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Social model of disability: review of disability models and survey questions

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Social model of disability: review of disability models and survey questions

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Table of contents

1. Introduction and background

The Equality, Race and Disability Evidence Units within the Welsh Government have commissioned the National Centre for Social Research (NatCen) to develop and test a set of survey questions that collect data on impairments and barriers experienced by disabled people.

Across the UK, data collection and the generation of statistics relating to disabled people are currently aligned with, and influenced by, the Equality Act (2010), and by extension, the medical model of disability. The questions that tend to be used are the Government Statistical Service (GSS) long-lasting health conditions and illness harmonised standard and the activity restriction harmonised standards, or the impairment harmonised standard.

Welsh Government adopted the social model of disability in 2002, making Wales one of the first countries in the world to do so. This model makes an important distinction between ‘impairment’ and ‘disability’ and recognises that people with impairments are disabled by barriers that commonly exist in society. The social model was developed by disabled people and is enshrined in the UN Convention on the Rights of Disabled People (UNCRDP), to which the UK is a signatory.

Welsh Government have identified that new questions are required to ensure the social model is reflected in its actions, data collection, and decision-making, and in the delivery of all services across Wales.

The aim of this project is to develop standardised survey questions that reflect the social model of disability, with the objective to use these questions in, where relevant, future social research conducted or commissioned by Welsh Government and in data collection via surveys. These questions will be shared with others including public bodies, the third sector, and other producers of statistics so they can be used more widely. Learning from this research will be shared to support the embedding of the social model within research and data collection more broadly across government.

1.1. Research overview

This research is divided into 2 stages. An initial ‘discovery’ phase aimed to assess what models and survey questions are available, and the requirements users of data and disabled people for disability-related questions. This is to be followed by the ‘alpha’ phase, where new questions based on the social model of disability will be developed and tested.

The discovery phase comprised of 3 consecutive, related, work packages:

- work package 1 (WP1): mapping data user needs and literature review
- work package 2 (WP2): review of existing survey questions
- work package 3 (WP3): deliberation workshops with disabled people

This literature review was undertaken in the early stages of the discovery phase. Within this context, the purpose of this literature review was to map what different models of disability exist in recent literature and explore how these align to existing surveys. Findings from this literature review supported the direction of future research activities. Welsh Government have published the findings from the rest of the discovery phase as a separate, standalone, report.

The aim of this review is to provide a high-level overview of models of disability within recent literature, allowing for later consideration and comparison of case studies across multiple countries. It should be noted, however, that the wider body of literature is both extensive and highly nuanced. While this report provides a summary of central points within the literature identified through the inclusion criteria set out below, it does not cover all aspects of the field, including variation in interpretation or application of models at an individual country level.

1.2. Report structure

The findings of this literature review are presented in 2 parts.

Part 1: models of disability. This section outlines different models of disability identified within the literature, synthesising evidence based on their reported advantages and disadvantages, both generally and, where possible, specifically in relation to the design and delivery of survey research.

Part 2: case studies. This section provides country-based case studies, outlining surveys and question sets that collect data on the prevalence and experiences of disabled people and, where possible, how they align to models of disability. Where available, case studies include accounts of survey or question set development work and cognitive testing, drawing out implications for future survey design.

2. Methodology

This review aims to address 3 research questions:

1. what models of disability exist?
2. what are the advantages and disadvantages of adopting these models, both generally and specifically in relation to the design and delivery of survey research?
3. what surveys have been conducted that attempt to collect data on the prevalence and experiences of disabled people, and how do they align to models of disability?

This review adopted a literature review research design. The purpose of a literature review is to collate relevant studies within a limited timeframe to draw broad conclusions of an evidence base. There are several limitations to conducting literature reviews when compared to more systematic forms of synthesis, such as rapid evidence assessments. This includes potentially missing relevant texts, introducing bias into study selection, and less rigorous quality assessment of studies included in the review.

To mitigate these risks, the literature review approach was supplemented with additional steps indicative of a more systematic approach. This literature review methodology therefore consisted of:

- the identification of peer-reviewed research papers through searching multidisciplinary academic databases using bespoke search strings (Annex A), and the manual review of pre-identified academic journals (Annex B)
- the identification of grey literature using simplified search strings to search grey literature databases, and the review of pre-identified websites including relevant UK-based organisations, international organisations, UK government agencies, and international government agencies relevant to data collection related to disabled people (Annex C)
- the inclusion of evidence recommendations provided by a subject expert in survey measurement of various impairment types and the social model of disability
- backwards and forward tracking of important text citations

The inclusion and exclusion criteria for the searching of both peer-reviewed academic literature and grey literature are as follows.

- Population: disabled people; people with impairments.
- Time period: 2014 onwards.

- Document type: peer reviewed academic articles that have been published and/or are in print.
- Language: English language only.
- Geographical area: UK, USA, Canada, New Zealand, Australia, and countries across Europe.
- Subject areas: limit to subject areas - Social Sciences, Psychology, Economics, Decision Sciences, Multidisciplinary, Arts and Humanities.
- Focus: studies that explicitly discuss the advantages or disadvantages of one or multiple pre-identified models of disability when conducting survey research that aims to categorise or measure experiences of disabled people.

Models in scope are:

- social model of disability
- (bio)psychosocial model of disability
- (bio)medical model of disability
- human rights model of disability

Search strings used keywords relevant to models of disability and people with impairments, in conjunction with terms related to the development of surveys, questionnaires, indicators, and measurement. The choice of keywords was also informed by search strings used in other reviews relevant to the study of ‘disability’ and questionnaire design. As a result of this process, and to ensure the review was able to address all research questions, some keywords used do not reflect social model of disability language and can be considered both outdated and offensive.

The search process used Boolean operators and truncation to ensure focus. Appropriate and proportionate approaches were also used to reduce the number of irrelevant hits, including restricting returns to journal articles only, and excluding reprints of studies originally published prior to 2014.

Initial piloting of search strings for peer-reviewed literature searching highlighted a high-volume of studies, a considerable proportion of which made only passing reference to models of disability as opposed to a detailed assessment of advantages and disadvantages. The approach therefore made use of simple search strings to identify a relatively high-volume of studies, which were then shortlisted for relevance on the basis of their title and abstract.

Peer-reviewed academic studies and grey literature were both shortlisted in 2 stages: a review of the title and abstract or executive summary, followed by a review of the full text. Approximately 50 studies were selected for inclusion in the review.

Studies were selected to ensure coverage of research questions as well as to provide case studies of surveys and questions sets.

