Hidden Voices of Maternity
Parents With Learning Disabilities Speak Out

Executive Summary
August 2015
Many organisations feel that most people do not understand what the maternity experience is like for a person with a learning disability.

CHANGE and PEN decided to ask parents with learning disabilities about their maternity experience.

They did this by giving out online surveys, running focus groups and doing other research.

NHS England supported CHANGE and PEN to do this.
CHANGE and PEN used their research to make a list of ideas that could improve the maternity experience for other parents with learning disabilities. These are:

1. **Strategy**
   A strategy is a plan that has a long term goal. Care commissioners could make a strategy that healthcare providers would have to follow to help parents with learning disabilities.

2. **Training**
   Easy to access training could be made available to healthcare professionals so they have better respect and understanding of people with learning disabilities.
3. Continued support
Parents with learning disabilities could have access to a reliable professional for advice and support. Some Trusts already provide this service.

4. Learning disability Leaders
Healthcare providers should have one person to support people with learning disabilities.

5. Support for parents
Parents with learning disabilities should have access to a parent support group in their local area.
6. Buddying up
Give parents with learning disabilities the option to buddy up with another parent with learning disabilities so they can support each other. This is called peer to peer parenting.

7. Accessible Information
Create easy read materials to make subjects about being a parent easier to understand for parents with learning disabilities.

8. Information standard for social workers
Have social workers start making and using accessible information by following the NHS England Accessible Information Standard.
9. Support Groups
Create local support groups for parents with learning disabilities. Two examples of these groups are **Geordie Mums** and **Camden People First**.

10. Dealing with loss
Give support to parents with learning disabilities when they lose the right to care for their child. An example of this could be moving them to another ward that could provide counselling.

11. Fathers
Look at providing services for fathers with learning disabilities as they often feel they can not be a part of services that already exist.
We would like to thank all the parents and groups that took part, these are:

CHANGE
Grapevine
Geordie Mums
Your Say Your Advocacy
York People First
Speak Up Rotheram
Camden People First

Thank you for reading this document.