



MISSING BILLION

Transforming health systems
to deliver for everyone

The Missing Billion:

How is access to health services and healthcare systems working for people with disabilities?

**Hannah Kuper
International Centre for Evidence in Disability
LSHTM**

Oliver McGowan death prompts mandatory autism training

🕒 5 November 2019

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NHS trust fined £2m for Connor Sparrowhawk and Teresa Colvin deaths

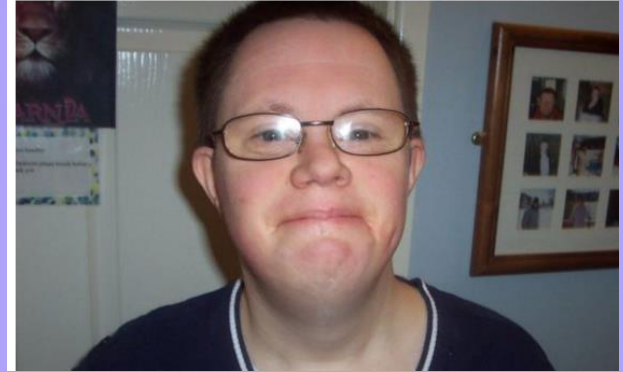
Southern Health fined over deaths of 45-year-old woman and epileptic teenager in its care



Richard Handley: 'Gross failures' in constipation death

🕒 8 February 2018

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The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK

	People with intellectual disabilities	Population comparison
Men: median age at death	65 years	78 years
Women: median age at death	63 years	83 years
Deaths <50 years age	22%	9%
Severity		
• Mild	68 years	
• Moderate	64 years	
• Severe	59 years	
• Profound	46 years	

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Severity		
• Mild	68 years	
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• Severe	59 years	
• Profound	46 years	
Avoidable deaths	49%	24%
Deaths amenable to good quality healthcare	37%	13%

HEALTH
is a HUMAN
RIGHT



CONVENTION
ON THE RIGHTS
OF PERSONS
WITH DISABILITIES



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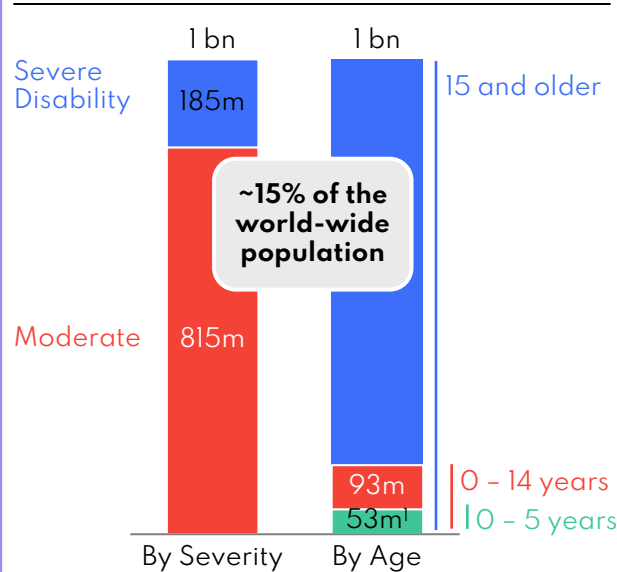
Are people with disabilities more vulnerable to poor health and early mortality? If so, why?

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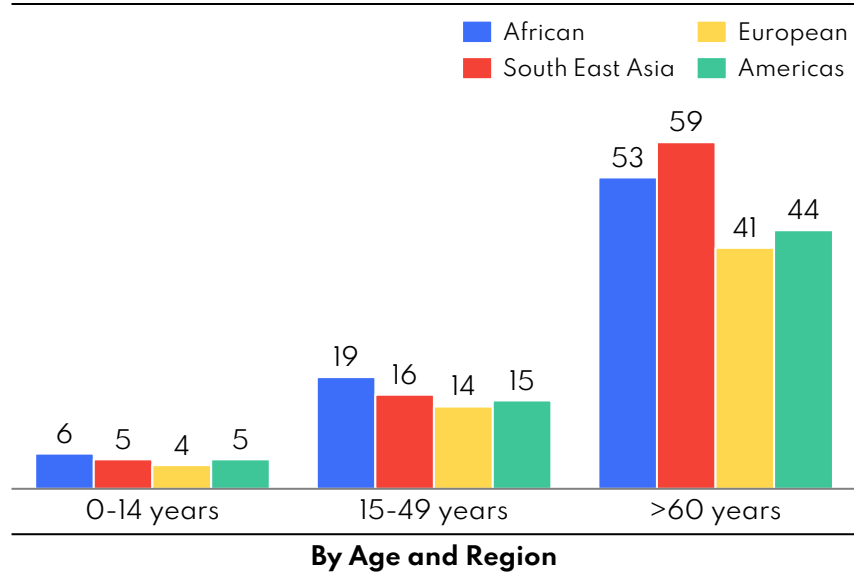
There are 1 billion people with disabilities worldwide