Once studies were shortlisted, a thematic framework was developed for data extraction, structured according to the research questions, based on the Framework Approach (Ritchie et al., 2014). The Framework approach involves summarising identified evidence in a matrix, with each row representing an individual evidence source, and the columns representing central themes and different models of disability. This approach ensured the review synthesised the most relevant evidence, and helped ensure central themes and evidence gaps were identified.

Given the limitations of a literature review approach and the extensive body of literature, the findings of this review should not be considered a comprehensive overview of the evidence base. Rather, this review provides a high-level summary based on the sample of publications identified through the inclusion criteria above. Care should be taken when interpreting the findings, particularly considering evolving variations in the context, understanding, and application of the models.

2.1 Overview of the evidence base

This review identified a relatively high-volume evidence base that explored the advantages and disadvantages of models of disability generally. The volume of evidence that explored the advantages and disadvantages of models of disability as they relate to the design and delivery of survey research specifically, was comparatively more limited.

Whilst this review identified several case studies that seek to collect data on the prevalence and experiences of disabled people, the extent to which they are explicitly and consistently attributed to specific models of disability varied. For that reason, parts of this review rely on the authors' interpretation of case studies' alignment with models of disability, as informed by the wider evidence contained in this report.

Not all evidence found during this literature review used social model language. When summarising the literature, it was important that the content of reviewed articles was accurately reflected, to avoid misconstruing or misrepresenting original sources. This means the report contains some terminology that does not correspond with social model language, as well as descriptions of impairments and 'disability' that may cause harm and offense.

3. Findings: models of disability

Over time, different models have been developed as systems to frame, measure, understand, describe, and explain what it means to be disabled (Forstner, 2022). These models have increasingly focused on social and environmental barriers and facilitators, moving away from biomedical aspects (Forstner, 2022). The following section outlines the main models of disability from within the reviewed literature and provides an overview of the reported main advantages and disadvantages.

3.1 Medical model of disability

Since the mid-1800s, the medical (or biomedical) model has been the main way to interpret and describe ‘disability’ and continues to have an influence on how it is interpreted and understood today (Cockburn et al., 2023). According to the medical model, being disabled is the consequence of pathological processes which leads to the loss of physical and mental abilities: it is a state of illness that results in a movement away from the ‘norm’ (Cappa et al., 2015; Cockburn et al., 2023).

Under the medical model, a person’s impairment is thought to require intervention to minimise impact and reduce severity, such as through treatment, rehabilitation, medications, prostheses, and other medical devices (Crawford et al., 2012; Cockburn et al., 2023). Because of the focus on impairment and deficit, the medical model views ‘disability’ as a problem emerging from within a person (Andrews et al., 2022). The language that comes from the medical model may be seen to reduce the person to diagnostic and pathological categories (Andrews et al., 2022; Cockburn et al., 2023).

Over time the medical model has developed more nuanced and complex conceptualisations of ‘disability’ and what it means to be disabled. This has included, for example, making a distinction between ‘impairments’, which affect specific physical or mental areas; ‘functional limitations’, which refer to the performance of basic actions and can involve the whole body; and ‘disability’, which is an individual’s behaviour from the interaction with the environment (Forstner, 2022).

Impact of the medical model on surveys and data collection

As outlined by Loeb et al. (2018), when conceptions of disability are based on the medical model, questions are often created around impairments or medical diagnoses. Whilst this can create a clear list of categories for survey responses, this approach tends to underestimate and under-identify disabled people through the use of non-comprehensive lists of diagnoses (Loeb et al. 2018). This, in turn, only identifies a small sub-population, described as those considered to have “more severe restrictions and not those with varying degrees of limitations” (Cappa et al., 2015, page 318).

Use of the medical model is also described as compounding wider social disadvantage, as it limits data collection to those who have access to healthcare and receive medical diagnoses (Loeb, et al., 2018). Categorising people by impairment type has also been described as perpetuating stereotypical views of disabled people, “such as wheelchair users, or as being blind or deaf” (Kappa et al., 2015, page 319).

3.2 Social model of disability

Between the 1960s and 1970s, the social model of disability began to emerge, following the activity of movements such as the Disabled People’s International and the Union of the Physically Impaired Against Segregation (Cockburn et al., 2023).

Whereas the medical model views the environment as a neutral or fixed factor and emphasises the need to cure or rehabilitate the person with an impairment to make them fit societal expectations and requirements (Burchardt, 2004), the social model rejects the idea of environmental neutrality. This has been interpreted as meaning that ‘disability’ under the social model is not necessarily due to, or inherent to, impairment itself (Koutsogeorgou et al., 2014), but comes from social barriers to inclusion and participation (Andrews et al., 2022; Cockburn et al., 2023; Crawford et al., 2012). The social model does not dispute that impairments exist or matter, but it does argue that impairments are not the cause of being disabled (Beaudry, 2016).

Under the social model, ‘disability’ is viewed as predominantly socially constructed, where a range of environmental factors are identified as responsible for disabling people with impairments by creating barriers and withholding support (Andrews et al., 2022; Cockburn et al., 2023; Crawford et al., 2012). These factors include societal and physical barriers that affect people with impairments more generally, as well as related contextual and psychological factors that are specific to an individual and are of a non-biomedical origin (Forstner, 2022).

Within this context, a central reported advantage of the social model is the identification and advocating for changes in the environment itself (for example, by addressing environmental, systematic, and social barriers) and on addressing socio-political factors to improve disabled people’s participation in society (Bennani, 2023; Burchardt, 2004; Cappa et al., 2015; Norwich et al., 2016).

Social model of disability and language

With the emergence of the social model of disability there has been an observable change in language: moving away from stigmatising and pathologizing terminology of the medical model (‘the disabled’) to a person-first (‘person with disabilities’) approach initially, that distinguished the person from their impairment (Forstner, 2023). This was followed by an identity-first (‘disabled person’) approach, adopted within many disabled communities as a way to reclaim their identity and autonomy (Andrews et al., 2022).

Criticisms of the social model of disability

Criticisms of the social model within the reviewed literature suggest that more recognition of the embodied nature of impairments is needed, and that the model can reproduce artificial boundaries and a disconnection between impairment, biology, and medicine on one hand, and disability on the other (Beaudry, 2016; Bennani, 2023). Others claim that, despite the differences between the medical and social models of disability, the 2 are interlinked. By adopting a rigid interpretation of the 2 models as fully separated, within the context of the social model, disability would be described as only due to barriers in social and physical environments, and not related to impairment (Koutsogeorgou et al., 2014). This interpretation would overlook the impact that impairments have on people’s daily life, regardless of contextual factors, and underestimates the intrinsic impacts and objective realities of impairments (Beaudry, 2016; Crawford et al., 2012).

