Multi-professional and patient collaboration to improve the experiences of deafblind people

Sarah Marsay, Public Engagement Account Manager, NHS England
Sarah White, Health Policy Officer, Sense
Barriers to healthcare

"A person is regarded as deafblind if their combined sight and hearing impairment cause difficulties with communication, access to information and mobility. This includes people with a progressive sight and hearing loss."

(Dept of Health, 1995)
The Accessible Information Standard

• Responding to feedback and acknowledging a problem:
  
  – *Why don’t many people with a disability or sensory loss receive accessible information and/or communication support from providers of NHS and adult social care?*
  
  – *What are the barriers, and what needs to change?*
  
  – *How can the issues be resolved?*

• Aim to provide direction to the health and care system such that people with information and/or communication needs relating to a disability or sensory loss consistently receive accessible information and any support they need to communicate.
Development approach: overview

• Co-production and partnership
• Planned and targeted engagement: accessible, inclusive, ‘bespoke’
• Relationships of trust
• Using existing networks
Development: views and experiences

- Diversity of organisations and individuals involved
- Different events and varied approaches
- Capturing experiences to understand issues
- Capturing ideas and views on solutions
- Considering all stages of information cycle and challenges faced by both service users and service providers
Development: Advisory Group

- Partners overseeing Standard development
- Ensuring co-production and consensus
- Offering insight and forum for debate
- Shared investment from members
- Trust and transparency
Demonstrating successful coproduction

• SCCI1605 Accessible Information.

• Co-production and partnership:
  – Shared ownership
  – Challenging barriers
  – Transparency
  – Ensuring that the Standard will deliver for service users and is deliverable for service providers.

• Impact for deafblind people
Demonstrating successful coproduction

“I was at the last event and shared my thoughts, today we’ve seen the standard in its draft form and I can see that what I said has been included. I feel like my voice has been heard”
Thank you.

Any questions?

Find out more:

www.england.nhs.uk/accessibleinfo
www.sense.org.uk