London Plus
Version 3 - 19.02.2019

Working group - Equalities monitoring data standards for Deaf and Disabled people: Terms of Reference

Background

London Plus is initiating a project with the aim of defining a consistent approach to capturing and recording equalities data for civil society organisations. The primary outcome of this project will be recommendations for the collection of equalities data.

This project will take a test and learn approach and will start by focusing on one area of equalities data standards. We will then run the process again for different equalities groups and refine the approach, feeding in our learning. The first area of equalities we will focus on is data standards for Deaf and Disabled people, specifically the terminology and categories used to capture impairment groups and access needs.

There exists a number of data standards for equalities groups, including those published by the Office for National Statistics (ONS) and the National Health Service (NHS). However, this programme of work sets out to recommend data standards that have been agreed and co-produced by civil society organisations, and that have a specific focus on the needs of people in London.

Purpose of the data standards for Deaf and Disabled people Working Group

- To identify ways in which current data standards around disability can be improved for civil society groups in London.
- Provide strategic leadership in the development and implementation of the data standards.
- Provide advice, support and assistance in developing the new standards.
- Assist in signposting to and promoting use of the standards once agreed.
- Act as representatives for the interests of their wider stakeholder groups throughout the process.

Overarching aims
The aim of this project is to agree on a standard for the terminology and categories used to capture Disability and impairment for London's civil society. Ultimately, we envisage that a consistent data standard will help to:
  a. Facilitate organisations ability to shine a light on often overlooked groups' participation in civil society and their experiences through the promotion of shared equalities monitoring standards.
  b. Enable high-level findings across civil society organisations of different sizes to be compared, to help inform policy and advocacy.

Membership

Membership aims to include key stakeholder groups with an interest in the use of consistent data standards for deaf and disabled people. Members will be drawn from groups who may be involved in using and collecting the data, and those with specific expertise in disability issues. This will primarily include representatives from deaf and disabled people's organisations, along with funders and data specialists. The membership also seeks to

include people who identify as deaf or disabled, and deaf and disabled people will be consulted throughout the programme of work.

The membership is as follows:

Natasha Codiroli Mcmaster – London Plus [Coordinator]

Christine Goodall - HEAR network

Hannah Goulding - The Greater London Authority

Iyiola Olafimihan – Camden disability action
Janine Volossevich – Deaf and hard of hearing women's group
Ealing

Kathleen Egan – Age UK London

Kristiana Wrixon - ACEVO

Kush Kanodia – Global disability innovation hub

Michael Paul – Disability Rights UK

Sarifa Patel – Alliance for inclusive education

Tracey Lazard - Inclusion London

The role of the individual members of the Deaf and Disability data standards Working Group includes:

- Attending meetings and actively participating in the group's work.
- Providing comments on draft documents as required.
- A genuine interest in the initiatives and the outcomes being pursued in the programme.
- Being committed to, and actively involved in, pursuing the programme's outcomes.
- Sharing their specific expertise and knowledge by contributing to ideas in discussions and highlighting any potential problems that may occur.
- Being an advocate for the programme's outcomes.

Accountability

The programme lead will collate and circulate appropriate documents prior to meetings, allowing members sufficient time to familiarise themselves with material.

Working methods

The working group will be discussion led and will aim to create a space for all members to share their expertise and knowledge.

The working group will meet monthly at the early stages of the project. This will be reviewed at each meeting, and it is likely that this will be reduced in the later stages. Members of the working group are encouraged to recommend a proxy to attend meetings if they are unable to attend, and to inform the coordinator of any changes in good time prior to the meetings.

Efforts will be made to include members who cannot attend in person through conference call or videophone, and members will have opportunities to contribute via email before the meeting if they cannot attend in any capacity. Members will actively listen to others' contributions during meetings, and respects others' contributions.