People with severe and moderate disabilities

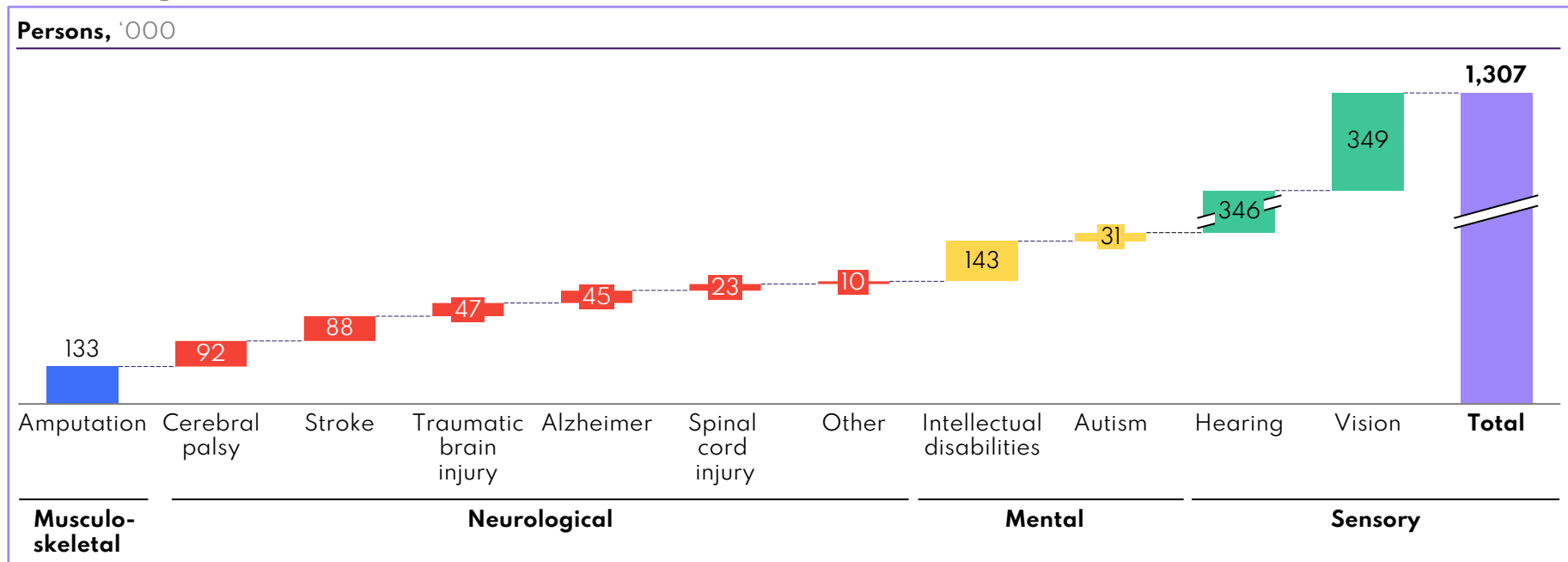
In absolute numbers, 2004



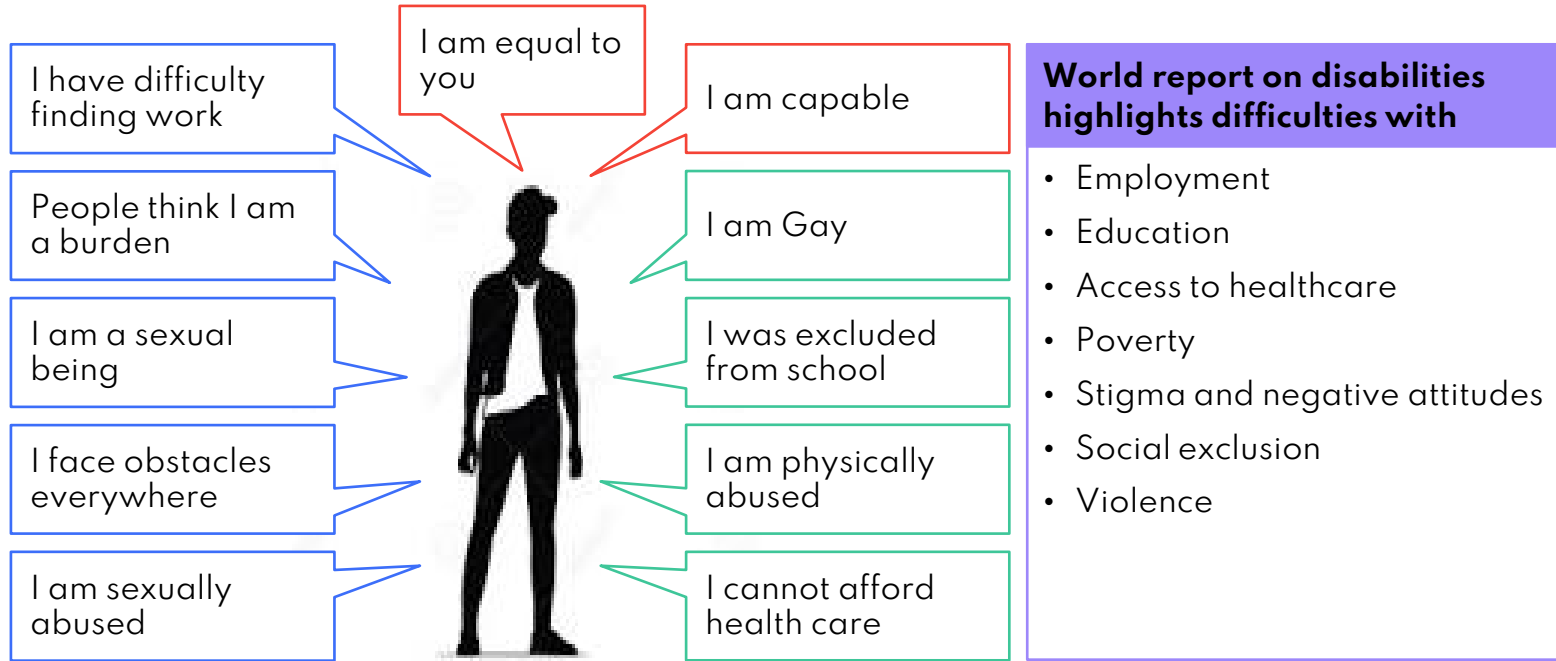
Prevalence, %



There are many different types and categoriza-tions of disabilities



People with disabilities left behind in different aspects of life

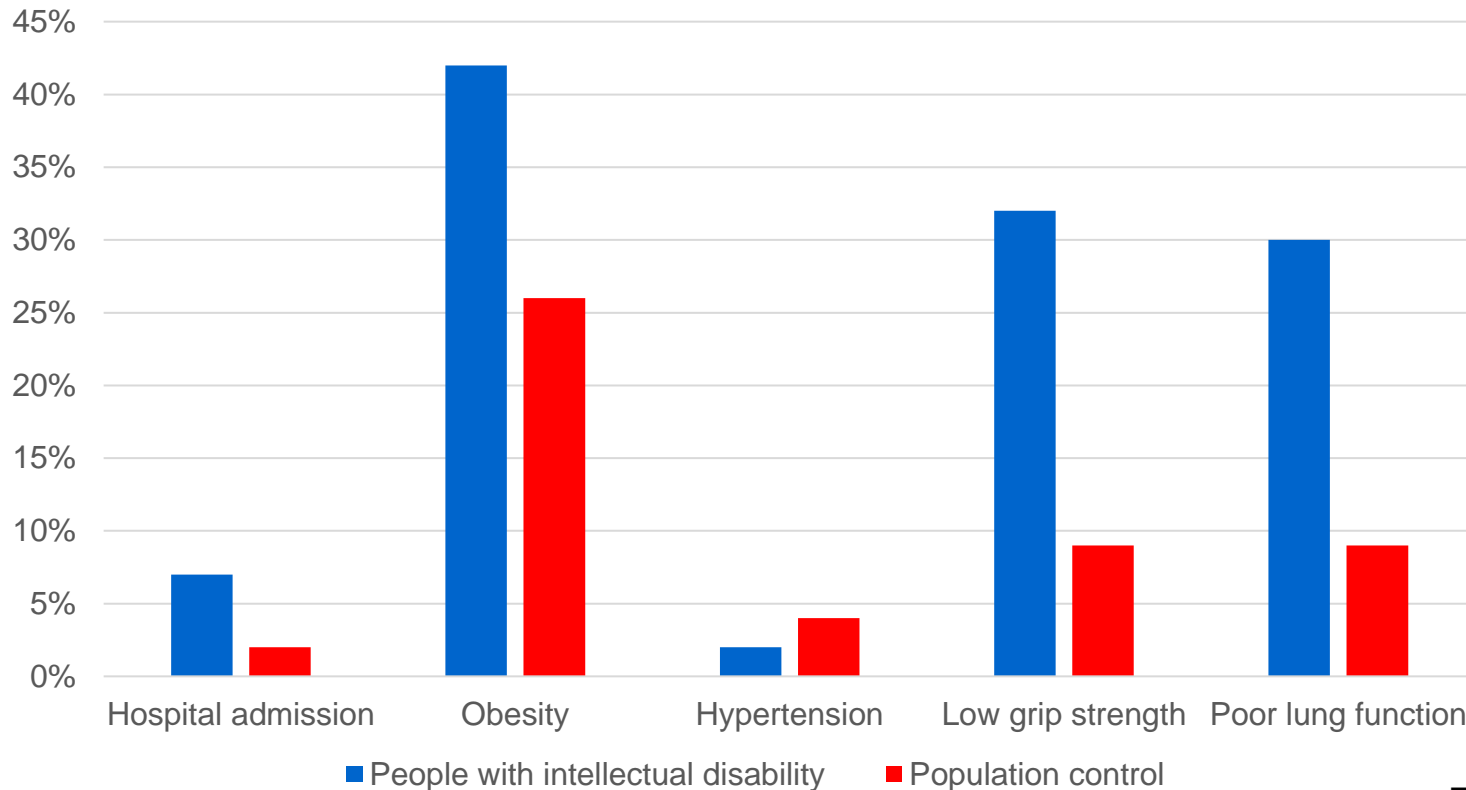


**Health needs
of people with
disabilities
are three-fold**

1

Higher vulnerability to poor health

Physical health and intellectual disability (Britain)



Emerson, Int J Equity
Health, 2016; 15:11



**Health needs
of people with
disabilities
are three-fold**

1

Higher vulnerability to poor health

2

Regular health needs

3

**Specialized medical treatment or
rehabilitation services**

Let's look at some examples...



United States

Dustin

Man with intellectual disabilities

"I am 20 years old. I live in a group home."

"My teeth hurt at night."



Malawi

Simon & Tuwafu

Boy with hearing impairment, and his father

"My 8 year old son, Simon, he cannot hear. I am a farmer with four children."

"I want Simon to get treatment for his hearing loss."



Ghana

Morowa

Woman with a physical impairment

"I am a 27-year-old mother."

"I am 7 months pregnant and am expecting my second child."



South Africa

Anesu

Woman with visual impairment and HIV

"I am 17 years old and I go to school. I was born blind and contracted HIV when I was younger."

"I am now on ARV treatment."



Brazil

Sylvia & Maria

Girl born with Zika syndrome, and her mother

"My Sylvia is 3 years old, she is a very calm child. I noticed some discharge from her little ear."

"We need to check if it is an ear infection."

Examples of observable issues on supply and demand side

Inaccessible facilities



Financial barriers



No proper assistive technologies



Lack of health worker skills

Deaf couple angry with hospital over lack of interpreter during birth of son

Couple says University College hospital, London, failed to provide them with information hearing patients would receive