3.3 Biopsychosocial model of disability

According to the reviewed literature, the biopsychosocial model of disability attempts to integrate medical and social models by interpreting ‘functioning’ and ‘disability’ as determined by the complex interactions between biological, psychological, and social factors (Bennani, 2023; Norwich et al., 2016). In 1980, various iterations of the biopsychosocial model and the medical model served as foundations of the International Classification of Impairments, Disability and Handicap (ICIDH), which the World Health Organisation (WHO) substituted in 2001 with a further classification based on the biopsychosocial model - the International Classification of Functioning, Disability and Health (ICF) (Norwich et al., 2016).

The identified studies provide an overview of the (biopsychosocial model) ICF framework, which defines ‘disability’ in terms of “the interaction of bodily functions and structures, activities and participation which takes place in a context represented by environmental and personal factors” (Norwich, 2016, page 5), or an “interaction between a person’s capabilities (limitation in functioning) and environmental barriers (physical, social, cultural or legislative) that may limit their participation in society” as described by the Washington Group on Disability Statistics.

This description is reaffirmed by Koutsogeorgou et al. (2014) and Loeb et al. (2018), which collectively describe the ICF’s biopsychosocial model as classifying impairments in a multidimensional way. It focuses on how a person, with their capabilities, interacts with the environment and barriers to societal participation. The reviewed literature suggests a central strength of the ICF biopsychosocial model is considering the difference between being able to carry out tasks and being involved in life situations in a standardised environment (capacity), and in the actual enabling or disabling environment in which they live (performance) (Bennani, 2023).

Within this context, the biopsychosocial model seeks to address the limitations of the medical model by viewing disability as a result of the interaction between an individual's impairments, and attitudinal and environmental barriers that hinder their full and effective participation in society, on an equal basis to others (Cappa et al., 2015). This in turn focuses on the diverse and varied nature of disabled people, as well as provides a basis to better understand 'disability' as dynamic, rather than a stable, social characteristic (Bennani, 2023; Cappa et al., 2015). As such, the WHO clarifies that the ICF, using the biopsychosocial model, does not classify people, but their health characteristics based on their individual life circumstances and the environment in which they live (Bennani, 2023).

Impact of the biopsychosocial model on surveys and data collection

Identified evidence suggests that use of the biopsychosocial model has generally produced prevalence rates of disabled people that are higher than those based on the medical model (Cappa et al., 2015). The ability of the biopsychosocial model to manage complexity can be observed in a recent patient and public involvement and engagement study on the concept of disability (Lammons et al., 2024). This study found that, overall, participants preferred the biopsychosocial model to both the social and medical models. It was described as more relatable, dynamic, and holistic, and allowed for a more complex representation of disability as it included many layers (medical, social, and psychological).

Criticisms of the biopsychosocial model

Critics of this model suggest that it is a "conceptual framework", rather than a scientific or explanatory model of disability. By including all biological, psychological, and social factors it creates an exhaustive explanation of all possible reasons for 'disability' to occur. This makes it challenging to identify the genuine factors and their interactions which explain 'disability'. As a result, they argue that the biopsychosocial model is too broad and lacks clear guidelines for its application (Roberts, 2023). Bennani (2023) also suggests that the biopsychosocial model ICF approach centres the medical model. By using limitations in basic activity functions as the main criteria for determining whether a person is disabled, it potentially overlooks psychological and social factors.

3.4 Other models of disability

Human rights model

By positioning 'disability' as a human rights issue, the human rights model of disability seeks to address systemic inequalities (Waddington and Priestley, 2021). Closely aligned with international human rights frameworks, particularly the Convention on the Rights of Disabled People (CRPD) (Degener, 2024), the primary focus of the human rights model is to advocate for the full participation of disabled people in all aspects of society, through promoting inclusion and equality (Degener, 2016; Dimitrova et al., 2024), and ensuring that disabled people enjoy equal rights and freedoms (Jackson, 2018). Emphasis is on the inherent dignity of the human being where the person is the focus of decisions affecting them, but the main ‘problem’ is placed outside the person and within society (Lawson and Beckett, 2020).

The human rights model distinguishes itself from both the medical and social models by prioritising rights and societal responsibilities (for example, relating to laws and policies; Lawson and Beckett, 2020) over addressing impairments or social barriers. Whereas the medical model perceives ‘disability’ primarily as a deficit or impairment that necessitates medical intervention (Retief and Letšosa, 2018), the human rights model reconceptualises ‘disability’ as a societal issue, shifting the focus from the individual to the societal structures that create barriers to inclusion (Lawson and Beckett, 2020).

This model therefore advocates for systemic change, emphasising that the obstacles disabled people encounter are often rooted in discriminatory practices and inadequate policies that perpetuate exclusion (Degener, 2016). Within this context, the human rights model complements the social model, emphasising the need to recognise people as 'rights-holders' and acknowledging people’s agency (Degener, 2016; Degener, 2024; Lawson and Beckett, 2020).

Quality of life model

The quality of life model is an emerging framework that suggests people’s lives are a complex system made of 3 different levels: microsystem (the environment closer to the person which directly affects them), mesosystem (the context surrounding the microsystem that directly influences it), and macrosystem (the larger social, political, economic, and cultural patterns that have a direct impact on values and beliefs) (Amor et al., 2023).

This model is closely aligned to the UNCRPD and shares the same values of equity, equality, empowerment, and support. It consists of 8 core domains: emotional wellbeing, physical wellbeing, material wellbeing, personal development, interpersonal relationships, social inclusion, rights, and self-determination (Amor et al., 2023).

Cultural model

The cultural model of disability views ‘disability’ not as a medical condition or individual problem, but as a cultural construct shaped by societal norms, beliefs, and practices. It examines how ‘disability’ is constructed and understood within different contexts, and explores not only the influence of media, language and representation, but also the importance of understanding disability as a cultural experience determined by history and social context, as well as the intersectionality of people’s identities (Waldschmidt, 2018).

As outlined by Bennani (2023), the cultural model moves away from the idea of disability as a universal experience and highlights the importance of developing culturally specific or culturally comparable indicators – such as ‘walking’ and ‘climbing stairs’ for mobility impairments.

No models of disability

Beaudry (2016) provides an overview of recurrent and dichotomous debate between proponents and critics of the social model of disability and argues much of the disagreement is political or theoretical in nature. This paper therefore suggests the broad concept of ‘disability’ could be substituted by discourses around more specific issues, to reflect the range and diversity of impairments, and their underlining (biological or social) causes (Beaudry, 2016).

4. Findings: case studies

This section of the report provides case studies of surveys and question sets that collect data on the prevalence and experiences of disabled people, and (where possible) how they align to models of disability.

