

Identifying the Circumstances of Disabled Children: A Global Perspective

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Talk Abstract

The social and economic circumstances and living conditions of disabled children are some of the most under researched issues in the World. Very few governments, international organisations or academics publish any reports about the lives of disabled children, yet the limited evidence that is available suggested that disabled children are often amongst the 'poorest of the poor'. Until the 2007 publication of the International Classification of Functioning, Disability and Health: Children & Youth Version (ICF-CY) by the World Health Organisation there was not even an international agreement on how childhood disability should be classified and defined. This talk will briefly summarise what is currently known about the living conditions of disabled children in both 'rich' and 'poor' countries and the potential of future research in this field.

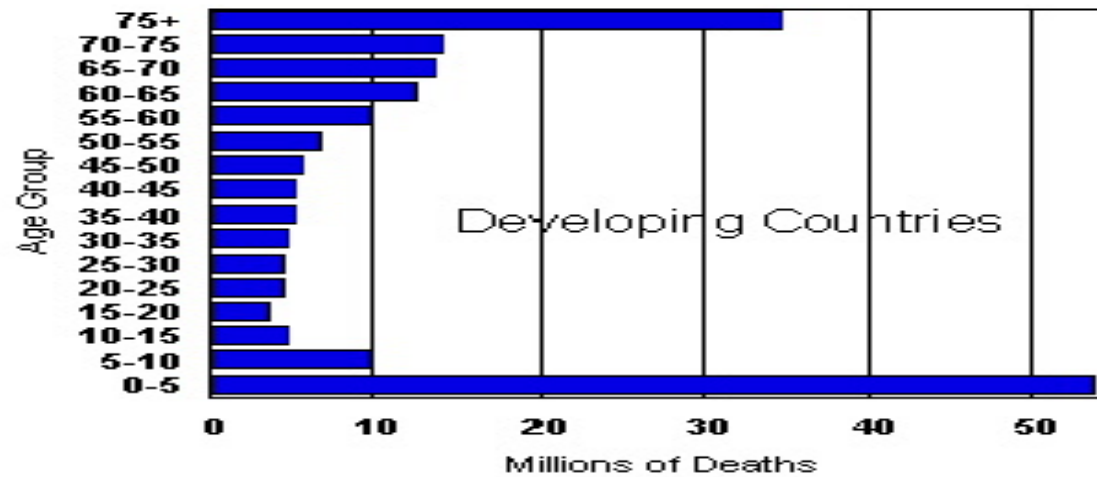
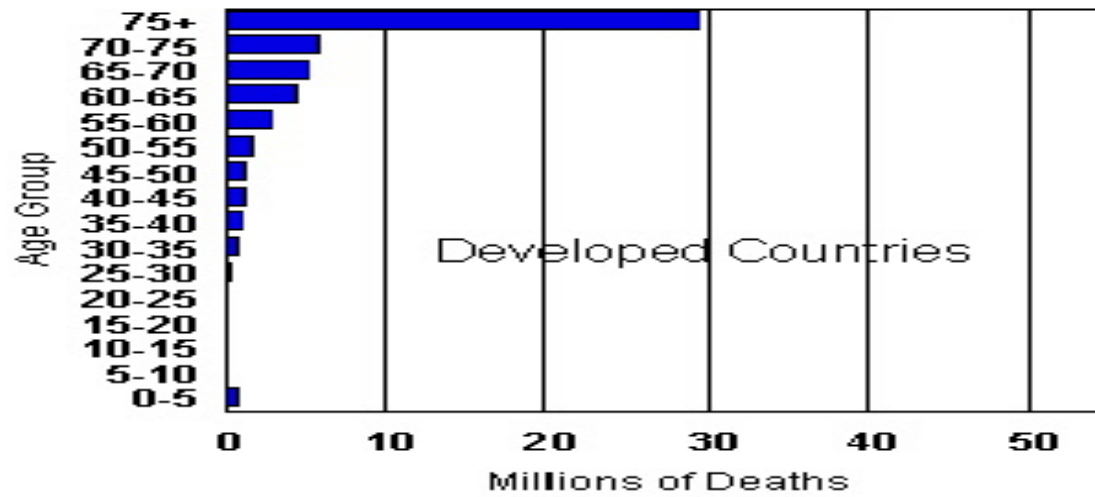
Talk Structure

- 1) The State of the World's Children
- 2) The circumstances of disabled children in Britain
- 3) What we currently know about the circumstances of disabled children in 'poor' countries
- 4) Future research plans

The State of the World's Children

In all countries of the World 'children are children' – a large majority are happy and inquisitive most of the time, they have parents who love and care for them and they have friends to play with – these are the things which are important to children, But...

