The Inclusive Data Charter: Sightsavers' experience from planning to practice

Washington Group Annual Meeting.
November 2018

Sightsavers | **Everybody** Counts

Content

- **The Inclusive data charter**

- **Sightsavers' Action Plan – Objectives and Actions**

- **Disability inclusive early childhood in Malawi**

Sightsavers | Everybody Counts

The Inclusive Data Charter - Background

- Little data is routinely disaggregated.

- Without major change, we can't effectively measure either the progress of the SDGs or whether specific population groups continue to be left behind.

- A task team was set up by the Global Partnership for Sustainable Development Data (GPSDD).

- The Charter was seen as a tool to help improve and strengthen data disaggregation

So what is the IDC?

Two parts:

- A high level vision and five principles

- A tailored action plan

- The charter has been designed to enable a wide range of organisations and countries to sign up.

Sightsavers | Everybody Counts

IDC Launch

Launched at a side event at the HLPF in New York on 17 July 2018.

10 Champions publically endorsed the Charter:

the governments of Colombia; Ghana; the Philippines; the UK Office of National Statistics (ONS)

UNFPA; UNICEF

Sightsavers; HelpAge International; Data2X; Development Initiatives

IDC launch event at the HLPF in New York. 17th July 2018

Sightsavers | Everybody Counts

IDC – Highlights since the launch…

- Global Disability Summit – DFID, the government of Kenya and the World Bank

- UN World Data Forum – side event on the IDC

- Other global events in 2018 and planning for 2019

- Wider outreach

- Building a repository of information to support IDC Champions

- Brokering relationships and sharing learning

Sightsavers | EverybodyCounts

Sightsavers' commitment to data disaggregation

Sightsavers' Inclusive Data Charter Action Plan

- Instrumental in developing the Charter

- Have made seven key commitments

  - Collection and use of inclusive and disaggregated data

  - Sharing our evidence

  - Working in collaboration

Sightsavers' Action Plan

Data Disaggregation – Get Use Share

8 Objectives with 28 associated time-bound actions

Increase capacity of Sightsavers' staff and partners to incorporate data disaggregation in to their work.

Systematic inclusion of disaggregated data in project systems and monitoring.

Continue to collect, report, analyse, and use data on age, disability, sex, economic status, and location data where relevant, and contribute to evidence base on how to.

Sightsavers | EverybodyCounts

Sightsavers' Action Plan

Develop and share learning with NSO, Ministry and CSO partners

Provide evidence to support implementation of the 2030 Agenda

Partnerships / working in collaboration

Testing new technologies for capturing and managing data to improve accuracy and speed of data collection and analysis

Sightsavers | Everybody Counts

Sightsavers' Action Plan Monitoring

- Monitoring the action plan:
  - deliverables
  - achievements
  - concerns/risks

- Review / evaluation:
  - Annual report

From planning to practice

Pilot projects:
- India Urban Eye Health
- Tanzania NTD TT camps
- Ghana Mass Drug Administration

Research:
- Malawi NTD TT camps – WGSS + EquityTool
- Malawi ECDE centres – WG/UNICEF Child Functioning Module
- DRC, Nigeria, Uganda and Guinea Bissau integrated WGSS and the EquityTool in to Treatment Coverage Surveys for NTDs
- Cameroon, Pakistan, India, Tanzania, Mozambique we integrated the WGSS and ET in to Rapid Assessment of Avoidable Blindness surveys
- Senegal and Cameroon – measuring political participation of people with disabilities – WGSS in household survey

Programme monitoring:
- Inclusive Eye Health Nampula, Mozambique
- Inclusive Eye Health Pakistan and Bangladesh

Sightsavers | Everybody Counts

Disability inclusive early childhood development in Malawi

Sightsavers | Everybody Counts

Background

- Delivered by volunteers in community based childcare centres

- Coverage low (<40%), quality variable

- Sightsavers project to improve disability-inclusiveness

- Volunteer caregiver training: effective?

- Separate research study in collaboration with University of Birmingham and Chancellor College, Malawi:
  - Child development scores
  - Caregiver retention

Children play a game of tag at the Community Based Childcare Centre in Chisomo, Malawi, June 28, 2016. © Sightsavers/Adriane Ohanesian