4.1 Australian Bureau of Statistics

Australia has long aligned its definition of 'disability' with that of the United Nations (UN) and World Health Organization (WHO). In 2001, Australia was among the member states who took part in the development and testing of the ICF, and they adopted it at the end of that year (Australian Institute of Health and Welfare (AIHW), 2002). Australia's Disability Strategy (2021 to 2031) is based on the social model of disability and in line with the UN Convention on the Rights of Disabled People (UNCRPD). Page 9 of the strategy states:

> "attitudes, practices and structures can be disabling and act as barriers preventing people from fulfilling their potential and exercising their rights as equal members of the community".

The Australian Bureau of Statistics (ABS) runs multiple surveys exploring the prevalence of disabled people and long-term health conditions. Its principal survey is the Survey of Disability, Ageing and Carers (SDAC) which has run every 3 to 4 years since 1981 and looks at disabled people, people aged 65 and over, and primary carers of disabled people. It is the most detailed and comprehensive source of the prevalence of disabled people. Additionally, the ABS runs a range of social surveys that include questions on impairment, such as the National Health Survey, and the Personal Safety Survey (ABS, 2022).

The SDAC has been developed to align with international measures of disability as described in the ICF. It also uses WHO's 10th revision of the International Statistical Classification of Diseases and Related Health Problems to classify long-term health conditions that meet the SDAC definition of disability, which could also have an impact on disability assessments (ABS, 2024). The exact definition of 'disability' differs across surveys. For the SDAC, it is understood as

> "at least one of a list of limitations, restrictions or impairments, which has lasted, or is likely to last, for at least 6 months and that restricts everyday activities".

The National Health Survey and Personal Safety Survey consider a person as disabled if they have at least one condition restricting their everyday activities for at least 6 months, whereas surveys for young people or students collect information on 'self-identified disability' (AIHW, 2024b).

The ABS groups impairment into 6 classifications: sensory and speech; learning and understanding; physical restrictions; psychosocial; head injury, stroke or acquired brain injury; and other (AIHW, 2018). Additionally, they look at impairments as how they relate to core activities associated with daily living, and in education and employment where people might experience additional difficulties or restrictions (ABS, 2023; ABS, 2024). This allows them to classify impairment into 4 levels of limitations (profound, severe, moderate, or mild) (ABS, 2024). The level of limitation is established based on whether a person needs help, has difficulty or uses aids or equipment with any of the core activities (self-care, mobility, communication) (ABS, 2024).

The SDAC is an in-depth survey on disabled people that includes a series of screening questions, as well as over 160 questions to identify impairment and establish the severity (ABS, 2022; AIHW, 2024a). The questions cover topics such as access (to venues, public transport), disability discrimination, social and community participation, as well as looking at medical conditions, restriction level, activities where assistance is required or difficulty is experienced, type of aids or equipment used for self-care, mobility and communication, education, and employment (ABS, 2024). Other ABS surveys use the Short Disability Module, a standard set of 16 questions, to identify whether a person is disabled and their type of impairment. The Short Disability Module is not recommended to measure the prevalence of impairments (AIHW, 2024a).

4.2 Statistics Canada

Statistics Canada started to move towards the social model in the early 2000s following the World Health Organisation (WHO) adoption of the ICF, when they redesigned their post-censal[1] survey on disabled people to be more in line with this definition (Pianosi et al., 2023). In 2012, Canada adopted new survey questions to measure ‘disability’ - the Disability Screening Questions (DSQ) which are based on the social model, while also taking into consideration activity limitations. Statistics Canada defined disability for the DSQ as “the relationship between body function and structure, daily activities, and social participation”. The DSQ was a further move towards the social model, following Canada’s ratification of the UNCRDP in 2010 (Pianosi et al., 2023).

The DSQ had 3 main objectives to improve the previous measures based on the census filter questions:

- capture people with non-physical impairment in a more inclusive way
- measure more precisely types of impairment as well as severity level

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[1] A post-censal survey uses a census question to identify the target population. It is conducted shortly after a census. Census staff and field infrastructure are used to select the sample and collect the data.

- measure impairment in a consistent way based on the social model of disability

The DSQ development also included a review of the previous models used in Canada, such as the Health Utilities Index Mark 3 (HUI3) and the Washington Group on Disability Statistics (WGDS). The HUI3 model measured functional health and was more in line with the medical model, which Statistics Canada wanted to move away from (Grondin, 2016). Conversely, the WGDS model measured task difficulty and impairment, which did not suit Statistics Canada's purpose. The DSQ was therefore perceived as a more consistent tool to look at activity limitations within Canadian surveys. It also aligned with previous surveys, such as the Participation and Activity Limitation Survey (PALS), which used a combination of functional and social model depending on the impairment type.

The DSQ was developed as a series of questions that could be included in a variety of existing general population surveys. It is separated into 10 impairment types, which are grouped into 5 higher-level categories: sensory (seeing, hearing); physical (mobility, flexibility, dexterity, pain); cognitive (learning, developmental, memory); mental health related; other/unknown. Additionally, the DSQ allows for a severity score (mild, moderate, severe, very severe) based on the intensity of the difficulty and the frequency of the daily activity limitations.

For sensory and mobility (except pain), the questions are structured to assess the intensity of the difficulty in performing certain tasks (even with the use of aids and assistive devices). If there is difficulty with tasks, this is followed by a question asking how often the difficulty leads to limitation of daily activities.

For cognitive impairments, mental health, and pain, the first question assesses for a health problem or condition. In the presence of a health problem or condition, this is followed by a question evaluating the frequency at which it limits daily activities, and a question on intensity.

The DSQ originally included questions on communication impairments. These were removed at the cognitive testing stage as they did not work as intended (Grondin, 2016).

While the DSQ in its longest iteration is 39 questions long, Statistics Canada also created a short version of the DSQ, consisting of 17 questions for the majority of participants. The short DSQ combines impairments into 5 categories (seeing, hearing, physical, cognitive, mental health-related) and so does not allow for information on each type of impairment. It also does not allow for calculating a severity score and has a more restrictive definition of impairment (Grondin, 2016). A modified version of the long questionnaire was discussed for use in general population survey to allow for better comparisons on disabled people between surveys, and to compute a severity score for analysis instead of using the short DSQ (Grondin, 2016).

Originally, the DSQ had a series of 6 filter questions which allowed for initial filtering of impairment before asking the screener questions (Grondin, 2016).

