



**Inclusive Futures**

Promoting disability inclusion

# PAL Network

**Collecting disability disaggregated data  
using Washington Group standards**

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**UKaid**

from the British people





# Disability inclusive data collection

Section 1

General introduction



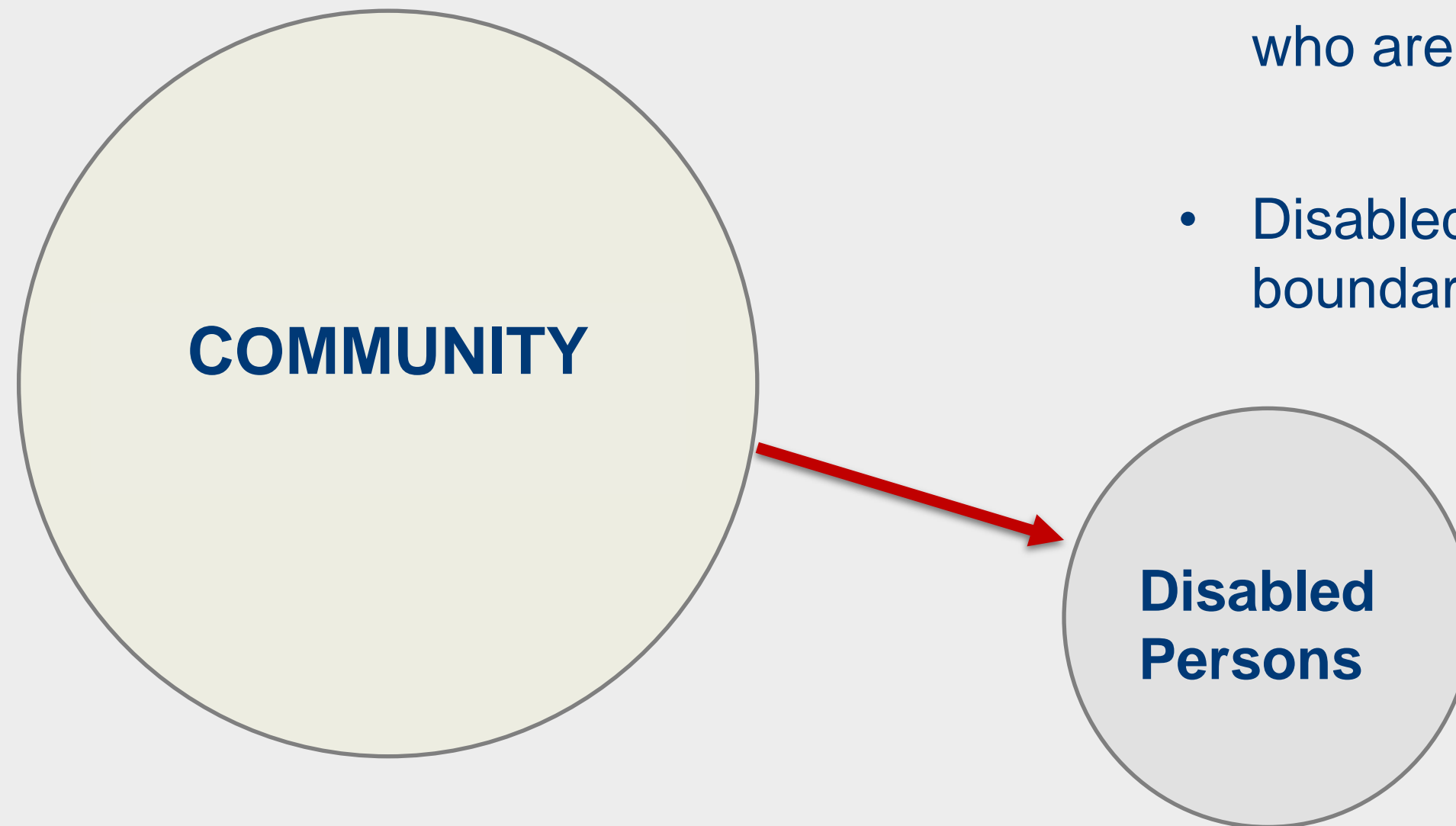
# What is disability?

What thoughts, words and images come to mind when you think about:

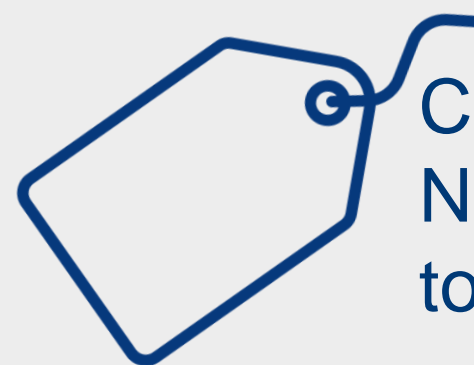
- The word 'disability'?
- What disability means in your work?