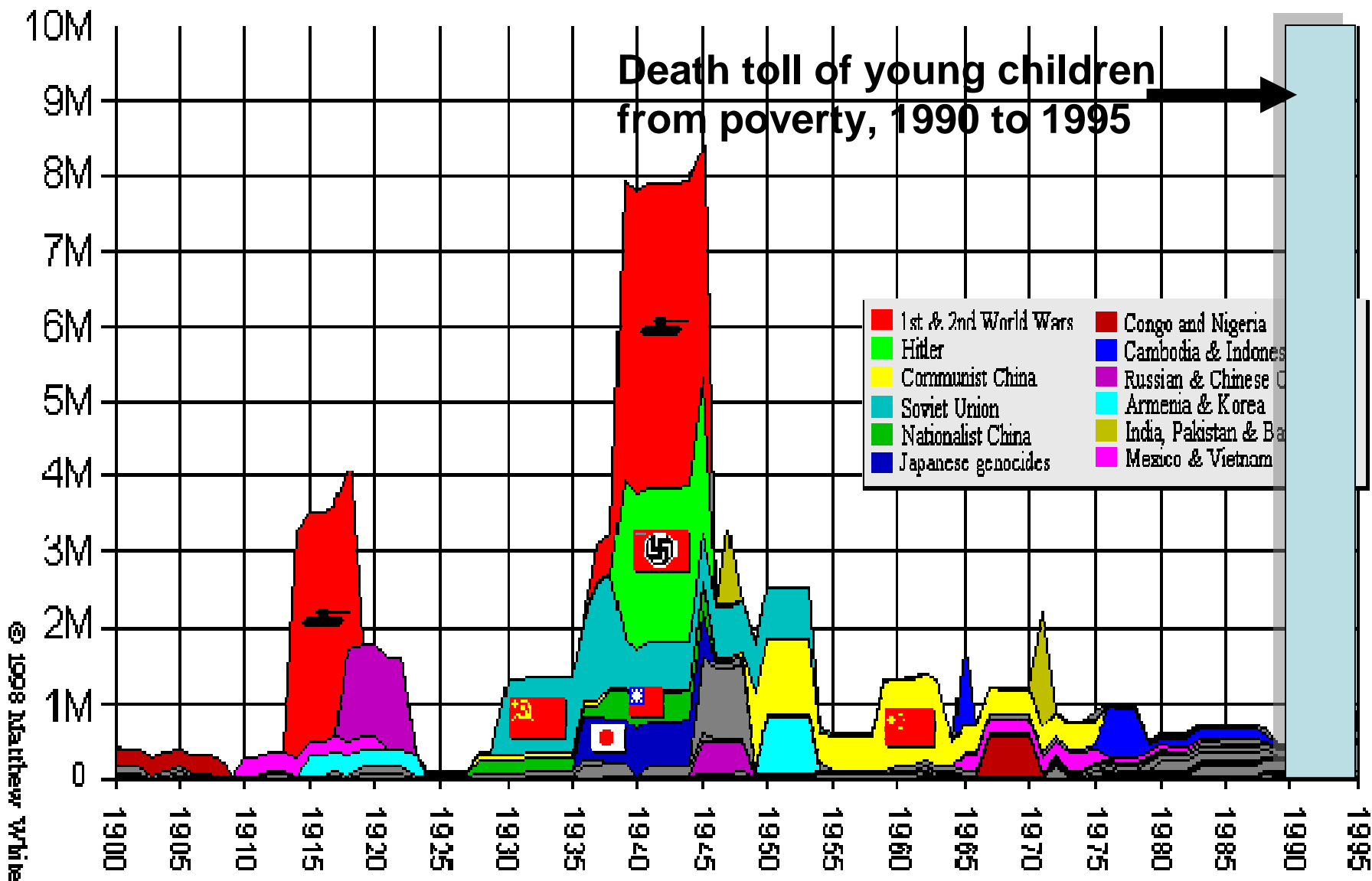
Age at death by age group, 1990-1995



Source: *The State of the World Population 1998*

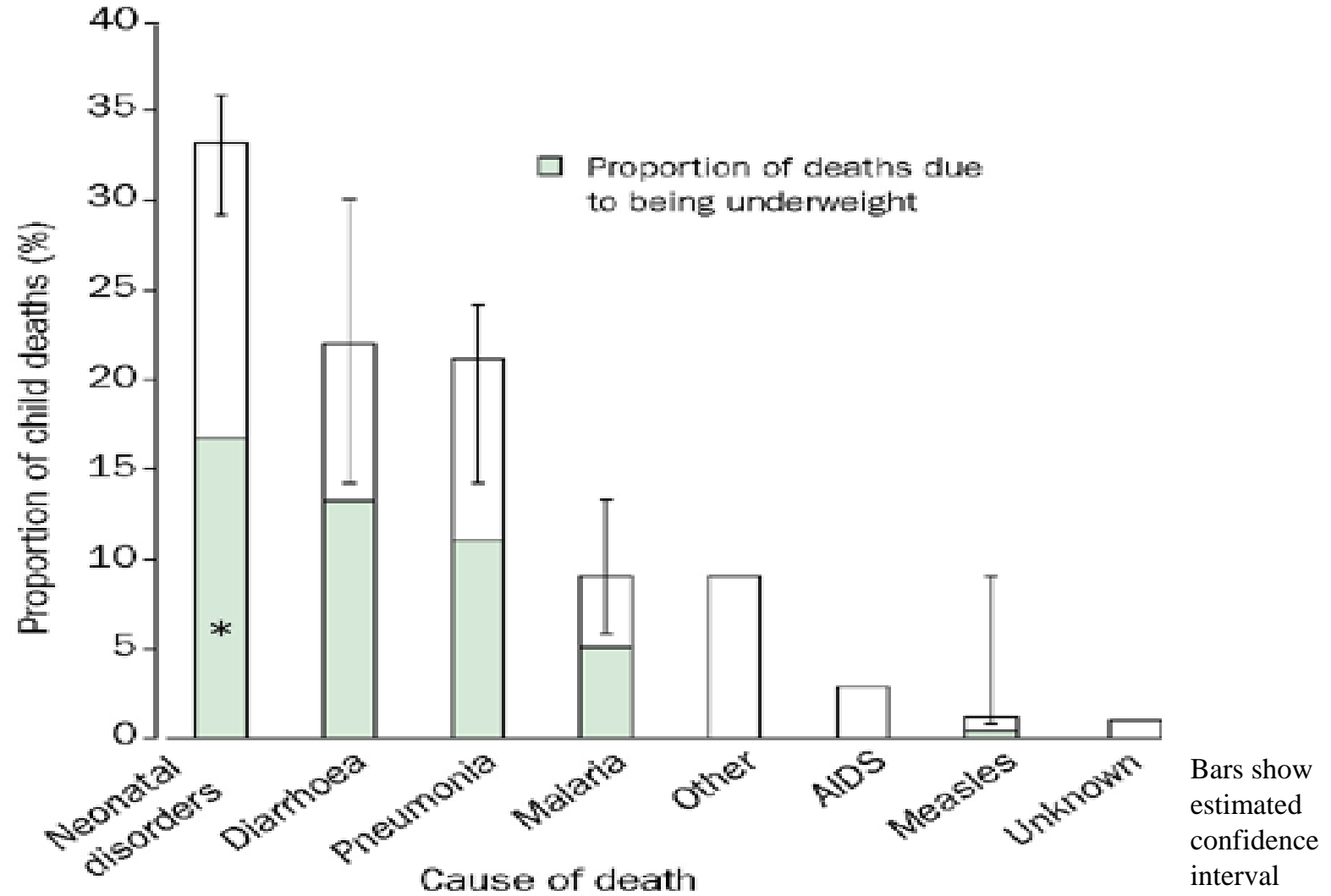
Death Toll of 20th Century Atrocities

<http://users.erols.com/mwhite28/war-1900.htm>



Only the good die young? – what kills children

Cause of death for children under five



“The world's biggest killer and the greatest cause of ill health and suffering across the globe is listed almost at the end of the International Classification of Diseases. It is given code Z59.5 -- extreme poverty.

World Health Organisation (1995)

Seven out of 10 childhood deaths in developing countries can be attributed to just five main causes - or a combination of them: pneumonia, diarrhoea, measles, malaria and malnutrition. Around the world, three out of four children seen by health services are suffering from at least one of these conditions.

World Health Organisation (1996; 1998).