Since 2012, the DSQ has been used in general population surveys such as the Longitudinal International Study of Adults (LISA), the General Social Survey (GSS) and the Canadian Income Survey (CIS), as well as specific surveys such as the Canadian Survey on Disability (CSD) (Grondin, 2016). The CSD was introduced in 2012 as a replacement for the Participation and Activity Limitation Survey (PALS) following Statistics Canada's move towards the social model. The CSD was further revised in 2017 and 2022, and the latest iteration also includes a question asking if people self-identify as disabled (Pianosi et al., 2023).

4.3 Stats NZ

Stats NZ has held the Disability Survey every 5 to 10 years, since 1996. The Disability Survey consists of 2 components: the Household Disability Survey (HDS) and the Disability Survey of Residential Facilities (DSRF, a reduced version of the HDS).

2013 Disability Survey: Household Disability Survey and Disability Survey of Residential Facilities

The 2013 Disability Survey defined 'disability' as:

> "an impairment which has a long-term limiting effect on a person's ability to carry out day-to-day activities. Long-term means six months or longer and limiting effect means a restriction or lack of ability to perform." (MacPherson, 2014, page 20).

The New Zealand Government ratified the United Nations Convention on the Rights of Disabled People in 2008 and because of this, some changes to the content of the 2013 Disability Survey were needed. Within this context, Stats NZ requested feedback on the 2013 Disability Survey to inform its development for the 2023 wave. The aim was to create content that embraced disabled people's views and addressed survey users' data needs.

Stats NZ held a consultation between September to October 2021 where the feedback of 200 individuals and organisations from across the country were collated (Stats NZ, 2022; Stats NZ, 2023). Those consulted were disabled people; family or whānau[2] of disabled people; disabled people's organisations; government agencies;

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[2] Whānau is a Māori word that is often translated as "family". It can include the immediate or a whole extended family. People who have died, or ex-partners of divorced people, are still seen as whānau members. Whānau is also used as a name for friends, or for a group with a common purpose.

district health boards; disability support and service organisations; local councils, researchers, and health and disability workers.

Consultation feedback suggested that the questions needed to be more aligned with the social and human rights models of disability to ensure all people can answer the same questions; including those who may not see themselves as disabled. This would also remove the use of assumptive language in the questions, such as question framing that might imply higher rates of depression, anxiety, and trauma amongst disabled people (Stats NZ, 2022). Concerns were raised that some of the survey content needed refinement or was outdated. Suggestions included improving existing questions, adding new topics, and making changes to the survey methods (Stats NZ, 2023). There was also agreement that neurodiversity, mental health, learning disability, fatigue, and pain need to be added, and that more detailed information was needed on specific and rare impairments.

Also, having a category of “mild impairments” was met with resistance as this group of people would not be recognised as disabled, despite having “some difficulty” with their basic functioning. In the survey, respondents had to indicate they have at least “a lot of difficulty” to a series of basic functioning questions to be classified as disabled. If they reported themselves as having “some difficulty”, then they were then classified in the “non-disabled category” of “mild impairment”.

The consultation feedback highlighted that the “Disability Survey questions and content development [was] seen to be framed by an individualistic” view and instead need to “apply a te ao Māori lens” – a holistic worldview that focuses on interconnections. It was suggested that the closed question format (usually used in surveys for population prevalence) should be replaced with face-to-face interviews or open answer questions as it allows for storytelling and would enable respondent experiences to be understood better (Stats NZ, 2022).

2023 Household Disability Survey

In response to the 2021 consultation, the 2023 HDS was adapted to reflect the biopsychosocial model. It explains ‘disability’ as

> “an interaction between a person’s capabilities (limitation in functioning) and environmental barriers that may limit their participation in society” (Stats NZ, 2023).

The following changes were implemented.

- The screening questions were changed to not be framed as either medical or social model, but instead focused on functioning and basic, universal activities such as hearing, seeing, or walking (Stats NZ, 2023). The proposed benefits of this approach were to reduce personal interpretation and ambiguity, and to provide some objectivity to help ensure ‘disability’ is being measured in a reliable and valid way. It also ensured the inclusion of people who do not consider themselves disabled but will often meet the functional criteria of ‘disability’ (Stats NZ, 2023).

- The scope of respondents was expanded to include disabled and non-disabled people, as well as all impairment types. This was to minimise the risk of disabled people being excluded during screening questions, as well as to support comparisons between disabled and non-disabled respondents (Stats NZ, 2022).
- The survey questions were expanded to capture respondents’ views on the suitability of the environment for example, a suitable job, transport, school, and housing (Stats NZ, 2022).
- The format of some questions relating to barriers were changed from closed to open to ensure the survey is inclusive through its ability to accommodate for storytelling (Stats NZ, 2022).
- Some question response options were altered to provide additional opportunities to explore reasons why respondents may not undertake particular activities, which may or may not be based on impairment (Stats NZ, 2022).

4.4 Washington Group on Disability Statistics

The Washington Group on Disability Statistics (WGDS) promotes and coordinates international cooperation. This includes “the development of disability measures suitable for census and national surveys” to have statistics on disabled people that are comparable across the world. The Washington Group question sets use the ICF framework and aim “to provide a common language for describing disability and functioning” (United Nations ESCAP, no date).

For the WGDS, functioning and ‘disability’ exists along a continuum and ‘disability’ occurs when a person’s difficulty starts to affect their participation in society. However, the point at which this happens can vary. This means there can be many estimates of the prevalence of disabled people depending on which questions are asked and the “level of difficulty chosen as the determination of disability” (Washington Group on Disability Statistics, 2020c). Also, the meaning of ‘disability’ can vary both across cultures and among people in the same culture. In some cultures, the term is attached to stigma and/or shame (Washington Group on Disability Statistics, 2020c). To avoid asking people questions that are culturally inappropriate or invasive, the question sets do not collect data on ‘disability’ directly but instead focuses on functioning (Washington Group on Disability Statistics, 2020c).

The Washington Group on Disability Statistics has developed 5 different question sets:

- WG Short Set on Functioning (WG-SS)
- WG Extended Set on Functioning (WG-ES)
- WG Short Set on Functioning – Enhanced (WG-SS Enhanced)
- WG/UNICEF Child Functioning Module (CFM)
- WG ILO Labor Force Survey Disability Module (LFS-DM)

These question sets will be discussed in the following sections.

The Washington Group Short Set on Functioning (WG-SS)

The first set of questions developed by the WGDS was the Short Set on Functioning (WG-SS). Under this approach, 'disability' is understood generally "to mean at greater risk for limitations in participation", for those who answer, "a lot of difficulty" or "cannot do it at all" to at least one of the 6 functioning questions – seeing, hearing, walking, self-care, cognition, and communication.