## Charity model

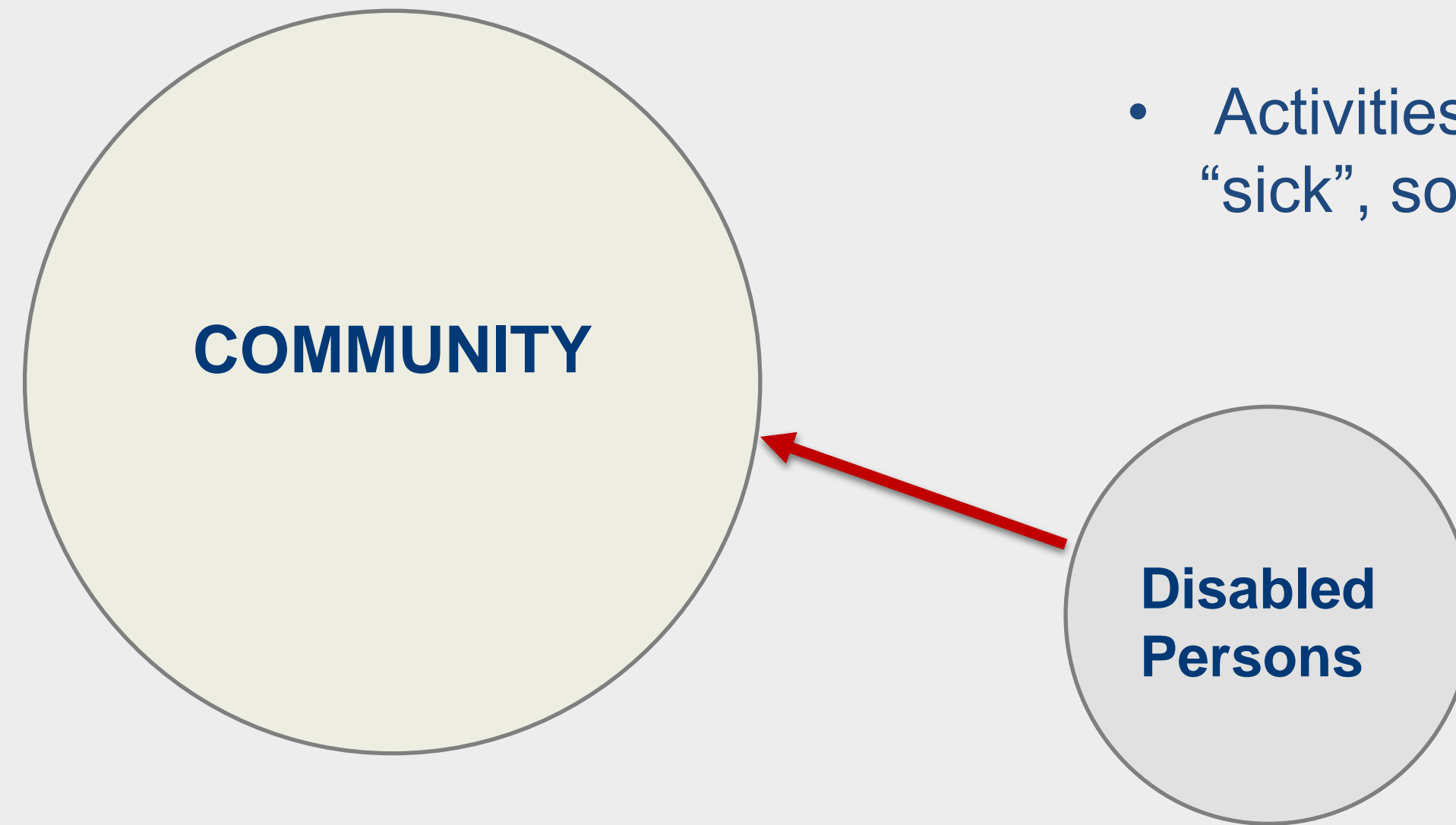


- Activities by society “help” disabled persons who are “helpless”.
- Disabled persons remain outside the boundaries of “normal” society”.