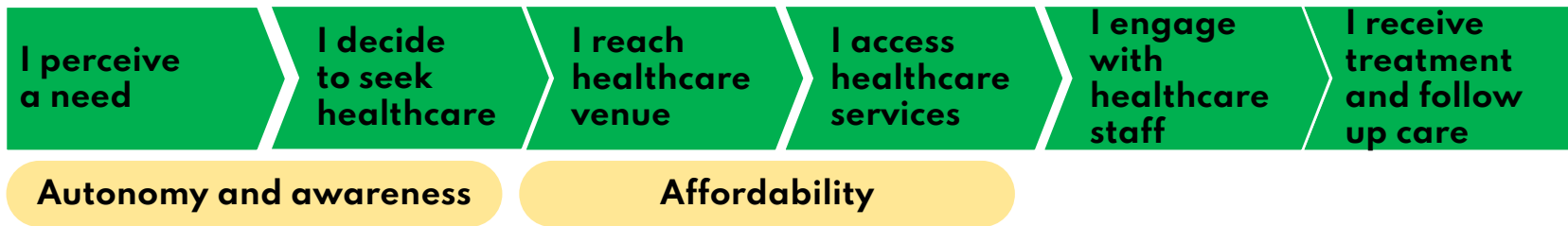
Lack of accessible transport



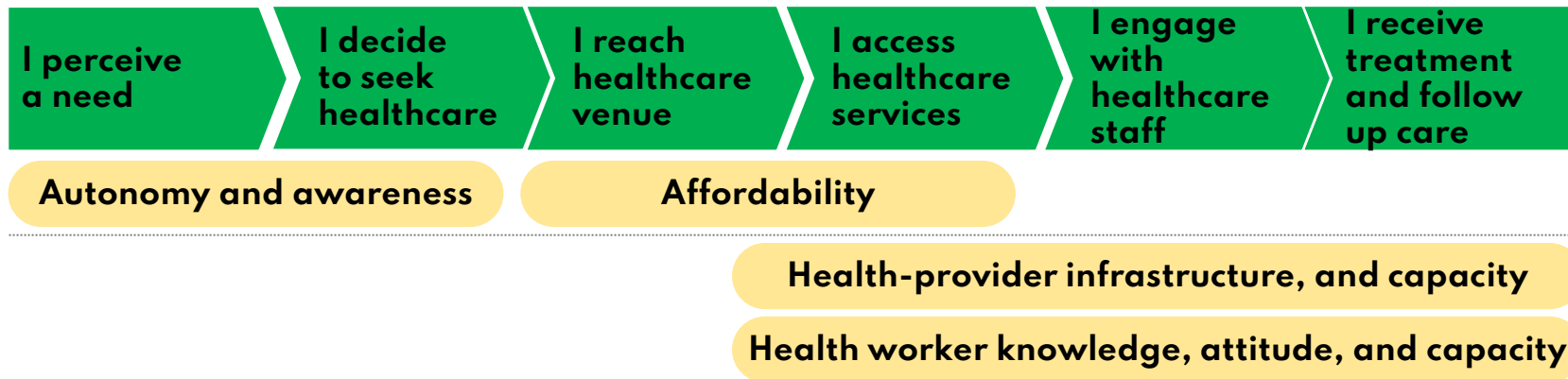
Stigma



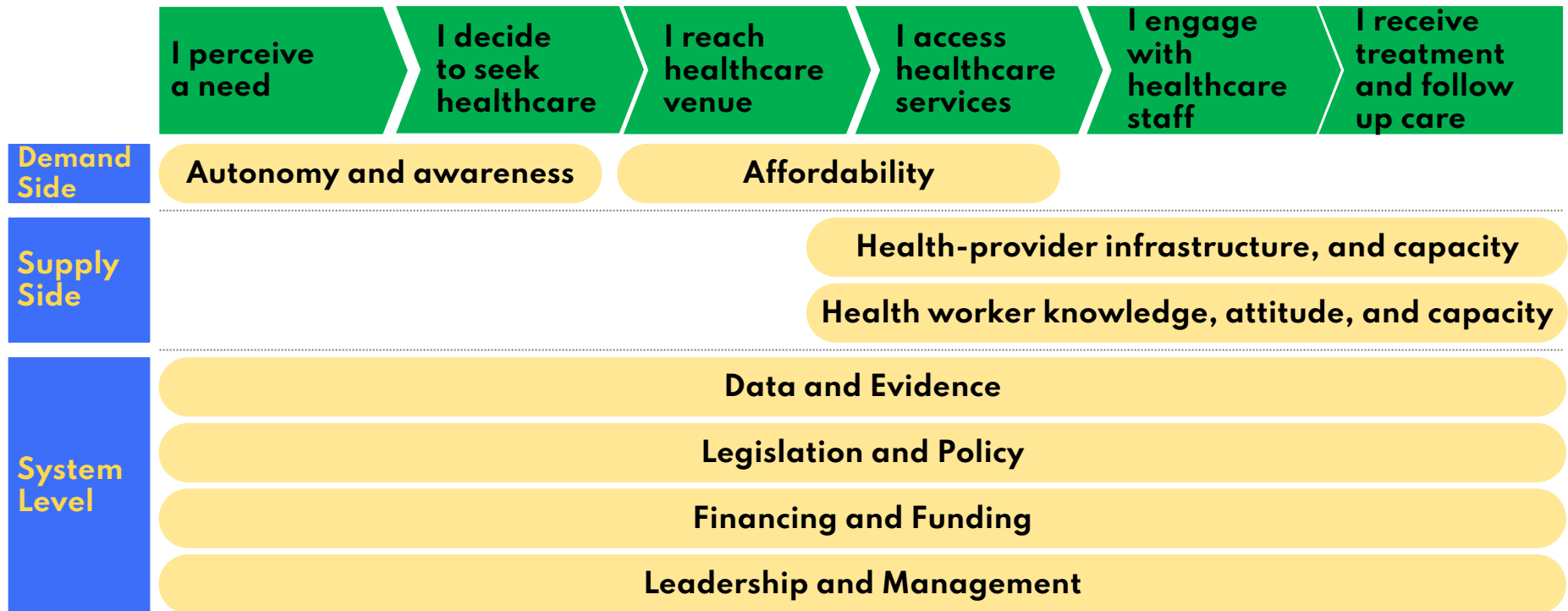
Barriers across health seeking journey



Barriers across health seeking journey



Barriers across health seeking journey



Examples....

Challenges

Evidence / examples

Affordability

- 50% of people with disabilities cannot afford healthcare
- 50% more likely to experience catastrophic health expenditure

Health workers knowledge and skills

- 80% of U.S. medical students received no clinical training for treating people with intellectual disabilities (in survey)¹

Specialized workforce capacity

- Only 6 physicians specialized in rehabilitation in all of sub-Saharan Africa

Health-provider infrastructure

- 65% of all German outpatient doctor offices are not accessible to people with mobility impairments²

Legislation and policies

- Most health plans don't mention people with disabilities
- Some insurance schemes exclude people with disabilities¹

Gaps across the spectrum of healthcare needs

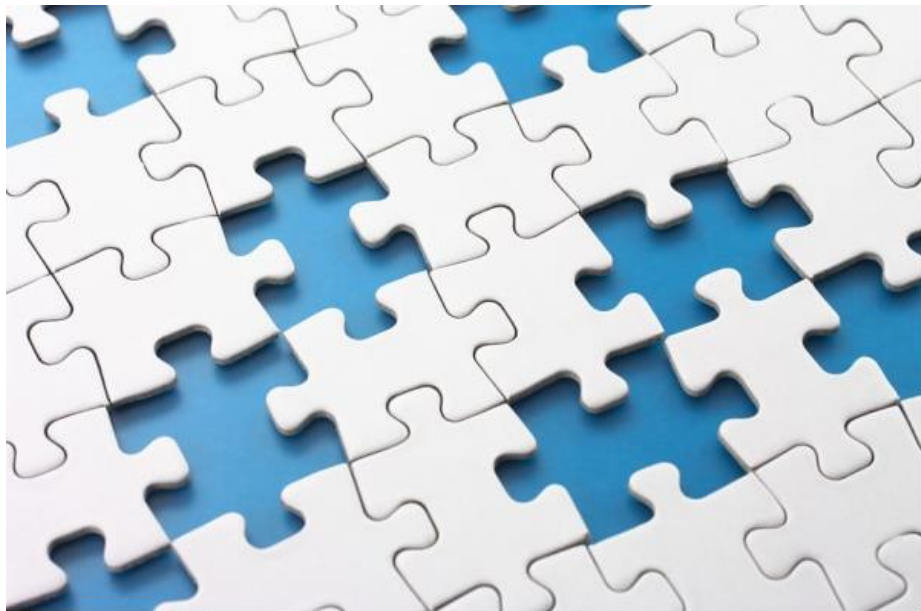


As a result health outcomes are worse in all areas of SDG3

Diabetes 3 x more likely	Malnourished and die as a child 2 x more likely	New study from Kenya¹ – Mortality children 4x HIGHER
Catastrophic health expenditure 50% more likely	HIV / Aids 2 x more likely	
Seriously ill as a child 10 x more likely	Health system reason for low life expectancy 40% of cases	

¹ Lancet Global Health 2019, Premature mortality in children with developmental disabilities
Source: The Missing Billion, Lit review, full details of studies included in Appendix

Large data gaps....