The main purpose of the WG-SS is to identify whether outcomes for disabled people and non-disabled people are different; in other words, identifying the "disability gap". The brevity and limited number of questions means it can easily be used in a census and most surveys. The 6 questions cover functions that most often limit individuals and result in restrictions to participating in society. Data collected from the WG-SS allows the maximisation of international comparability as it applies to people from all societies of all nationalities and cultures (with varying economic resources) and is universally applicable (Washington Group on Disability Statistics, 2020c).

Bennani (2023) highlighted that the WG-SS takes a risk-based approach, where disabled people are defined as having a "greater risk" of facing restrictions during tasks, activities, or participation. It is not the actual restrictions that disables people but the greater risk of societal exclusion in an unaccommodating environment. For example, where people have adjustments which removed personal or environmental barriers, they would still be considered to have a greater risk of experiencing restrictions than the general population. This means they would still be defined as disabled and implicitly described as different from the norm. This explanation is different to the ICF and UNCRPD, and by extension the social model. To be categorised as disabled, a person must be limited in basic functional activities and not by environmental factors. This risk-based approach places the individual, and not societal barriers, at the centre of whether they are disabled or non-disabled.

One identified limitation of the WG-SS is that the questions only ask about one aspect of the social model: a person's functional limitations (United Nations ESCAP, no date). Ideally, the questions would capture information on all aspects of impairments, activity limitations, participation restrictions, and environmental barriers and facilitators outlined in the ICF to identify every disabled person within every community (Washington Group on Disability Statistics, no date).

The WGDS also highlights how WG-SS does not include psychosocial impairments. Whilst it captures participants answering the cognition, communication, and self-care questions with “a lot of difficulty” or “unable to do”, respondents would not be identified specifically as having a psychosocial impairment. The WG-SS does not include questions specifically on psychosocial difficulties (Washington Group on Disability Statistics, 2020c). This limitation has been addressed through the addition of 4 questions relating to anxiety and depression; this new set formed the Extended Set on Functioning (WG-ES) (which is discussed in the following section).

Another limitation is the WG-SS is not appropriate for children under age 5 and under-identifies disabled children over age 5 due to the exclusion of the behavioural and developmental domains that are central to a child’s functioning (Cappa et al., 2018; Washington Group on Disability Statistics, 2020c). This was addressed by the development of the Washington Group / UNICEF Child Functioning Modules (CFM), one for children aged 2 to 4 years old and one for children aged 5 to 17 years old (see below).

The Washington Group Extended Set on Functioning (WG-ES)

The Extended Set on Functioning (WG-ES) was developed to address some limitations of the WG-SS. This set embedded the 6 WG-SS questions; added more functional domains on upper body functioning, affect (anxiety and depression), pain, and fatigue; and asked more questions within each domain, for example on functioning with and without the use of devices, assistance and/or aids where applicable (Washington Group on Disability Statistics, no date c).

There are 34 questions plus 3 additional ‘optional’ questions in the WG-ES. It is considered too long to include in a census and is intended for use in population-based health surveys and surveys that focus specifically on disabled people. It can also be used in surveys that focus on other topics where the survey design collects extensive information on certain adult family members and information directly from a respondent, rather than a proxy (Washington Group on Disability Statistics, 2022b).

The Washington Group Short Set on Functioning – Enhanced (WG-SS Enhanced)

The WG Short Set on Functioning – Enhanced (WG-SS Enhanced) also embedded the 6 questions from the WG-SS and has the same intended use as the WG-ES. To maximise international comparability, this 12-question set collects information on most of the same functioning domains as the WG-ES but excludes pain and fatigue

(Washington Group on Disability Statistics, 2022b; Washington Group on Disability Statistics, no date b).

The Washington Group / UNICEF Child Functioning Module (CFM)

In 2009, the WGDS began to address the methodological issues associated with collecting data about disabled children. The Child Functioning Model (CFM) was developed using ICF domains and survey questionnaires already in use in several countries. It was designed to avoid the medical model approach and be in line with the biopsychosocial model of disability (Loeb et al., 2018; Cappa et al., 2018). There are 2 versions of the CFM: for children aged 2 to 4, and children aged 5 to 17, and both are administered through primary caregivers (for example, parents) (Washington Group on Disability Statistics, no date d).

The CFM has undergone cognitive interview and field testing to produce the final set of questions. This addressed several examples of ambiguous or confusing language, and a lack of clarity around the questions' scope or conceptual focus. It also found that providing examples would help clarify the questions' intent but should be limited to not provide too much distraction. An example of this was where a country specific example was used for walking and had helped respondents "evaluate their children's ability to walk in their usual environment". It also helped address issues around participant responses being rooted in cultural context. For example, respondents in Oman answered questions about walking from the perspective of a culture that does not depend on walking because of extreme heat and the availability of cars (Massey, 2018).

Testing identified that respondents with disabled children were sometimes unsure whether they should compare their child's functioning to disabled or non-disabled children. Respondents with non-disabled children were also not sure as to what would be considered as a "normal" level of difficulty. This issue was lessened by item revision, but there were still some differences in the way these questions functioned across subgroups in the finalised CFM set (Massey, 2018).

The CFM was finalised in 2016 and assessed functional difficulties on a rating scale in:

> "vision, hearing, mobility, communication or comprehension, behaviour and learning (all ages); dexterity and playing (2 to 4 years); and self-care, remembering, focusing attention, coping with change, relationships and emotions (5 to 17 years)" (Washington Group on Disability Statistics, no date d).

Using a rating scale means children with a greater risk of exclusion in an unaccommodating environment can be identified.

This question set was developed for "inclusion in UNICEF's Multiple Indicator Cluster Surveys (MICS) and is suitable for population-based surveys that collect data on children" or in national household surveys (Washington Group on Disability Statistics 2020; Washington Group on Disability Statistics 2020b). It was also endorsed as the recommended tool for collecting information on disabled children as part of disaggregating data for the Sustainable Development Goals (International Disability Alliance, 2017).

Both CFM sets are designed to collect information specifically from children with a knowledgeable proxy respondent (such as, a parent or guardian) providing information for each child. However, for children aged 5 to 17, the older children were able to respond for themselves (Washington Group on Disability Statistics, 2022b).

