

Hidden Voices of Maternity

Parents With Learning Disabilities Speak Out

Executive Summary

August 2015



Prepared by



Supported by



CHANGE AND PEN worked together supported by NHS England to give a platform to the seldom-heard voice of parents with learning disabilities in order to improve the maternity experience for parents with learning disabilities.

Several advocacy organisations felt that the maternity experience for parents with a learning disability was not fully understood and therefore we created an approach to help give these parents the opportunity to share their experience and to be heard. Our approach had 4 elements:

- Over a six week period we invited professionals to take part in an on-line survey.
- From January to April 2015 we held a series of five focus groups with parents with learning disabilities across the country: in Leeds, Coventry, Newcastle, Bath and London.
- To support the focus groups we invited parents across the country to take part in an easy read accessible survey.
- We also undertook some desk research to understand the resources, papers and materials available more widely.

From all of this we have pulled together some key recommendations and next steps. We know some of these may not be easy, and we do not know how some of this may be achieved, however, these are the key areas coming out of our work with both parents and professionals:

- 1. Strategy:** Ensure each CCG locality area has an antenatal and postnatal care commissioning pathway for parents with Learning Disabilities – or create National guidance. Providers also to focus on Learning Disabilities in their maternity strategy. For example Leeds has a 5 year maternity strategy where parents with a learning disability are identified as a key group with a pathway planned and a key focus for the next 5 years.
- 2. Training:** Provide more widely available training for professionals (social workers, midwives, health visitors and receptionists) to improve communication – empathy, respect and understanding (e.g. LD is not MH). For example it is felt that Children’s social workers do not have specific training in this area. It was felt that by providing training to students it would start to cut through the stigma. Professionals comment they are not consistently offered specialised training in this area.
- 3. Continuity:** Parents to have access to a trusted professional throughout their experience – having their phone details for direct access. This continuity was seen to work well for teenage pregnancies and could be extended to all parents with a learning disability; some Trusts already provide this. Clearly this will only work where the professional is trusted and supportive. Ideally have specialist learning disability midwives or liaison nurses. A key issue is that professionals do not always know who may have a learning disability and some parents may not wish to admit it to avoid the stigma; good questions to ask may be “what support are you going to need?” and sharing some easy read information and asking “would you like more information like this?”
- 4. LD Lead:** Have a visible lead in a provider organisation whose role is to support learning disabilities – similar to the Mental Health lead which is perceived to work well. Some Trusts have implemented this but it is not the norm.
- 5. Parental Support:** All parents should have access to a local parent support session – if they want it – focussed on parents with learning disabilities if possible. This includes the fathers who often feel excluded. In one area Barnado’s offered parenting classes in the home and there were felt to be very helpful.

“I would like more people to be aware and trained about what a learning disability is so we don't get mistreated and misjudged.”

6. **Buddy:** The option to buddy with another parent – peer to peer parenting - was seen to have been working well in one area, although the funding has subsequently been removed for this. It was felt this would be one of the most powerful support for this parent group. Moving forwards commission peer support that is provided via local community based services with timescales dictated by the parent e.g. NCT, 3rd sector.
7. **Accessible information:** Option to access easy read materials – midwife to know they are available and offer the option. Ensure these are at the right level – not too simplistic or babyish. Materials already exist and are relatively inexpensive to purchase. One midwife had successfully supported her parent by taking pictures for example of how to hold the baby and how to feed it, and sharing these. Provide templates of easy to read letters for professional to access – sometimes parents receive letter they do not understand and so miss important appointments and are perceived to be irresponsible – whereas they simply did not understand. Offer more accessible information on key facets e.g. can you afford this baby, premature babies, when baby is unwell, children > 5.
8. **Information Standard for social workers:** Social workers to follow the lead of health and make resources easy read now – use the NHS England Accessible Information Standard as the lever.
9. **Support groups:** Commission and create local support groups for parents with learning disabilities. Where support groups are in place these work well e.g. Geordie Mums and Camden People First. In some areas the Parents came together for the first time e.g. in Coventry and Bath and it was clear the parents valued the opportunity to meet other parents in similar situations. Explore who will run these and how they will be managed and funded.
10. **Loss:** Provide support for parents who do lose the care of their child – there is a system-wide lack of compassion and understanding at this tragic stage. Simple things like moving the Mum from maternity to another ward when their baby has been removed to more complex bereavement type counselling.
11. **Fathers:** Commission and provide specific antenatal and postnatal services for fathers who have a learning disability as they reported they felt excluded from existing services and valued peer support.

“I feel powerful because I have kept my children and I have worked hard to keep them.”

We would like to thank CHANGE and Catherine Carter in particular for co-working with Ruth Evans – it’s been fantastic to get to know you

We’d also like to thank the parent groups who took part:

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

Thanks also to all the professionals who took part in our survey and to the parents who completed their survey. And of course thanks go to NHS England who have funded this opportunity to hear some of the hidden voices, allowing parents with learning disabilities to speak out.



CHANGE CHANGE is a national human rights organisation led by disabled people. CHANGE employs people with learning disabilities to co-lead and work alongside a non-learning disabled colleague for an equal salary. People with learning disabilities at CHANGE use their expertise to educate health and social care professionals to improve their practise. CHANGE supports people with learning disabilities to consult peers and lead projects to tackle discrimination and participation in society fully as equals.



PEN is a not for profit organisation whose ambition is to recognise, celebrate and share what is working well in the experience of care. PEN has written a series of reports to highlight the great work in the maternity experience of care, children's and young people's services and the experiences of families with children who are long term ventilated, amongst others.

For further information please contact:

Ruth Evans at PEN
r.evans@patientexperiencenetwork.org

or **Catherine Carter at CHANGE**
catherine@changepeople.org