Disability not yet recognized in global health

Key policy documents



- SDG 3 Action Plan – 123 pages

“Global Action Plan for **Healthy Lives and Well-being for All**”

Mentioning

- Disability – 10x
- Rehabilitation – 3x
- Assistive technologies – 0x
- Gender – 95x
- Malaria – 21x, HIV 19x



- Key Asks from UN High-Level Meeting

“Leave No One Behind - Pursue equity in access to quality health services with financial Protection”

- Disability – 0x
- Rehabilitation – 0x
- Assistive technologies – 0x

- UN Resolution – 83 points

- Disability – 2x
- Rehabilitation – 1x
- Assistive technologies – 1x



- Declaration of Health Ministers – 53 declarations

“We reaffirm the right of every human being, without distinction of any kind, to the highest attainable standard of physical and mental health”

- Disability – 1x
- Rehabilitation – 0x
- Assistive technologies – 0x

This situation matters

Health goals not attainable



uhc2030



Failure to ...

- Maximize the individuals' quality of life
- Comply with international law
- Improve health services for all
- Achieve all SDGs

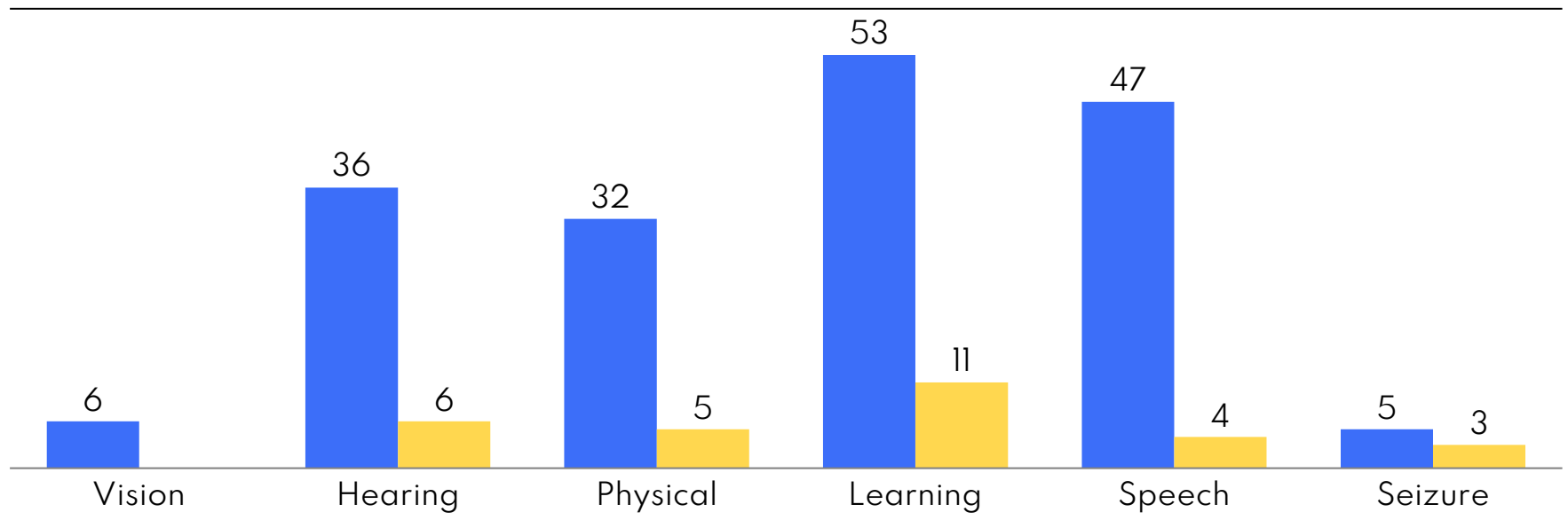
Example: HIV

Overall, 33% of HIV positive children had disabilities, compared to 7% of controls



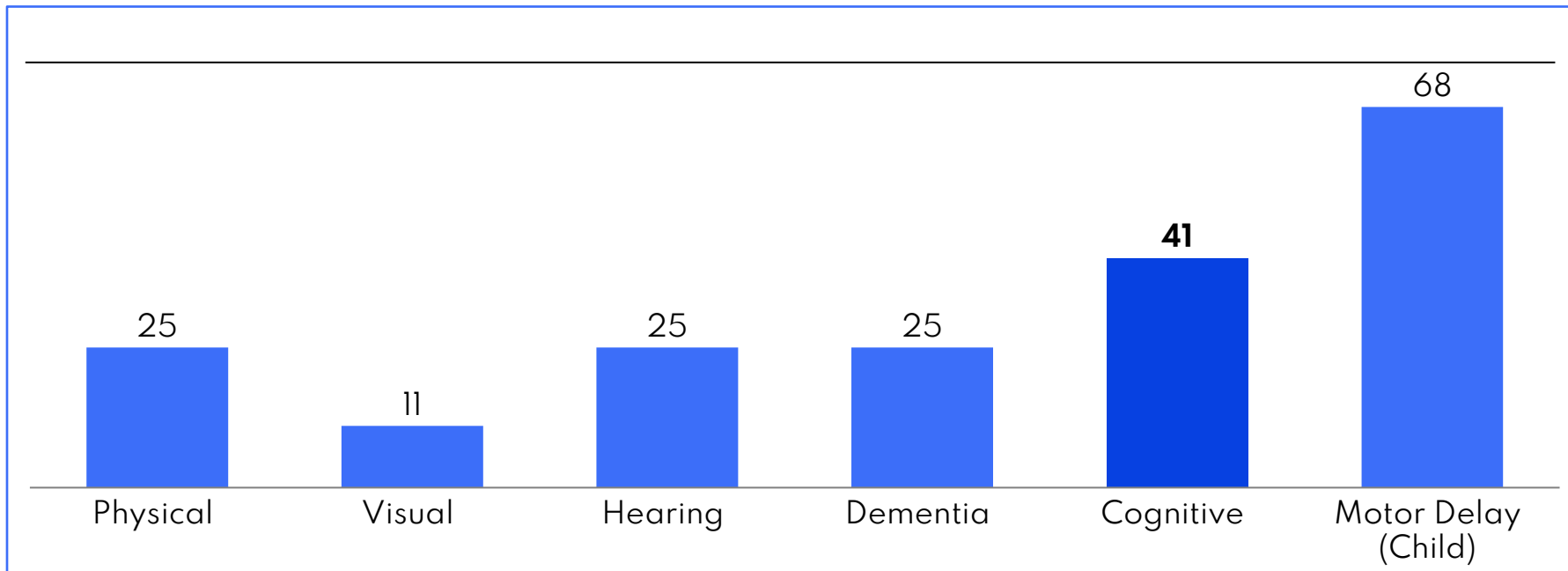
Children reporting disability, In % of all surveyed