Sightsavers | EverybodyCounts

Methodology

Cluster randomised control trial:
- Intervention: training
- Control: business as usual (training after final data collection)
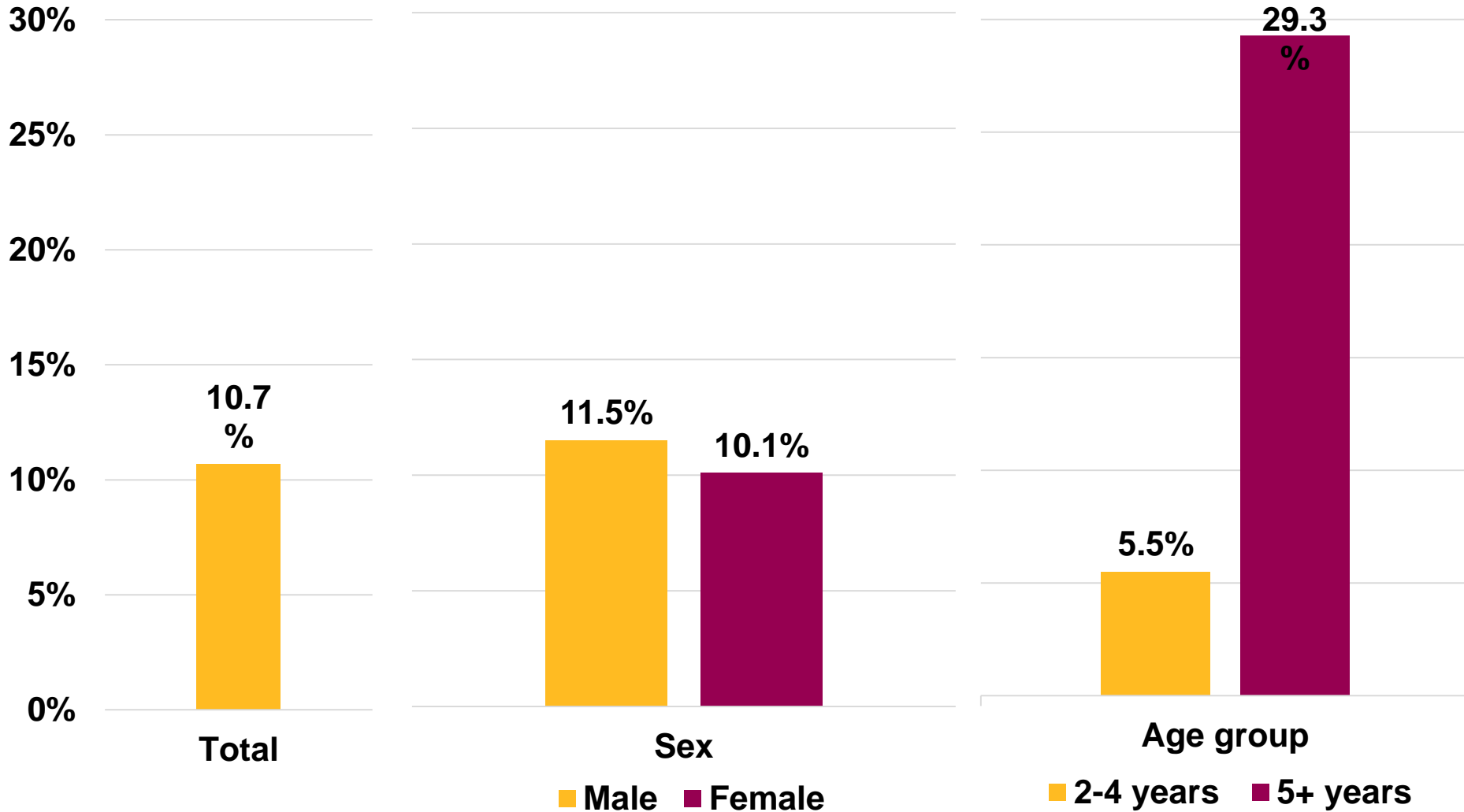
48 centres, 20 children in each: 960 children aged 2-6 years in total

Various tools, including CFM and Malawi developmental assessment tool (MDAT)