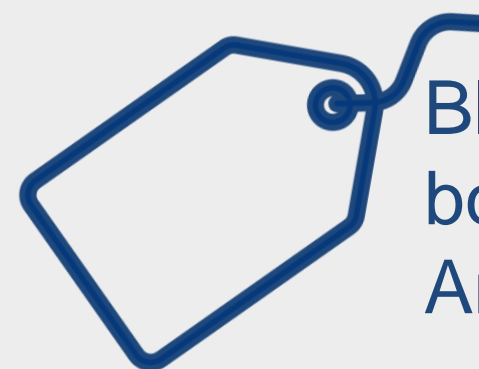


Can't work; Dependent; Unable to live independently; Need assistance; Separate specialist services; Expensive to support; Welfare recipients....

## Medical model



- Activities “fix” disabled person, who is “sick”, so they can join “normal” society



Blind; Deaf; Uses wheelchair; Crippled; Wheelchair bound; Can't see; Can't hear; Can't walk; Slow learner; Amputee; Autistic; Abnormal; Prosthesis; Rehabilitation...

# Human rights approach



- Explicit recognition that disabled persons are a **normal part of all communities**
- Emphasis is on the **right to development & inclusion**
- Recognises human **diversity**
- Ableist attitudes & structures create **barriers**
- Beneficiaries become **agents of change**

# Disability as a protected characteristic

## UN Convention on the Rights of Persons with Disabilities (2006)

**‘...disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society, on an equal basis with others’**

**Source: CRPD Preamble (e)**

**Impairment + barriers = disability**





# Disability inclusive data collection

Section 2

How can we make data collection more inclusive of disability?



# What the data can tell us

Prevalence and patterns of prevalence

- How many children have a disability? What are their characteristics? Where do they live?
- Utilise validated data methods e.g., Washington Group question sets

Disaggregation of outcome indicators by disability status

- What are the gaps in poverty, education, health, social protection, etc.
- Importance of intersectionality, by gender, age, location, ethnicity...

What are the barriers to participation?

- Inaccessible infrastructure, inaccessible information, attitudes, laws and institutions, unaffordability of services...

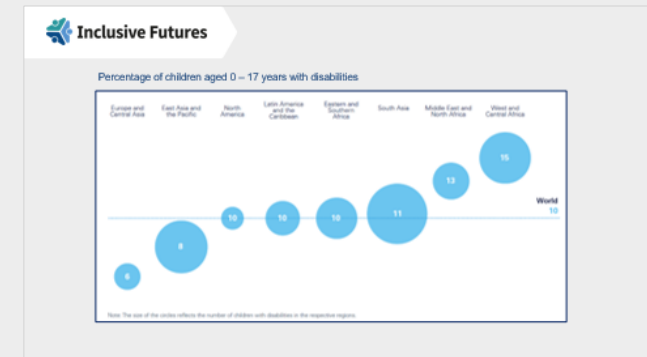
What are the different support requirements for inclusion?

- What kind of human assistance, assistive devices, home/workplace adaptations (...) do people require for basic survival and to promote participation?