■ Case ■ Control



Source: Devendra A, Makawa A, Kazembe PN, Calles NR, Kuper H (2013) HIV and Childhood Disability: A Case-Controlled Study at a Pediatric Antiretroviral Therapy Centre in Lilongwe, Malawi. PLOS ONE 8(12): e84024

Prevalence of impairments among people living with HIV: Sub-Saharan Africa



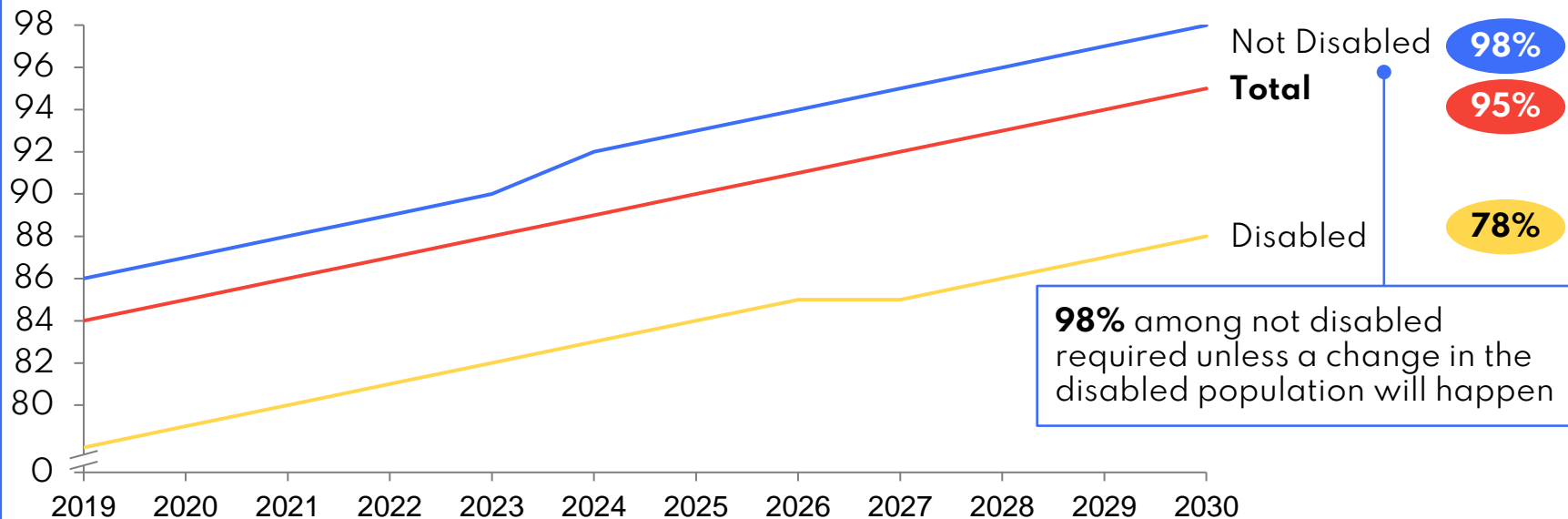
1 De Francesco et al, BMC Infect Dis 2016; 16:617.

Source: Banks et al, The Relationship between HIV and prevalence of disabilities in sub-Saharan Africa, TMIH, 2015:20:411-29

To reach the 95% target, 98% of all non-disabled people must be tested

PRELIMINARY

% of People living with HIV who know their status, by disability, Based on data from South Africa



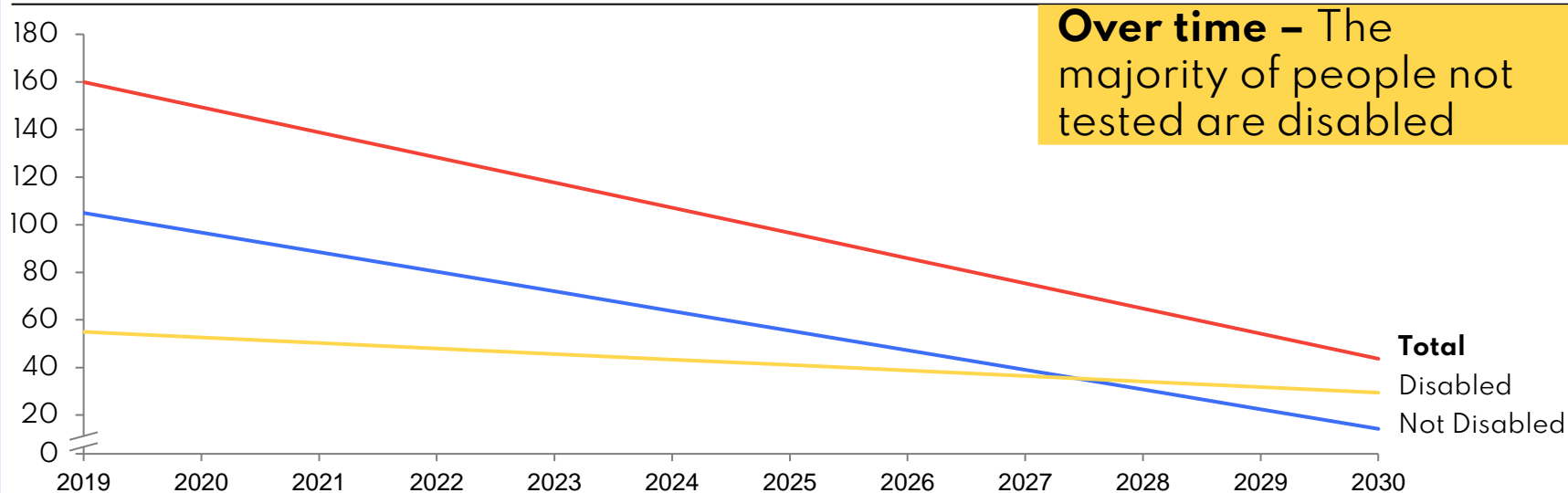
Note: Key assumptions applied in modelling – 1) 10% lower testing rate for people with disabilities; 2) 25% of all people with HIV have disabilities
Source: Missing Billion Team

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People with disabilities more likely to be left untested

PRELIMINARY

People living with HIV not tested, From a cohort of a hypothetical 1000 patients, based on data from South Africa