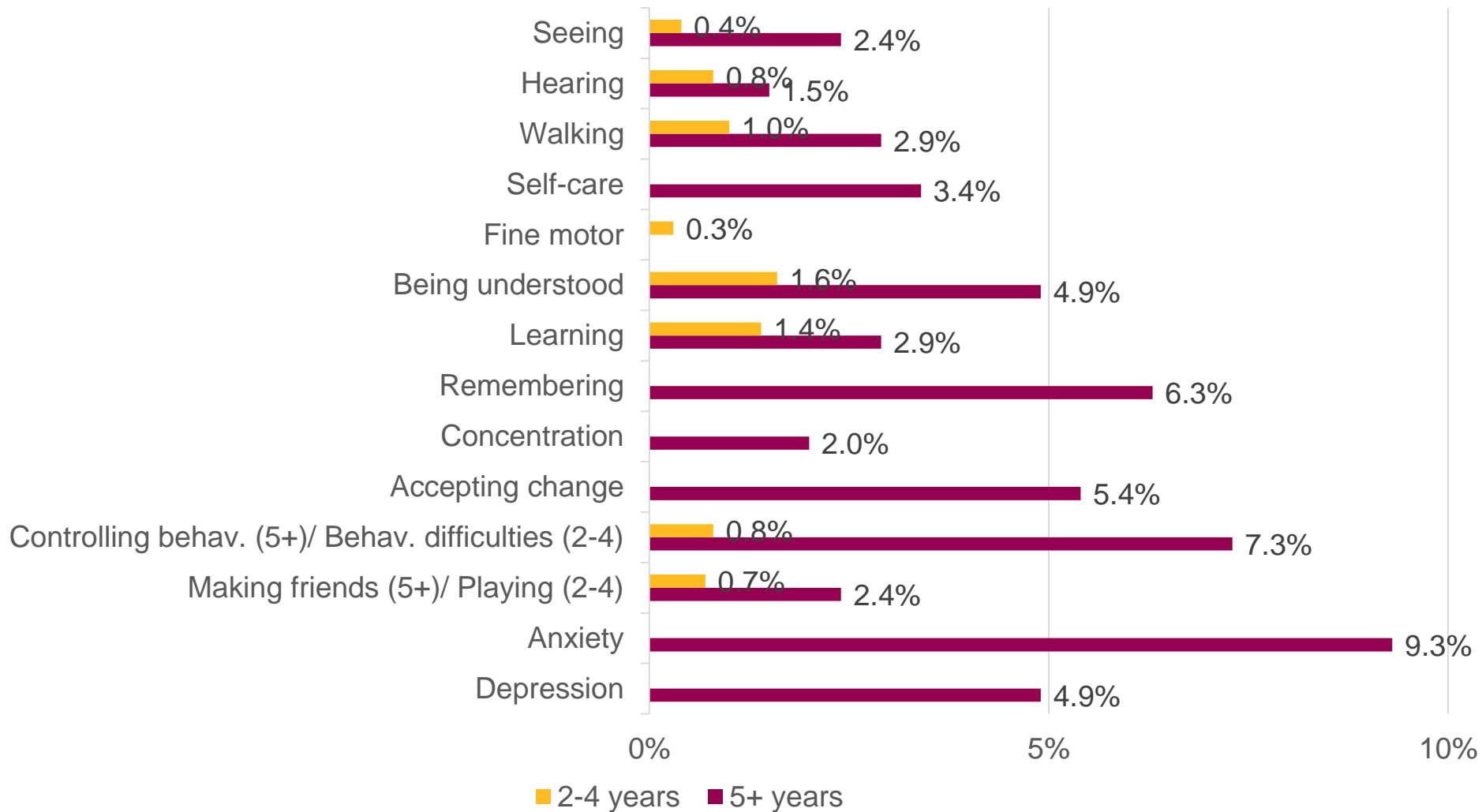Cut-offs used:
- a '**lot of difficulty**' or '**cannot do at all**' in any one of the domains;
- '**daily**' for anxiety and depression;
- '**more**' or '**a lot more**' for behaviour (2-4 years) ;
- '**a lot more**' for behaviour (5+ years)

Sightsavers | **Everybody** Counts

Results (1): Prevalence 935 (97.4% response rate)

Total: 10.7%

Sex: Male 11.5%, Female 10.1%

Age group: 2-4 years 5.5%, 5+ years 29.3%

Sightsavers | Everybody Counts

Results (2): prevalence by domain

Domain	2-4 years	5+ years
Seeing	0.4%	2.4%
Hearing	0.8%	1.5%
Walking	1.0%	2.9%
Self-care		3.4%
Fine motor	0.3%	
Being understood	1.6%	4.9%
Learning	1.4%	2.9%
Remembering		6.3%
Concentration		2.0%
Accepting change		5.4%
Controlling behav. (5+)/ Behav. difficulties (2-4)	0.8%	7.3%
Making friends (5+)/ Playing (2-4)	0.7%	2.4%
Anxiety		9.3%
Depression		4.9%

■ 2-4 years ■ 5+ years

Discussion

Functional difficulties high, especially among 5+ children

The most common difficulties were anxiety, controlling behaviour, remembering, accepting change, being understood and depression.

High correlation between functional difficulties and developmental delay (OR 4.8; p<0.001)

➢Finalise trial results

➢Programme implications

➢Future research

Sightsavers | Everybody Counts

Thank you

For more information on Sightsavers work on data disaggregation:

Email: **Ejolley@sightsavers.org**
Email: **Jbell@sightsavers.org**
Visit: **www.sightsavers.org/everybodycounts**

For more information on the Inclusive
Data Charter, please see:
http://www.data4sdgs.org/initiatives/inclusive-data-charter

Or alternatively, please contact: Linsey
Winter (Inclusive Data Charter
Coordinator - lwinter@sightsavers.org)

Sightsavers | **Everybody**Counts