The Washington Group / ILO Labor Force Survey Disability Module (LFS-DM)

The LFS-DM was developed for inclusion in Labor Force Surveys and population-based surveys for collecting data on adults in employment. The respondent is helped to focus on general difficulties (like the previous Washington Group sets) as well as physical or mental health. Included are difficulties that occur in a health context and not those caused by a lack of resources (Washington Group on Disability Statistics, 2023). It consists of 5 sections:

1. 'disability' identification which includes the WG-SS question set and 2 additional optional affect questions on depression and anxiety
2. barriers to employment, intended for all disabled household members of working age who are not currently employed
3. accommodations in the workplace, intended for disabled household members of working age who are currently employed
4. employer or worker attitudes to disabled people in the workplace, intended for disabled household members of working age regardless of current employment status
5. social protection, intended for disabled household members of working age regardless of current employment status

4.5 UK Statistics Authority (UKSA)

The UK Statistics Authority (UKSA) has been working to enhance the collection and analysis of data relating to disabled people. This effort has been aligned with the Equality Act 2010, which defines 'disability' as a "physical or mental impairment that impacts daily activities for at least 12 months" (UK Government, 2020a). In 2022, the Inclusive Data Taskforce (IDTF) advised the Office for National Statistics (ONS) to transition its measures of 'disability' to approaches based on the WHO ICF and ICF-CY biopsychosocial model conceptual frameworks. This contributes towards the aim of transitioning toward the social model of disability (UK Statistics Authority, 2022).

To meet the definition of disabled under the Equality Act, the UK government currently uses a combination of questions:

- the long-lasting health conditions and illness harmonised standard, which asks “Do you have any physical or mental health conditions or illnesses lasting or expected to last for 12 months or more?”
- the activity restriction harmonised standard, which asks “Does your condition or illness / do any of your conditions or illnesses reduce your ability to carry out day-to-day activities?”

If a respondent says “yes” to the long-lasting health conditions and illness standard question and then either “yes, a little” or “yes, a lot” to the activity restriction question, then under the legal definition they are disabled. Where this is the case, participants should then be asked “For how long has your ability to carry out day-to-day activities been reduced?”. This approach has been implemented in several large UK surveys, including:

- 2021 Census for England and Wales
- Labour Force Survey
- Family Resources Survey
- Health Survey for England
- Millennium Cohort Study
- National Travel Survey
- Scottish Household Survey
- Living Costs and Food Survey

These questions can be complemented by the impairment harmonised standard which examines the functions that a person either cannot perform or has difficulty performing because of their health condition. Participants can select multiple responses from a list of 10 impairment types, including vision; mobility; mental health; and others, regardless of whether they receive any treatment or medication, or use assistive devices or technology, for example a hearing aid.

UK Disability Survey

In 2021, the Disability Unit based in Cabinet Office conducted the UK Disability Survey. This survey was designed to allow disabled people, carers, and the general public to share their lived experiences and views with the Disability Unit, informing the development of the National Disability Strategy.

The UK Disability Survey included several questions that measured socio-environmental aspects of the experience of disabled people. These questions covered topics such as the physical accessibility of public spaces and buildings, feelings of safety in public places, and access to and retention of employment. For example, the survey found that

> “over a quarter of disabled respondents often had difficulty accessing public buildings, while 1 in 3 often had difficulty accessing public spaces” (Disability Unit, 2021).

With their focus on how socio-environmental factors disable individuals, these questions can be said to align with the social model of disability.

The UKSA is committed to improving the collection and analysis of data relating to disabled people by transitioning to measures based on the WHO ICF and ICF-CY biopsychosocial model conceptual frameworks. This shift aims to better understand and address the barriers faced by disabled individuals, ensuring their full participation in society. The ongoing development of inclusive measures and surveys reflects this commitment to inclusivity and accurate representation.

Life Opportunities Survey (LOS)

The Life Opportunities Survey (LOS) was conducted by ONS on behalf of the Department for Work and Pensions (DWP) between 2009 and 2014. It was the first major social survey to explore ‘disability’ in terms of barriers to participation. It assessed the participation levels of people with impairments and the barriers they face in 8 areas including work, education and training, leisure activities, and accessibility inside and outside the home.

LOS adopted a social model approach to survey questions, with examples including:

> “Are you limited in the type or amount of paid work that you do, for example, what you can do, how long you can work for, when you can work, or where you can work?”.

This was followed by the question: “Why are you limited in the type or amount of paid work that you do?”, with multiple choice responses including “difficulty with transport”, and “lack of special aids or equipment”. The LOS reported higher rates of disabled people compared to medical model-based surveys (Scottish Government, 2022).

4.6 Scottish Government

The Scottish Government has been actively working to improve the collection and analysis of data on disabled people. This effort aligns with the guidelines set out in the Equality Act (2010) and involves collaboration with ONS and the now Disability Unit, as part of the Office for Equality and Opportunity. The goal is to develop a harmonised suite of questions, first produced as guidance in 2012 (Scottish Government, 2022).

As of 2022, the development of these questions is ongoing, guided by the ICF. The ICF presents ‘disability’ as a process that integrates medical, individual, and societal factors. It recommends considering 3 concepts:

- illness or condition: an attribute of the individual, such as glaucoma
- impairment: a reduction in physical or mental functioning, for example, sight loss
- disability: a restriction in activities and participation due to the interaction between functional impairment and the provision of support, whether personal, mechanical, or environmental, and/or societal

(Scottish Government, 2022).

The Scottish Government is committed to improving the collection and analysis of data relating to disabled people, shifting from the medical model to the social model. This shift aims to better understand and address the barriers faced by disabled individuals, ensuring their full participation in society. The ongoing development of new indicators and harmonised questions reflects this commitment to inclusivity and accurate representation.

Questions in Scotland’s 2022 Census and other surveys like the Annual Population Survey (APS), Labour Force Survey (LFS), and Family Resources Survey (FRS) primarily follow the medical model. However, the Scottish Government acknowledges that these are outdated and is working towards adopting the biopsychosocial model, as recommended by the Inclusive Data Taskforce (IDTF) (Scottish Government, 2022).

Recommended questions by the Scottish Government

Participants are considered disabled if they answer “Yes” to the question: “Do you have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more?”, and “Yes, a lot” or “Yes, a little” to the follow up question of: “Does your condition or illness/do any of your conditions or illnesses reduce your ability to carry-out day-to-day activities?”.

The Scottish Government has also developed new indicators to measure the barriers faced by Scottish citizens in fully participating in society, each of which are reported by equality breakdowns, including ‘disability’ (Scottish Government, 2024).

5. Conclusions

This literature review was part of the first phase of research to develop survey questions, response options, and guidance that reflect the social model of disability. Its purpose was to summarise academic and grey literature that met the search criteria to assess:

- what models of disability exist?
- what are the advantages and disadvantages of adopting these models, both generally, and specifically in relation to the design and delivery of survey research?
- what surveys have been conducted that attempt to collect data on the prevalence and experiences of disabled people, and how do they align to models of disability?