Child Poverty in the World

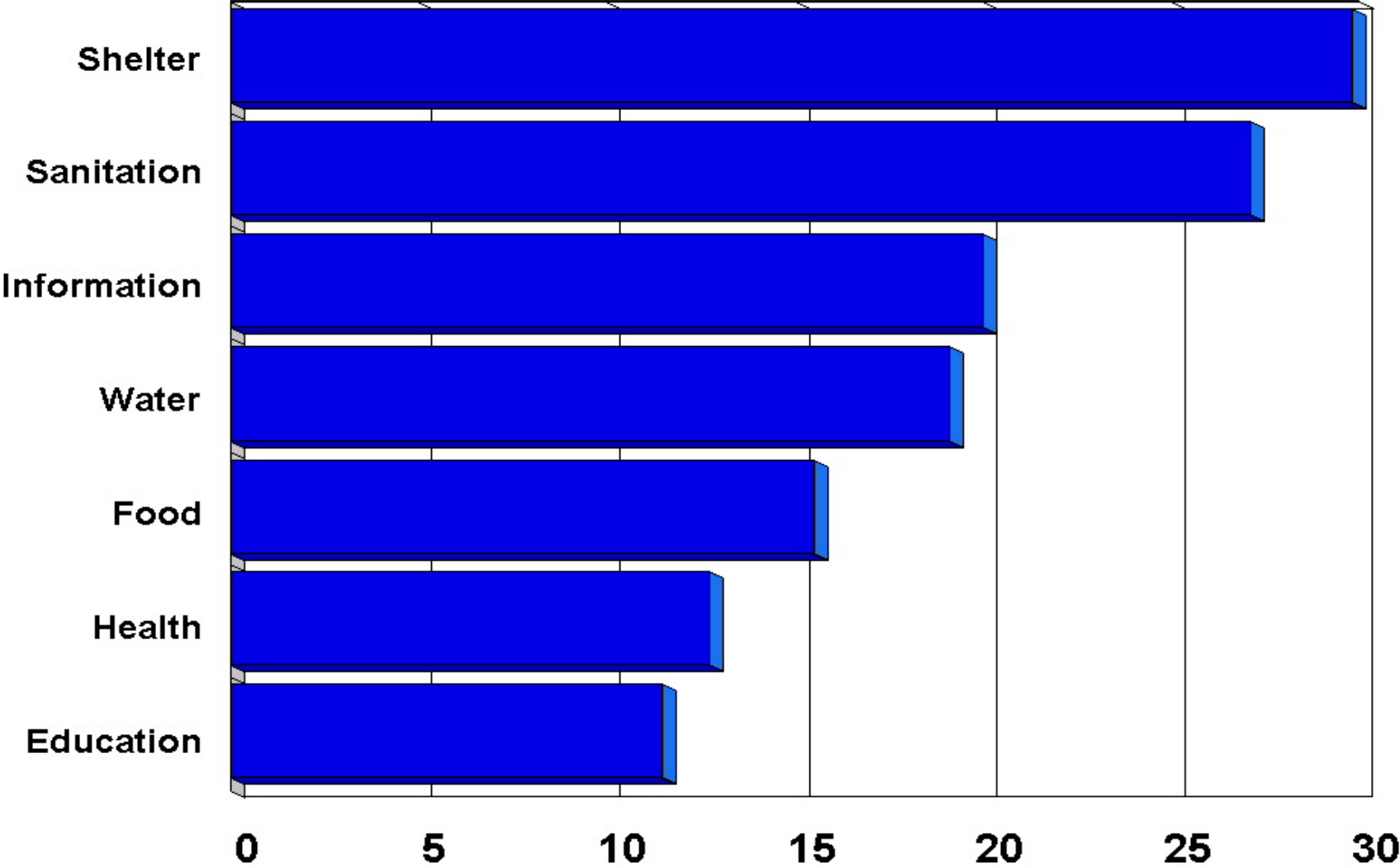
Over one billion children – **half** the children in the world- suffer from severe deprivation of basic human need and **30%** (650 million) suffer from absolute poverty (two or more severe deprivations).

‘severe deprivation of basic human need’ are those circumstances that are highly likely to have serious adverse consequences for the health, well-being and development of children. Severe deprivations are causally related to ‘poor’ developmental outcomes both long and short term.