Disability-inclusion is a necessity to achieving HIV targets

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However there are large gaps in HIV National Strategic Plans

Examples of key policy documents

- | | |
|--|---|
| • Malawi 2015 – 2020, National Strategic plan | <ul style="list-style-type: none">• Disability recognized as vulnerable group• Training should include disability• Encourages disability-friendly infrastructure• Confirms disability-inclusion is enshrined in law |
| • Zambia 2017 – 2022, National Strategic plan | <ul style="list-style-type: none">• Disability recognized as vulnerable group• Address inequities in access to treatment in those left behind, including people with disabilities, and strengthen targeted approach to retain them in treatment services |
| • Nigeria 2017 – 2021, National strategic plan | <ul style="list-style-type: none">• Footnote that vulnerable groups include people with disabilities |
| • Haiti 2018 – 2020, strategic plan | <ul style="list-style-type: none">• No mention of disability |



**What should be
done?**

Recommendations

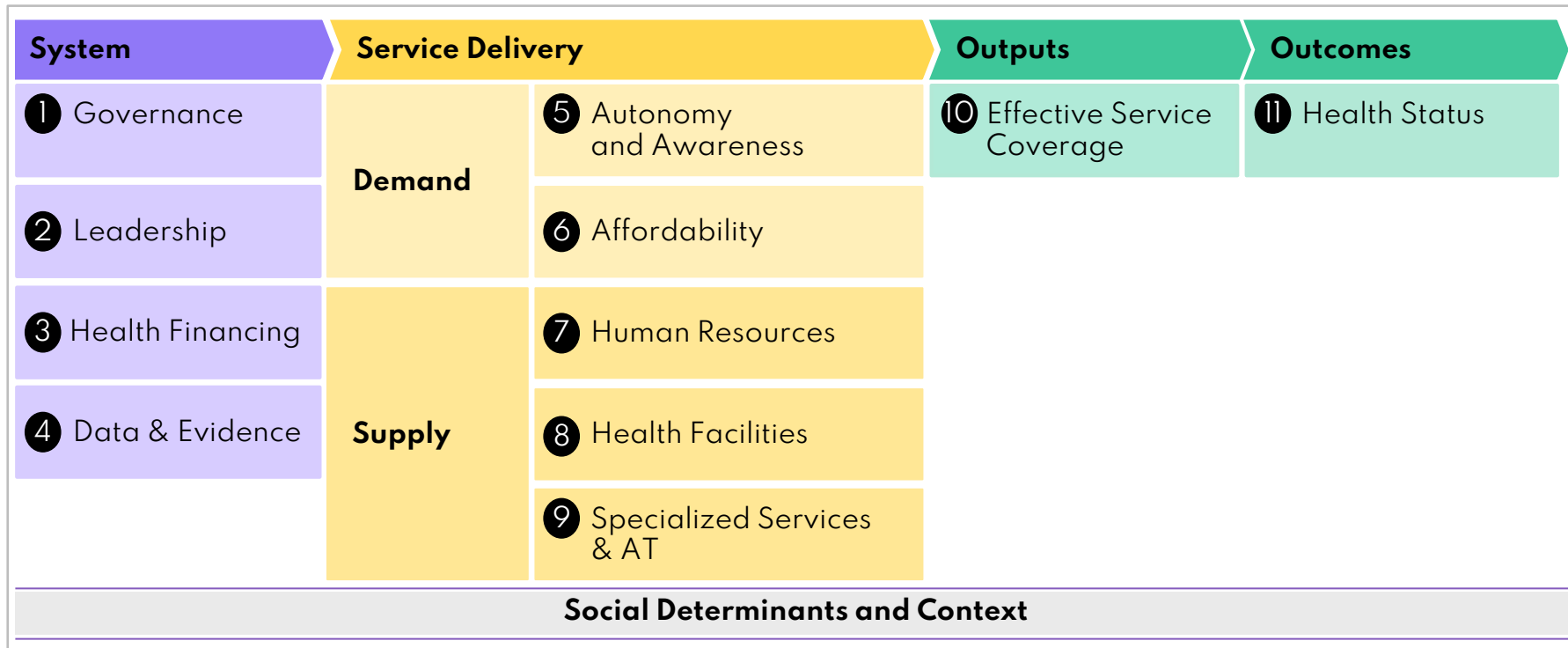
- Data collection through NHS
- Reasonable adjustment, audited
- NICE guidelines
- Annual health checks
- Mandatory training of healthcare workers....

Confidential Inquiry into
premature deaths of people
with learning disabilities (CIPOLD)

