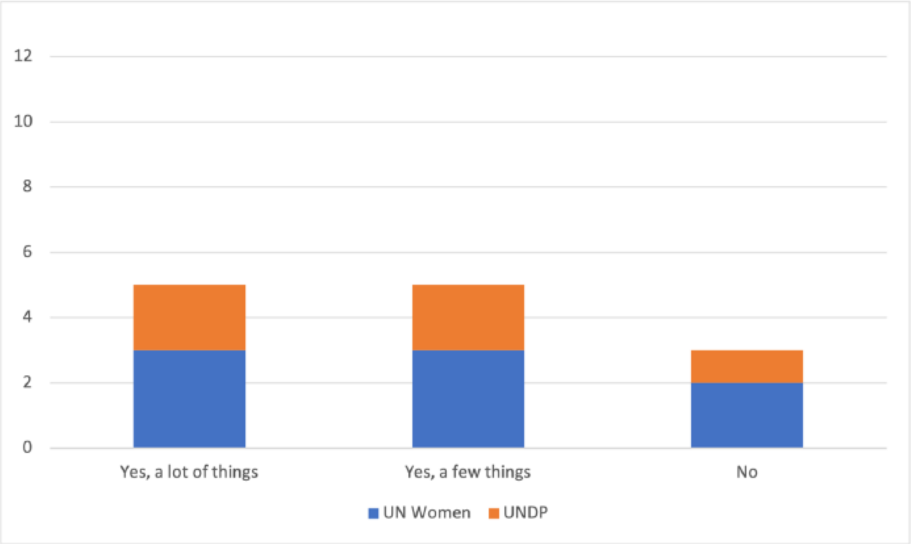


Figure 2
Responses to question "Were you told anything highly sensitive or that surprised or even shocked you during the interview(s)"?

Three enumerators from UN Women and one enumerator from UNDP experienced a lot of problems during the interviews, two reported a few problems, , with seven reporting no problems. The most significant problem highlighted was the reluctance of women being interviewed to share their stories with the enumerators. One enumerator felt that this was because participants found it hard to trust that the enumerators would not humiliate them. Another felt that participants did not understand some of their questions.

Of the enumerators from UN Women, six reported that support was available to them during the interviews, provided by the project team. While five said they were happy with the support available during the interviews, three would have liked further support to enable them to signpost women with disabilities to entrepreneurship and capacity-building opportunities.

One enumerator from UNDP said that support was available to them during the interviews, whilst the remaining four were unsure. Only one enumerator said that they would have liked additional support (a psychiatrist and motivational speaker were mentioned).

In summary, enumerators felt privileged to meet women with disabilities and hear their stories. They were proud to be part of the project and hopeful that more interviews could be conducted to hear from more women with disabilities. One enumerator felt that most women with disabilities do not share their experiences with anyone.

Impact on enumerators and Post-interview Support

In the final section of the survey, enumerators were asked about the impact that talking to women with disabilities had on them, and post-interview support.

Enumerators emphasised the emotional impact that their role had on them, sharing that they felt “very sad”, “heartbroken”, “heavy” and “traumatised” immediately after the interviews due to the stories that they heard and having witnessed how prejudices in society are impacting women with disabilities. Concurrently, they liked the experience of talking to women with disabilities about their rights.

For some, conducting the interviews was overwhelming as they were also women with disabilities and could relate to the stories being shared.

At the time feedback was given, the enumerators felt “motivated”, “responsible” and “empowered” to be part of initiatives and to try to make a difference to the lives of women with disabilities. They felt that the information they had gathered was valuable and important and could be used positively within the project. They were pleased that they were able to listen to women with disabilities. Three enumerators highlighted the positive impact that their involvement in the project had had on them, including increased confidence.

Ten of the 13 enumerators had talked to someone about their feelings in relation to the interviews.

Of the enumerators from UN Women, seven said that, if offered, they would be very likely to attend a meeting with other enumerators to share their experiences and views about the interviews and the project more generally. The final enumerator said that they would be somewhat likely to attend. Three enumerators noted they would prefer to meet with a small group from their organisation, three preferred to meet with all 13 enumerators (across UN Women and UNDP), and two were happy with both options.

All five enumerators from UNDP said that they would be very likely to attend a meeting with other enumerators to share their experiences and views about the interviews and project more generally. Four said that they would prefer to meet with all 13 enumerators (involved across UN Women and UNDP), and one was happy to meet as either a large or small group.

Conclusion

In summary, 13 enumerators shared their experiences of administering the WDSI. Their feedback emphasises the emotive and sensitive nature of the interviews they conducted and raises important ethical considerations about the support provided to enumerators before, during and following such interviews. There is a consensus in the feedback that enumerators would like a meeting to discuss their experiences, although the group from UN Women were split as to whether this would be best offered in small groups or as one large group, whereas the majority of enumerators from UNDP would prefer to meet as a large group.