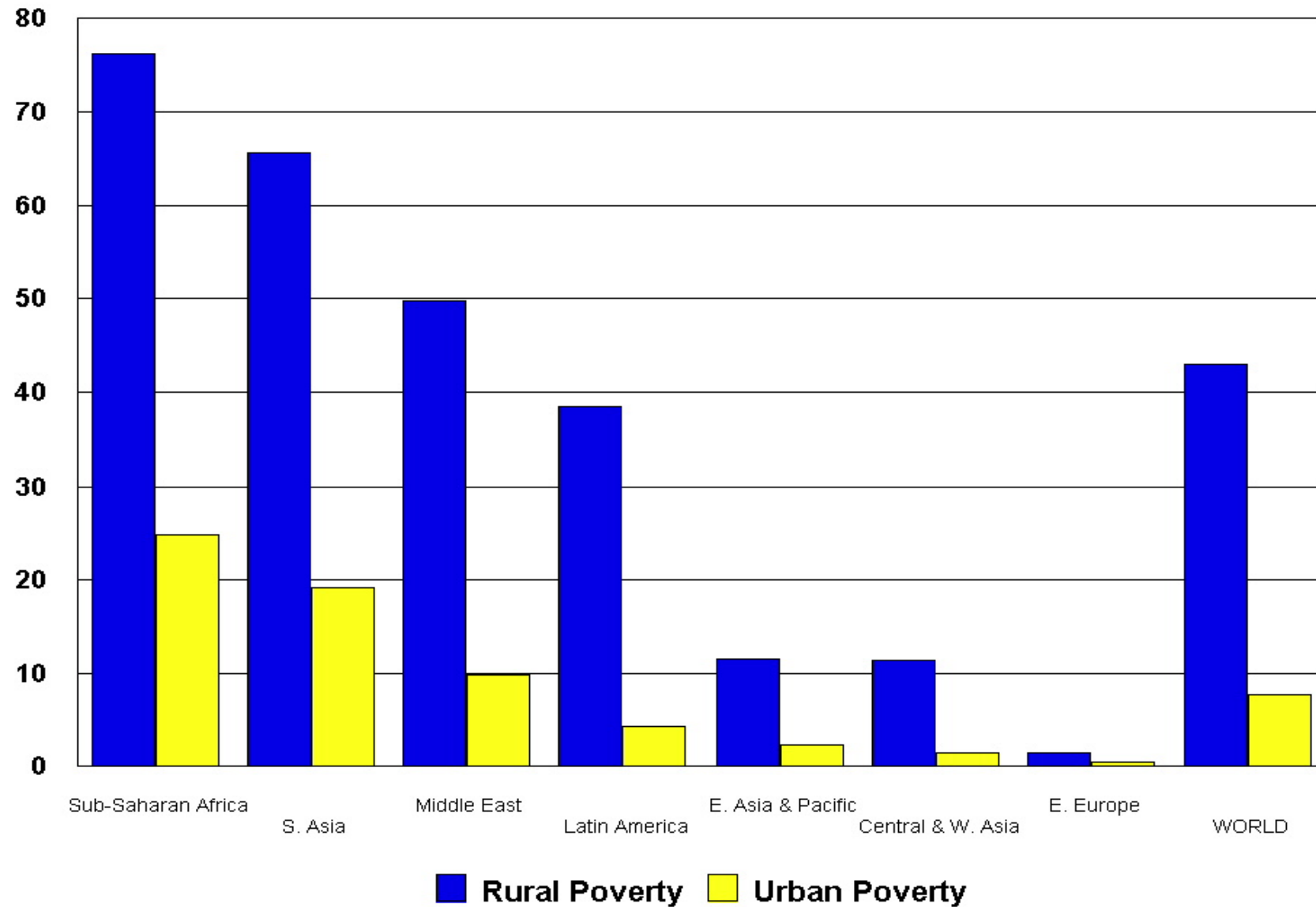
Severe Deprivation of Basic Human Need

- Almost a third of the world's children live in dwellings with more than five people per room or which have a mud floor.
- Over half a billion children (27%) have no toilet facilities whatsoever.
- Over 400 million children (19%) are using unsafe (open) water sources or have more than a 15-minute walk to water.
- About one child in five, aged 3 to 18, lacks access to radio, television, telephone or newspapers at home.
- Sixteen percent of children under five years in the world are severely malnourished, almost half of whom are in South Asia.
- 275 million children (13%) have not been immunised against any diseases or have had a recent illness causing diarrhoea and have not received any medical advice or treatment.
- One child in nine aged between 7 and 18 (over 140 million) are severely educationally deprived - they have never been to school.

Percent of the world's children severely deprived of basic human needs



Absolute Poverty of Children: Rural and Urban Distribution

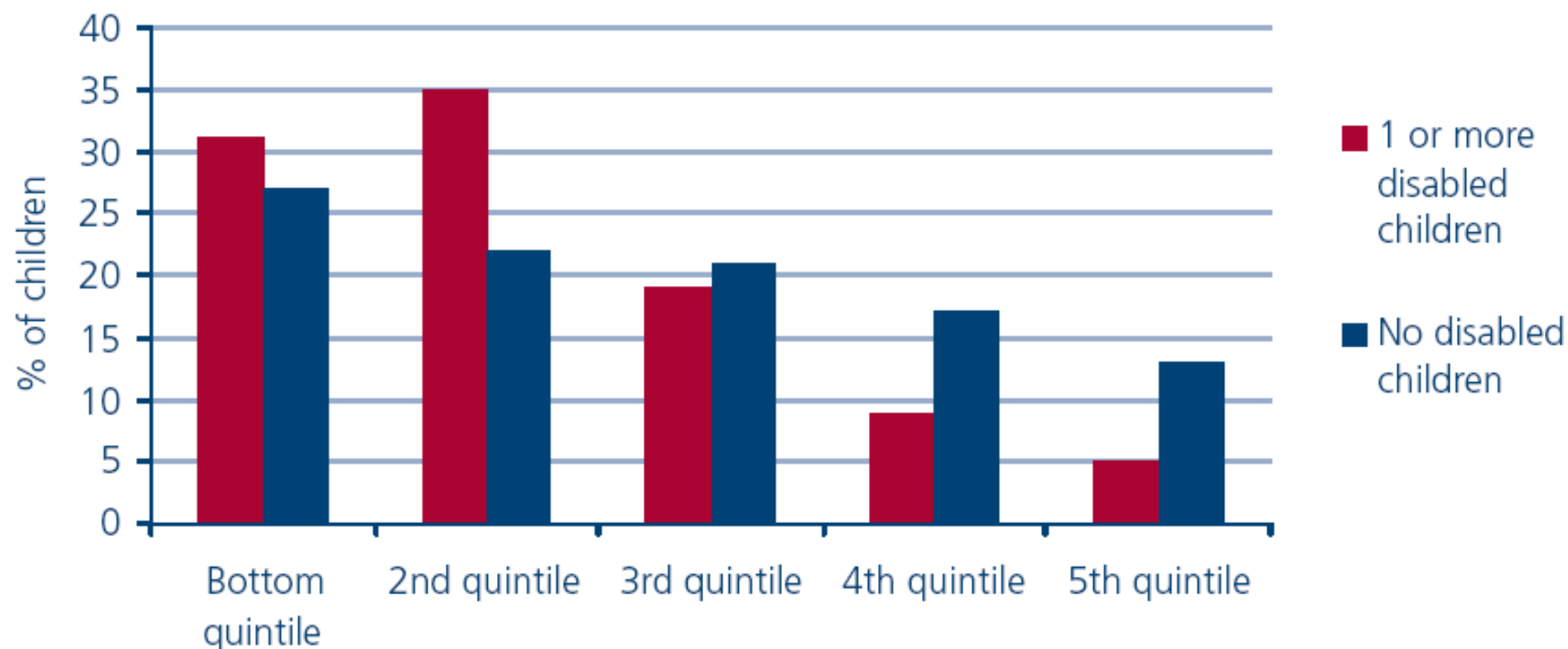


The circumstances of disabled children in Britain

The problem of disability & child poverty

- Three quarters of parents with a disabled child say they do not have enough money to care for their child
- Meeting basic needs costs more for families with severely disabled children.
- Families with a disabled child have significantly lower incomes than other similar families.
- Inadequate income is a source of anxiety for parents and it also prevents them from gaining access to other resources, such as purchasing domestic help and child care (Beresford, 1995)
- Mothers with a disabled children are much less likely to be in employment than their peers, yet research shows that many would like to work and maternal employment provides both material and social resources and results in lower levels of stress (Lawton, 1997)

Figure 2.14: Quintile distribution of income for households with and without disabled children



Source: Households Below Average Income (2003).

The Cost of Childhood Disability

The budget standards estimated an average cost of £8,205 a year to bring up a child with a severe disability. This is at least three times more than the amount required to bring up a child without a disability.

Benefits for severely disabled children would need to be increased by between 20 and 50 per cent, depending on the child's age and type of impairment, to meet the costs of the minimum essential budgets

The Financial Effect

Parents of disabled children spent almost twice as much on basic goods and services (£67.59) as parents of non-disabled children (£32.21).

All parents strived to spend enough to meet the needs of their children. To achieve this they spent less on themselves and made other savings wherever they could. 80 per cent of families had an income of £310 or less per week

Parents were only able to spend half of what they felt was required to ensure a reasonable standard of living. The biggest shortfall between actual spending and the budget standards was for children aged up to five years.