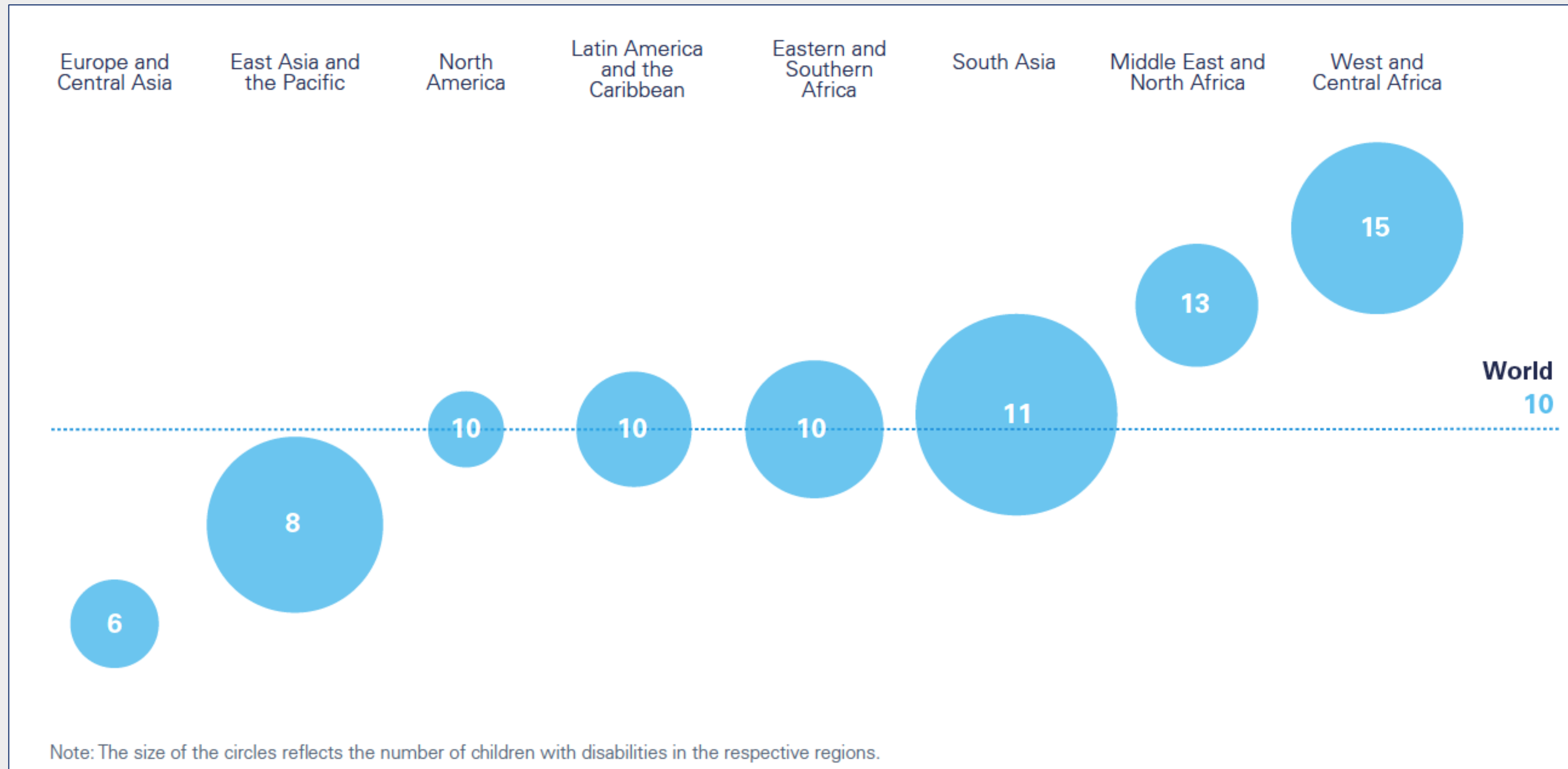
# Why disability is important

- **240 million children living with disabilities globally (around 1 in 10 children)<sup>1</sup>**
- **The largest number of children living with disabilities by region can be found in South Asia (64.4m); West and Central Africa (41.1m); Eastern and Southern Africa (28.9m)**
- **Most children have only one disability. The proportion of impairments varies, but psychosocial difficulties consistently affect the largest share of children across all age groups**
- **Having a disability increases the chances of also showing signs of anxiety and depression**
- **Most children experience moderate rather than severe disabilities**
- **High risk of exclusion & poverty. In most countries the proportion of children with disabilities is significantly higher in the poorest households**
- **Greater risk of violence especially for girls, non-binary & trans adolescents**
- **1:3 of the out-of-school population is a child with a disability<sup>2</sup>**





## Percentage of children aged 0 – 17 years with disabilities





**A lower percentage of children with disabilities attend early childhood education than their peers without disabilities, and this disparity is more pronounced among girls**