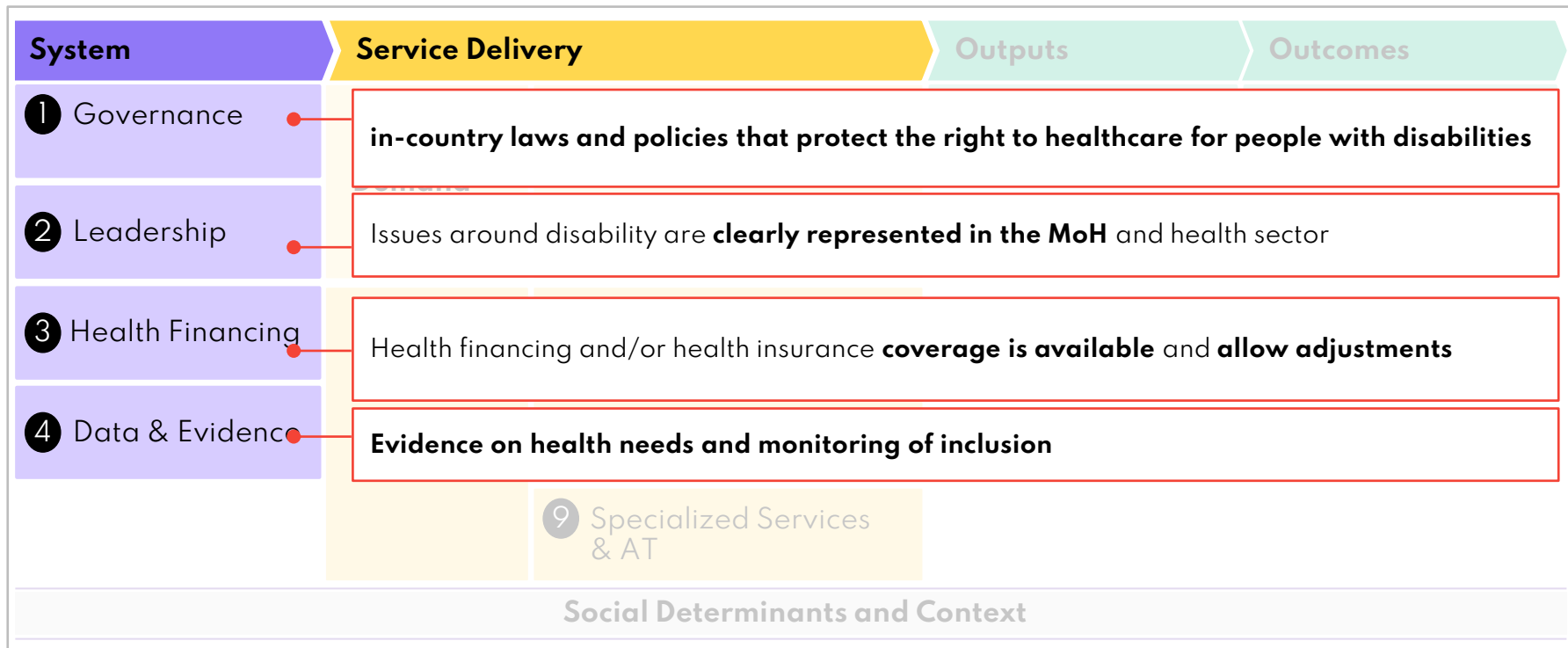
Final report



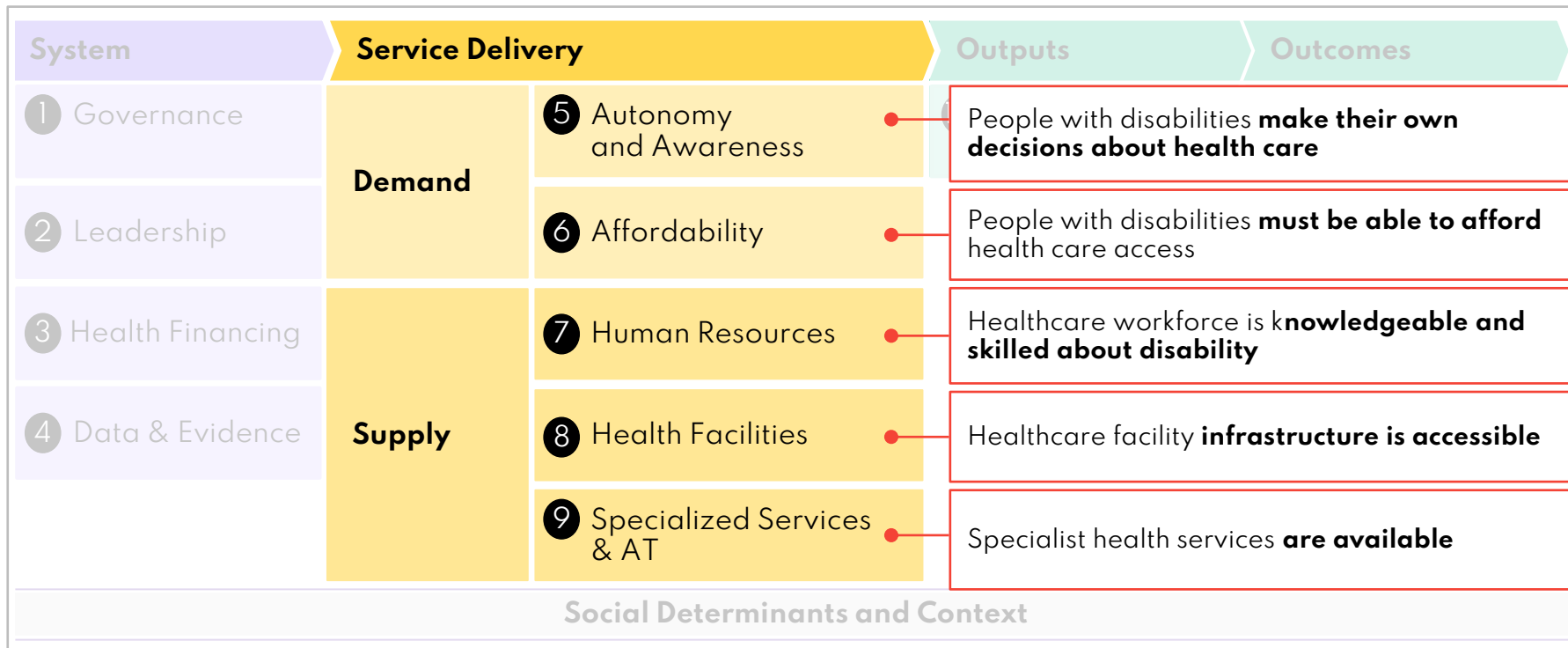
Inclusive health systems framework



“Must have’s”



“Must have’s”



The background is a solid yellow color. On the left and right sides, there are two large, solid red circles. They are positioned such that they appear to be framing the central text. The circles are partially cut off by the edges of the frame.

**What isn't
counted doesn't
count...**

Missing Billion Initiative work

Partner with governments to **measure** and **improve**

Diagnostic methodology and toolkits for Ministries of health to scope and prioritize improvement interventions

Menu of best practice intervention

Advise health actors and funders on adjusting investments in health

Insights on diseases programs

Menu of best practice interventions

Investment guidelines

Co-design solutions and **innovate** where there are gaps

Missing Billion Innovation Accelerator – Human-centered design to identify and co-create interventions for issues or white spaces that Ministries of Health, systems actors and communities face

Advocate for awareness, action and change

Senior policy maker engagement and convenings

Uniting voices and **bringing to the fore the lived experiences** of people living with disabilities

Oliver McGowan death prompts mandatory autism training

5 November 2019



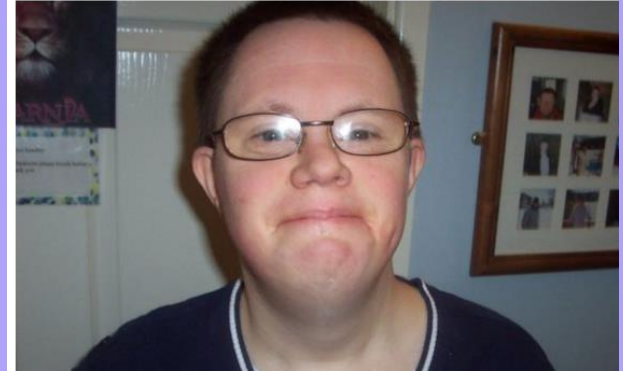
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**Thank you for
your time and
attention**