Benefit Levels are Too Low for Disabled Children

Minimum Essential Costs and Maximum Benefit Income Available, 1997/98

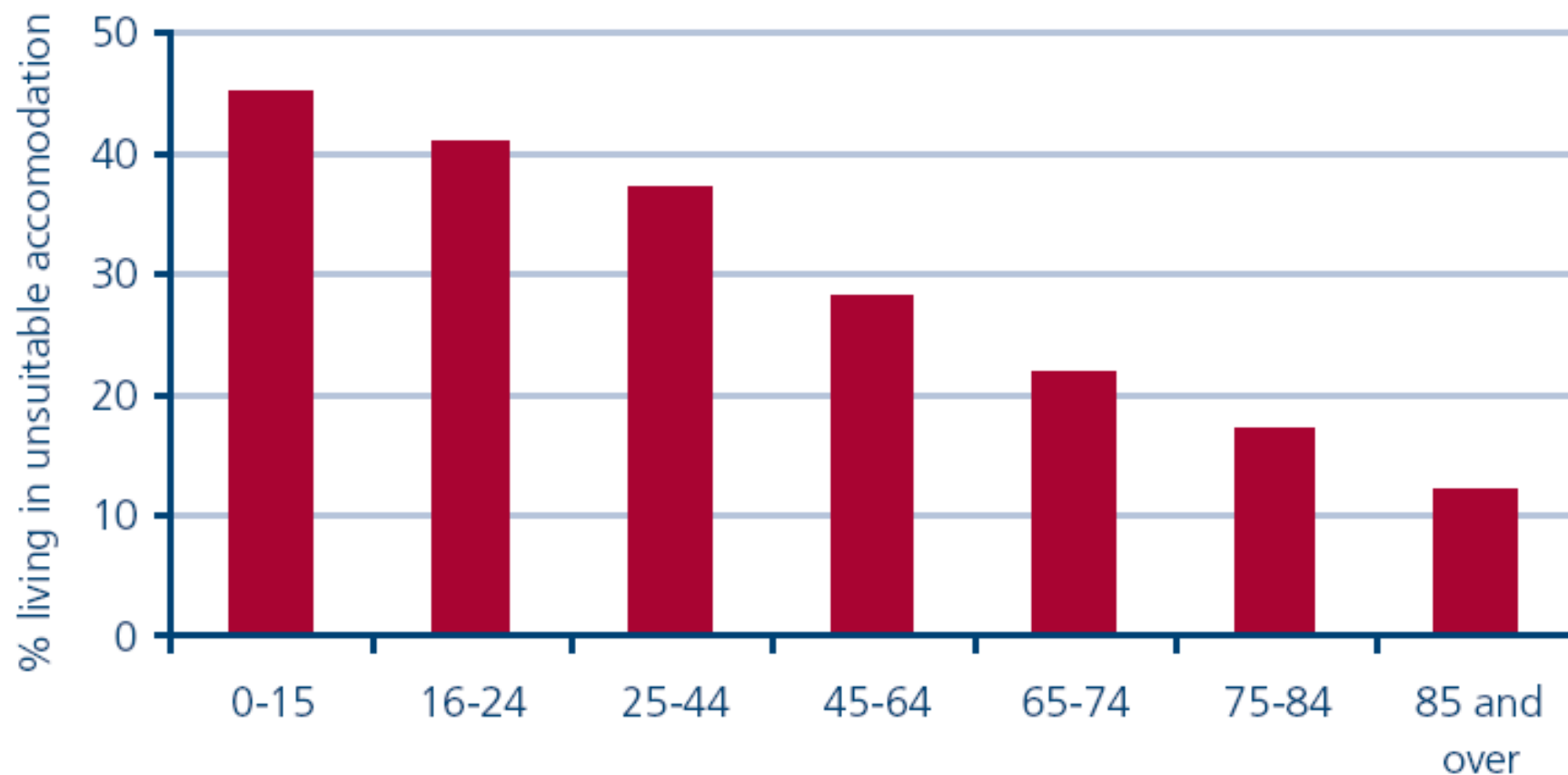
Age Group	Mobility Disability	Maximum Benefit Income	Difference £	Sensory Disability	Maximum Benefit Income	Difference £
0-5	£170.68	£87.35	-£83.33	£143.20	£70.95	-£72.25
6-10	£151.08	£121.95	-£29.13	£131.23	£84.10	-£50.13
11-16	£169.61	£129.80	-£39.81	£126.63	£91.95	-£34.68

Barbara Dobson and Sue Middleton (1998)

Housing Conditions of Families with Disabled Children

- Three quarters said their housing was unsuitable
- Two fifths said their housing was 'poor' overall
- Just under a fifth of all respondent families lived in cold, damp housing in poor repair
- Limited play space affected a third of families
- A quarter of families reported difficulties with stairs
- A quarter of families reported a lack of room for storing equipment.

Figure 2.17: Percentage of disabled people living in unsuitable accommodation



Source: ODPM (2003) Housing in England 2001/2.

Education Act, 1944

Required local Education Authorities to ascertain the needs of children in their area for special educational treatment, and recommended that they be educated in ordinary schools whenever possible.

A group of children were considered ineducable or 'imbecile', but for those considered educable in ordinary or special schools eleven categories of handicap were established.

- Blind,
- Partially sighted
- Deaf
- Partially deaf
- Delicate
- Diabetic
- Educationally subnormal
- Epileptic
- Maladjusted
- Physically handicapped
- Speech defective

Oral history of life in Special Schools for the Blind, 1944-1981

There was one girl, June her name was, and for whatever reason she would wet herself occasionally, and Miss H used to really lay into June. When you're a child you accept it because you think it's normal, you think it's the way people treat other people, you don't realise that there is anything wrong with it, you accept it as a normal way for adults to behave. I can see from that angle how abused people can become abusers because they think it's the normal way to carry on.