**FIGURE 4.2** Percentage of children aged 36 to 59 months who are attending an early childhood education programme



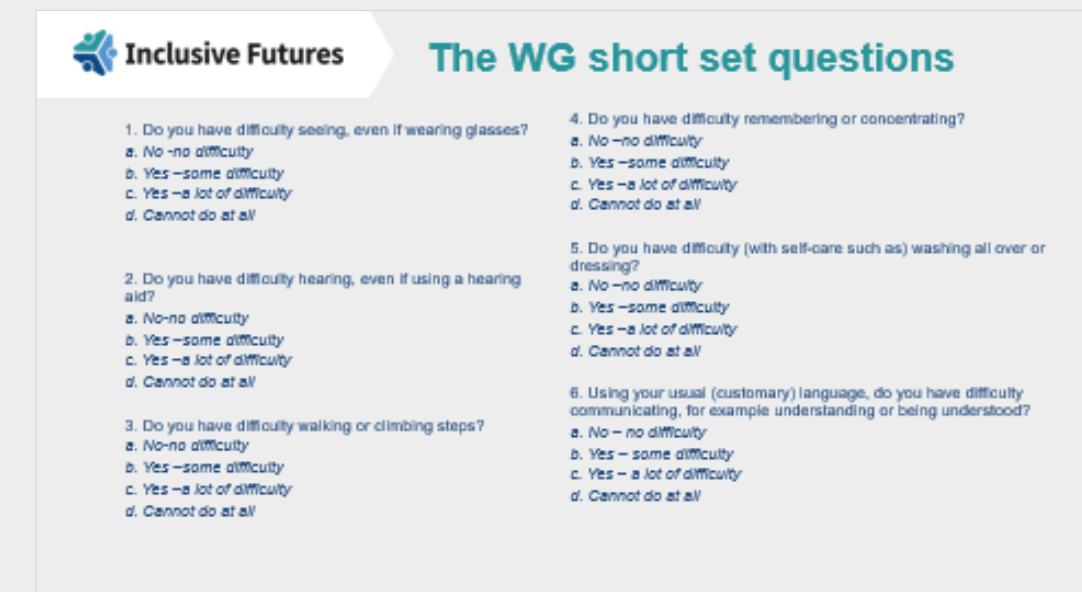
- **There are concerted efforts to collect disability disaggregated data**
- **However, data on disability remains sparse globally**
- **UNICEF 2021 Report – Seen, Counted, Included used data to shed light on the wellbeing of children with disabilities**



# The disability data dilemma

- Not a straightforward process – simply asking ‘do you have a disability’ is not effective. Why?
  - Many people do not label themselves as disabled
  - Having a disability can be shameful
  - Disabilities are not always obvious
  - Feelings of disability can be comparative (time/space)
- This leads to inconsistent data which often significantly underestimates real world prevalence
  - Not comparable
  - Not reliable

- WG questions came about as a specific response for the need to collect valid, reliable data on disability using a social / human rights model in the most efficient way possible
- Focus on identifying people who have difficulties in basic, universal activities which puts them at risk of exclusion in unaccommodating environments
- Original Short Set questions designed for use in census exercises and are therefore deliberately short
- They produce prevalence data only – they are not diagnostic; they pay no attention to barriers; they are not the same as a disability survey





# The WG short set questions

1. Do you have difficulty seeing, even if wearing glasses?

- a. No -no difficulty
- b. Yes –some difficulty
- c. Yes –a lot of difficulty
- d. Cannot do at all

2. Do you have difficulty hearing, even if using a hearing aid?

- a. No-no difficulty
- b. Yes –some difficulty
- c. Yes –a lot of difficulty
- d. Cannot do at all

3. Do you have difficulty walking or climbing steps?

- a. No-no difficulty
- b. Yes –some difficulty
- c. Yes –a lot of difficulty
- d. Cannot do at all

4. Do you have difficulty remembering or concentrating?

- a. No –no difficulty
- b. Yes –some difficulty
- c. Yes –a lot of difficulty
- d. Cannot do at all

5. Do you have difficulty (with self-care such as) washing all over or dressing?

- a. No –no difficulty
- b. Yes –some difficulty
- c. Yes –a lot of difficulty
- d. Cannot do at all

6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

- a. No – no difficulty
- b. Yes – some difficulty
- c. Yes – a lot of difficulty
- d. Cannot do at all

## Analysing the data

- Population identified as disabled includes all those with difficulties in *at least one domain of functioning* recorded at *a lot of difficulty* or *cannot do at all*.
- But disability is a continuum, and any level of difficulty can be used as a point of reference for analysis.



## In summary

- Designed for quantitative analysis
- For identifying disability prevalence, it should not be used in place of a disability survey
- Further analysis required to understand barriers (qualitative)
- Build into data disaggregation requirements to help nuance outcomes – gender and disability nexus

# Question set options

There are several different question sets available:

- Short set (adults and young people – ideally 18+)
- Extended set (adults and young people – ideally 18+)
- Child Functioning set (children 2 - 4 years; 5 -17 years)
- There is also a Labour Force Survey Module and an Inclusive Education Module (under review) for use in very specific contexts



# Tips on implementing

- Clear mandate from the start with plenty of communication
  - Webinars
  - FAQs
  - 1:1 support
- Ensure there is a purpose to the data and everyone knows how to collect it and why its being collected
- Allow plenty of time. Translations have to be considered and enumerators must be trained
- Ensure you know how you are going to make use of the data

Any questions?





# Find out more

[www.disabilityinclusion.org.uk/inclusive-futures](http://www.disabilityinclusion.org.uk/inclusive-futures)

Email: [enquiries@disabilityinclusion.org.uk](mailto:enquiries@disabilityinclusion.org.uk)