5.1 Models of disability

This review outlines existing evidence relating to 3 main models of disability: the medical model, social model, and biopsychosocial model. Other models of disability discussed in the literature were the human rights model, quality of life model, and cultural model. Each model provides a different framework for understanding ‘disability’, has advantages and disadvantages, and influences survey design for collecting data about people with impairments.

The medical model of disability was one of the earliest frameworks which, in its simplest terms, states that it is a physical, cognitive, or psychological impairment or difference within the individual that is the problem. It is something that needs diagnosing and treating by either curing or managing a person’s impairment or condition (Andrews et al., 2022). In the UK, the medical model has shaped policy, legislation (for example the Equality Act, 2010), and the harmonised standard questions for collecting data about disabled people. Within the identified literature, surveys based on the medical model tend to have clear criteria and can lead to targeted interventions or improvements for disabled people, for example access to services. However, the narrow focus based upon medical diagnoses can under-identify disabled people and the pathologizing language can reinforce stigma (Loeb et al., 2018).

As a direct response, the social model of disability was developed, making the distinction between a person’s impairment and the societal structures and attitudes that disable people. Instead of locating the problem within the individual, the social model looks to the environment to identify barriers to society and participation (Burchardt, 2004; Cockburn et al., 2023). Surveys based on the social model can focus on issues that disable people, with research suggesting that identifying and removing these barriers advocates for positive change and empowers disabled people. Critics of this model suggest a potential risk of downplaying realities of having an impairment, and suggestions that issues experienced by disabled people could be resolved solely through environmental and societal changes (Beaudry, 2016; Bennani, 2023).

The biopsychosocial model of disability interprets ‘functioning’ and ‘disability’ as resulting from complex interactions between biological, psychological, and social factors. Findings from the reviewed research suggest that this approach can provide a basis to better understand ‘disability’ as nuanced and dynamic, rather than a stable, social characteristic (Bennani, 2023; Cappa et al., 2015). However, it has been criticised for its broadness and lack of clear guidelines for application (Roberts, 2023). Concerns around using this model in practice were highlighted in the literature, with some survey measures becoming focused on impairment with little consideration to environmental and societal influences (Bennani, 2023).

5.2 Existing surveys and question sets

Case studies highlighted a variety of UK and international data collection and surveys that currently capture information related to disabled people. The reviewed literature found that most existing surveys focused more on a person’s impairment and used language that referred to health conditions, suggesting a focus on the medical or biopsychosocial models. Societal barriers faced by disabled people were not adequately captured, with some studies recommending that specific questions relating to barriers and accessibility need integrating into surveys (Loeb et al. 2018; Cappa et al., 2015; Lammons et al., 2024). Similarly, various studies suggested that current questions and surveys are limited in their ability to capture fluctuating or co-occurring impairments, and specific impairments related to neurodivergence or mental health conditions (Loeb et al., 2018).

Many of the reviewed survey questions used closed question formats which may reduce participant experiences and impairment to a single yet broad category, for example, ‘mental health’ or ‘vision’. This can limit the granularity of data and can reduce participant engagement if they are unsure which category to select. In contrast, having multimodal accessibility and using mixed-format questionnaires can enhance engagement and allows for storytelling and would enable respondent experiences to be understood better (Stats NZ, 2022).

The importance of having a balance between collecting in-depth and meaningful data, whilst not being too lengthy and discourage people from participating was found. Shorter versions are ideal for large-scale surveys or where time is constrained (Bennani, 2023). In contrast, longer versions can provide a more detailed understanding and capture a wider range of experiences faced by disabled people (Grondin, 2016).

The literature review identified a linguistic shift was required to adopt the social model of disability in surveys. Using inclusive, person-first language (for example ‘disabled person’) aligns with the social model and was shown to affirm identity and promote respect for individuals' experiences (Andrews et al., 2022; Cockburn et al., 2023).

5.3 Next steps

None of the identified questions or surveys solely used the social model of disability. Of the examples identified, even those that stated they used the social model were found to align more closely with the biopsychosocial model of disability.

Findings from the literature indicate that scope exists to develop new measures that better align with the principles of the social model. This could include questions on barriers; language and terminology reviewed in relation to the concepts outlined in the social model of disability; and an approach that balances the depth of data collected against the necessary brevity of surveys.

While specifics of the social model adopted by the Welsh Government may vary from the broader definitions commented on within the literature, criticisms should be noted throughout the future stages of the research. This will help to avoid inheriting limitations associated with certain interpretations of the model and ensure appropriate application during the development and testing of new questions.

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7. Annexes

7.1 Annex A: search strings

Models of disability: ((model* W/2 disab*) OR (model* W/1 social) OR (model* W/1 biopsychosocial) OR (model* W/1 psychosocial) OR (model* W/1 biomedical) OR (model* W/1 medical) OR (model* W/1 "human rights"))

Survey and questionnaire design: ("disab*" w/3 "survey*" OR "question*" OR "measur*" OR "instrum*")

Disability: (disab* OR impair* OR handicap* OR illness OR chronic or "people with disabilities" OR "disabled people" OR "disabled persons" OR "persons with disabilities")

7.2 Annex B: academic journals

Australia and New Zealand Journal of Developmental Disabilities

Australian Journal of Developmental Disabilities

Disability and Health

Disability and Rehabilitation

Disability and Society

Disability Policy Studies

Disability Studies Quarterly

International Disability Studies

Journal of Intellectual & Developmental Disability

Journal of Intellectual Disabilities

Journal of Learning Disabilities

Journal of Literary and Cultural Disability Studies

Learning Disability Practice

Learning Disability Quarterly

Review of Disability Studies

The British Journal of Development Disabilities

7.3 Annex C: grey literature sources

Equality Commission for Northern Ireland

Eurostat

Government of Ireland - Central Statistics Office

Government Statistical Service (GSS)

International Network of the Disability Creation Process

Northern Ireland Statistics and Research Agency

Office for National Statistics (ONS) - 2021 Census

Office for National Statistics (ONS) - Centre for Equalities and Inclusion

Office for National Statistics (ONS) - Disability data

Office for National Statistics (ONS) - Life Opportunities Survey (LOS)

Scottish Government - Data collection and publication on disability

Statistics Canada

Stats New Zealand - Disability

The Survey of Health, Ageing and Retirement in Europe (SHARE)

The Washington Group on Disability Statistics - Question sets

UK Disability Unit

UK Statistics Authority (UKSA) - Inclusive Data Taskforce

United Nations - Convention on the Rights of Disabled People

Welsh Government - Disability Equality Forum

Welsh Government - Disability Rights Taskforce

Welsh Government - Equality, Race and Disability Evidence Units

Welsh Government - StatsWales disability data

World Health Organisation - Classifications and terminologies

World Health Organisation - Strengthening the collection of data on disability