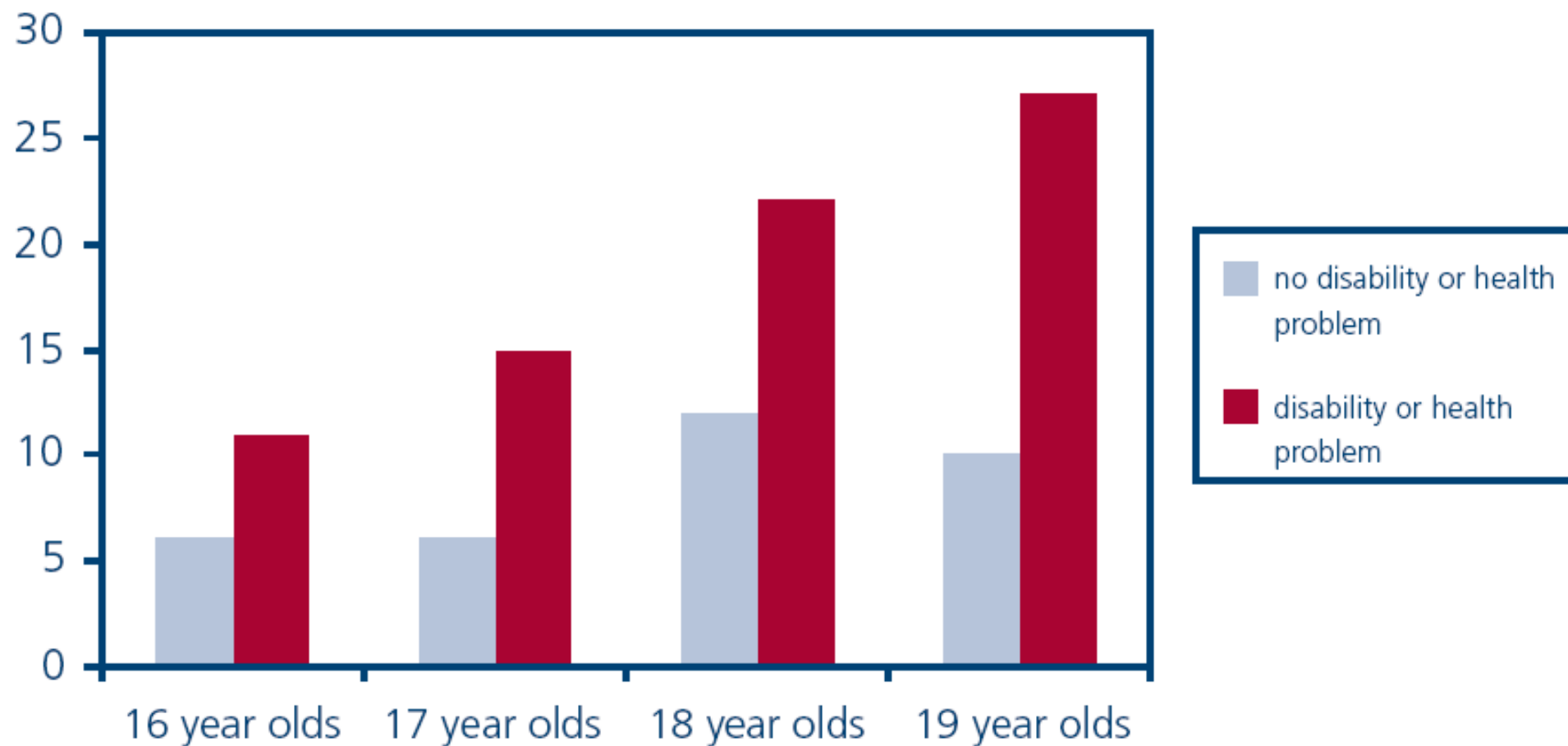
There was another poor girl called Lena. Lena was bent down to the left, she had a hearing aid, she was partially sighted, she had heart and lung problems and problems with her legs and her back. She was very placid and inoffensive but the staff really had it in for her. They were absolutely abominable. On walks they would taunt her shouting 'get a move on!' and call her all sorts of names and try to get us to join in. One day she sat down in the middle of the road and refused to go on but they dragged her up. They poked and pushed her forward and clouted her. She hadn't long left the school when she died at seventeen. I completely believe that they killed her. If they hadn't bullied her like that she might not have died. They wore her out. They killed her.

French & Swain (2006)

Exclusion of disabled children

- The educational experiences of disabled children has vastly improved yet childcare services and play and leisure activities open to non-disabled children and young people frequently exclude disabled children and young people. The ordinary sources of having a 'break' are therefore closed to parents and they have to look to specialist provision which often means segregated provision – facilities and services which separate their children from their peers and the wider community.
- The human rights of disabled children (for example, their right to be consulted) are often not recognised in practice, particularly in the case of those who have high levels of support needs.

Figure 2.10: Percentage of young people not in education, training or employment, by age and whether they have a disability or health problem



Source: The Youth Cohort Study (YCS) (2003) Cohort 10, Sweep 4.

Improving the life chances of disabled people

The early years are a critical period for disabled children. Child development and future life chances – as well as those of siblings – are critically affected by the support and services received by young disabled children and their families. Targeting support at these families will also play a major role in helping to eradicate child poverty.

Chapter 5, Improving the life chances of disabled people (January 2005)

<http://www.strategy.gov.uk/files/pdf/disability.pdf>

Meeting the child-care challenge

‘....the growth in available child-care provision in recent years has not been matched by a comparable growth in schemes which make child-care available for disabled children. Specialist services for disabled children need to be fully integrated within a range of early years and other services so that parents have access to a full range of options.’

Early Years: The Problem?

"My view is disabled children are still seen as sub-species of child. There is definitely a perception in the early years sector that they know more about Martians than they do about disabled children. There is so much fear and ignorance about. Too many childcare workers see the disability first rather than the child, although there are some honourable exceptions."

Christine Lenehan,

Director of the Council for Disabled Children (Guardian 23/2/2005)

The Plan: 'Ordinary' Lives

- Overarching vision for accessing 'ordinary' lives:
- By 2025, all families with disabled children to have access to high-quality, affordable childcare and early education.
- A lack of childcare and early education means that many families with disabled children are socially and economically disadvantaged.

**What we currently know about the circumstances
of disabled children in 'poor' countries**

How many disabled children?

- 1) The World Health Organisation claims that an estimated 10% of the world's population - approximately 650 million people, of which 200 million are children - experience some form of disability (*World report on disability and rehabilitation concept paper*)
- 2) The United Nations Disability Statistics Database (DISTAT) has disability prevalence estimates from 112 Census and Survey datasets, the rates for children aged 0-14 are typically less than 2%. Often the 'rich' countries report higher rates than 'poor' countries.
- 3) UNICEF's recent MICS-3 surveys based on the Ten Questions have produced child disability prevalence rates (aged 2 to 9) of between 14% and 35%

Problems of definition and question design

Pakistan Census 1998

God forbid, is there any disabled person in the household, if so, state the nature of disability.

1. Blind
2. Deaf/Dumb
3. Physical handicapped
4. Mentally retarded
5. Multiple disabled
6. Insane
7. Others

Cape Verde Census 2000

P11. Tem alguma deficiência?

United Republic of Tanzania 2002

6. Does (name) have any disability
 - Physically Handicapped / Leprosy
 - Visually Impaired
 - Dumb
 - Hearing / Speech Impaired
 - Albino

Ten Questions (TQ) for child disability (aged 2 to 9)

1. Compared with other children, did (name) have any serious delay in sitting, standing, or walking?
2. Compared with other children does (name) have difficulty seeing, either in the daytime or at night?
3. Does (name) appear to have difficulty hearing?
4. When you tell (name) to do something, does he/she seem to understand what you are saying?
5. Does (name) have difficulty in walking or moving his/her arms or does he/she have weakness and/or stiffness in the arms or legs?
6. Does (name) sometimes have fits, become rigid, or lose consciousness?
7. Does (name) learn to do things like other children his/her age?
8. Does (name) speak at all (can he/she make himself/herself understood in words; can he/she say any recognizable words)?
9. a. Ages 3–9: Is (name)'s speech in any way different from normal?
b. Age 2: Can he/she name at least one object (animal, toy, cup, spoon)?
10. Compared with other children of his/her age, does (name) appear in any way mentally backward, dull or slow?

Results from two recent studies based on survey data from many countries

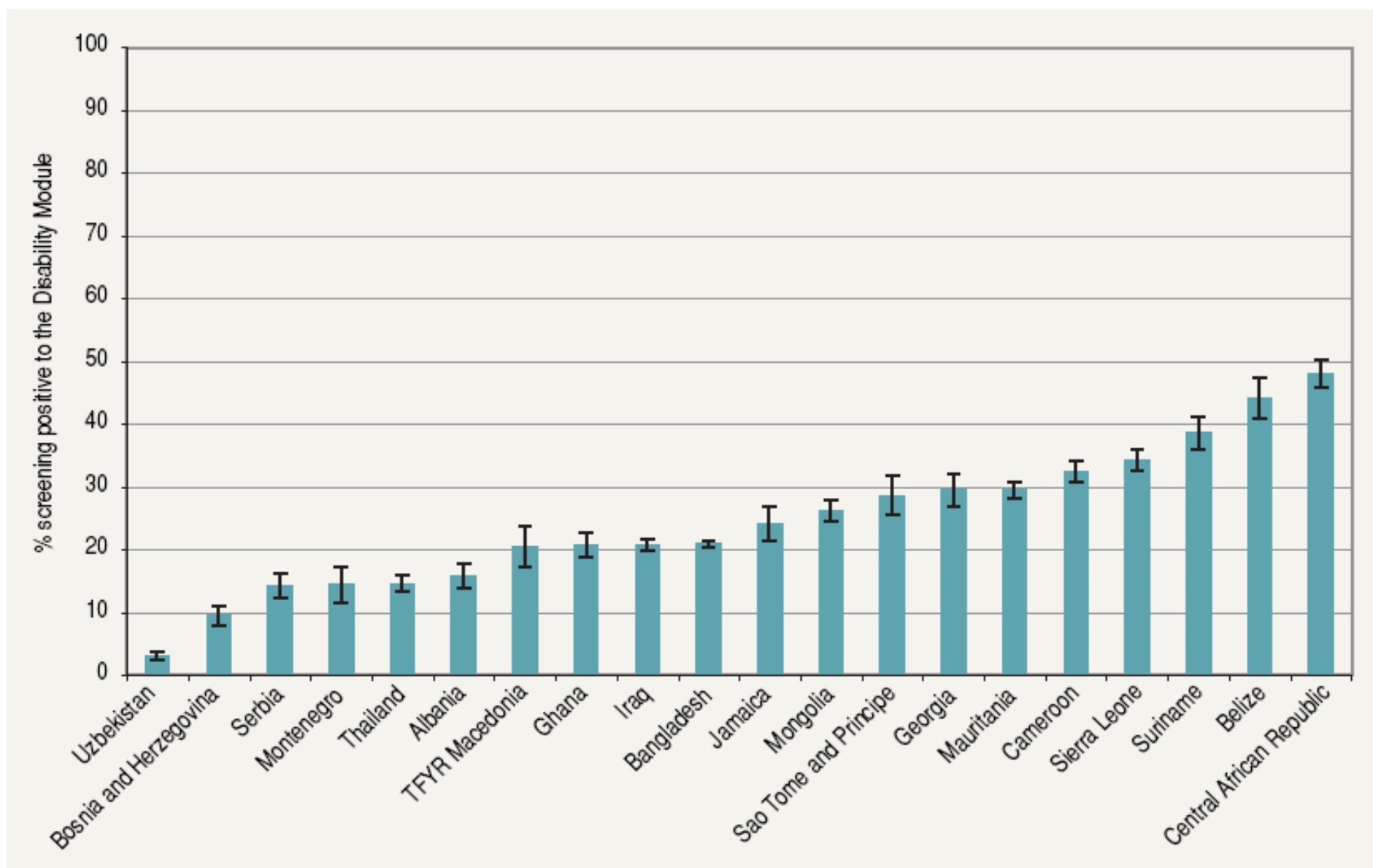
A) Filmer (2008) '*Disability, Poverty and Schooling in Developing Countries: Results from 14 Household Surveys*' found

- 1-2 percent of the population had a disability, and prevalence rates were 'not always sensitive' to the wording of the question asked about disability
- Child disability (aged 6-17) was not correlated with poverty – disabled children were not poorer than their peers
- In all countries disabled children were significantly less likely to be attending school

B) UNICEF/University of Wisconsin (2008) '*Monitoring Child Disability in Developing Countries*' found in 20 Household Surveys that

- Between 14% and 35% of children aged 2 to 9 were disabled
- Child disability was weakly correlated with poverty/lack of wealth in 12 out of 18 countries – disabled children were probably poorer than their peers
- Disabled children were just as likely to be attending school as their non-disabled peers in all countries

FIGURE 2. Percentage of all children ages 2–9 years screening positive to the Disability Module, by country (95% confidence intervals).



Source: Monitoring Child Disability in Developing Countries (2008)

FIGURE 9. Percentage of children ages 2–9 years screening positive to the Disability Module by age group, by country.

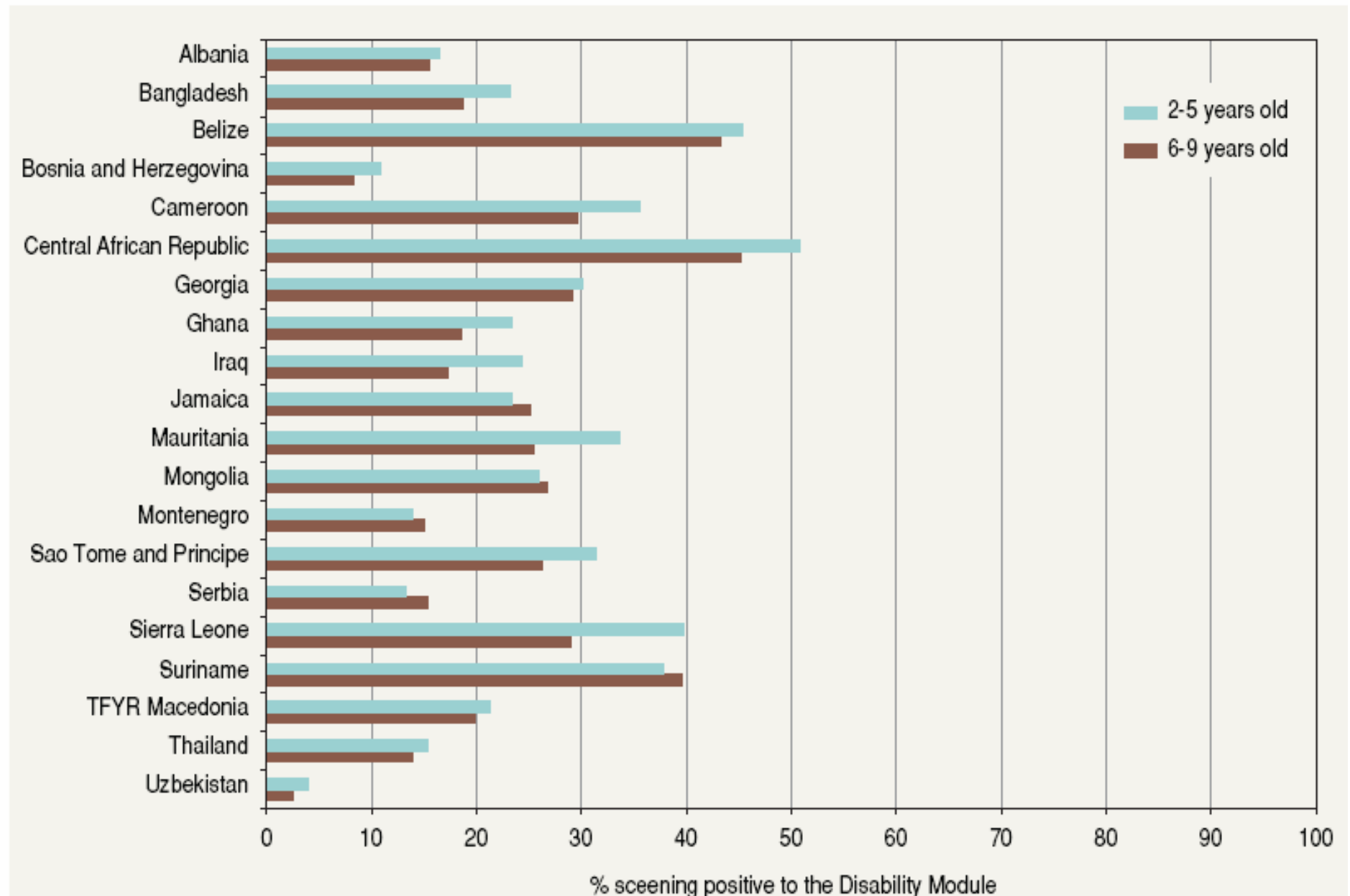
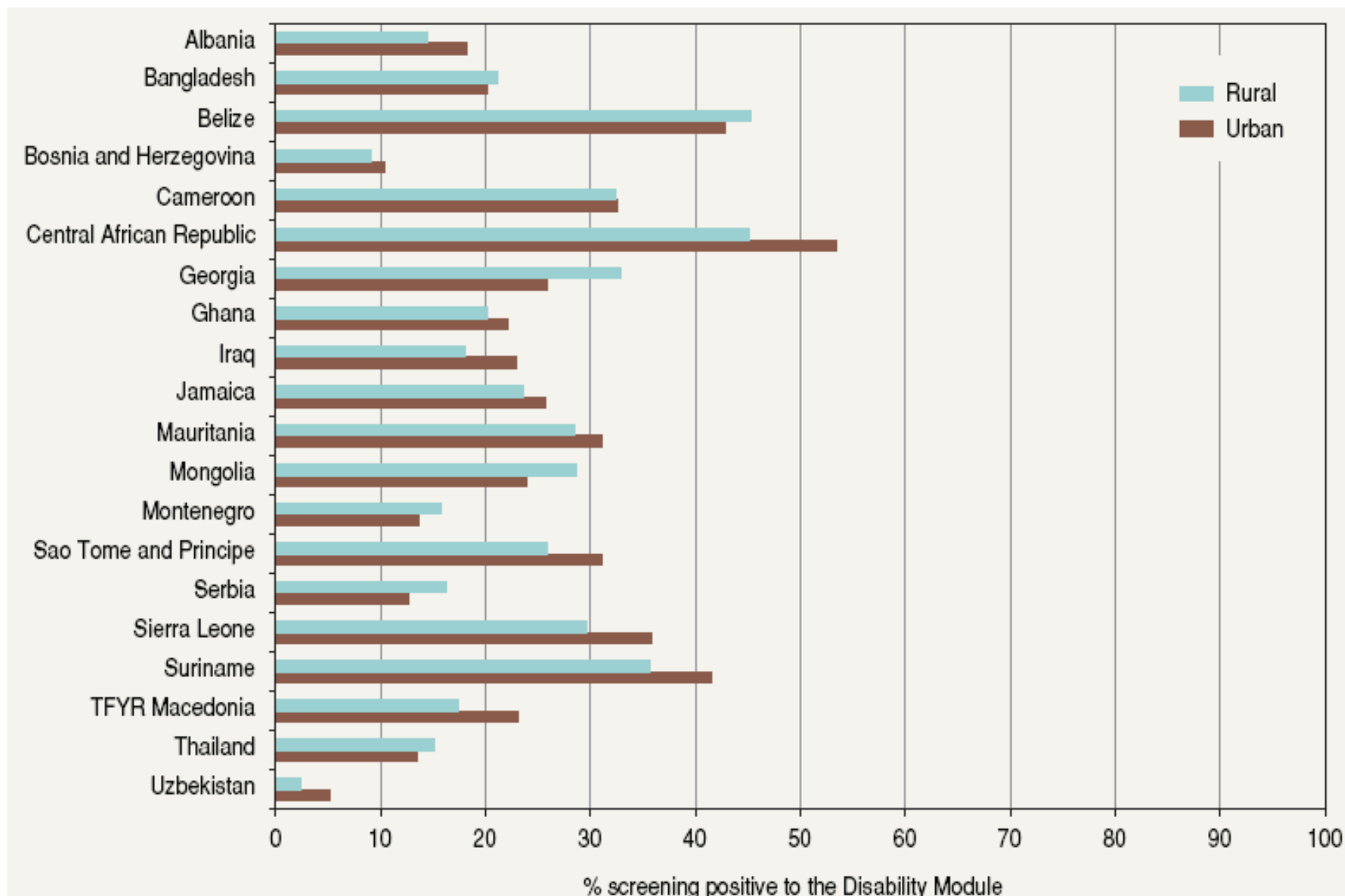


FIGURE 10. Percentage of children ages 2–9 years screening positive to the Disability Module by place of residence, by country.



Percentage of children aged 6 to 9 attending school

	School Attendance	
	Disabled	Not Disabled
Jamaica	97	100
Suriname	96	96
Belize	96	99
Albania	96	95
Thailand	95	99
Serbia	94	95
Georgia	93	96
Montenegro	91	92
Ghana	86	82
Mongolia	85	86
TFYR Macedonia	83	92
Bosnia and Herzegovina	83	84
Bangladesh	82	85
Sao Tome and Principe	81	84
Iraq	80	82
Uzbekistan	80	77
Cameroon	73	79
Sierra Leone	68	71
Central African Republic	54	51
Mauritania	41	42

Future research plans

Currently working on developing a joint bid involving academics at the University of Warwick, Bristol and elsewhere to investigate the social and material circumstances of disabled children in developing countries (e.g. housing, education, etc.).

- 1) We aim to look at 3 countries (Colombia, Iraq, South Africa) in different regions of the developing world and compare the results from household survey data and national Census for the same countries in order to determine if there are any systematic biases, but also to produce an enriched analyses not available from Census data alone.
- 2) To determine if the rights of disabled children in the UNCRC & UNCRPD are being fulfilled
- 3) To examine the consistency of available data with the ICF-CY.
- 4) Produce analyses from a larger number of countries with available Census data with the aim of working towards a representative global picture of the living conditions of disabled children