

Hidden Voices of Maternity

Parents With Learning Disabilities Speak Out

August 2015

Hidden Voices of Maternity Parents with Learning Disabilities Speak out

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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 for this group of parents.

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.

In summary, based on our research we recommend the following (see page 22 for further details):

1. *Ensure each CCG locality area has an antenatal and postnatal care commissioning pathway for parents with Learning Disabilities – or create a National guidance*
2. *Provide training for professionals (social workers, midwives, health visitors and receptionists) to improve communication – empathy, respect and understanding (e.g. LD is not MH)*
3. *Parents to have access to a trusted professional throughout their experience – having their phone details for direct access*
4. *Establish a visible lead in a provider organisation whose role is to support learning disabilities as opposed to mental health or other area*
5. *All parents should have access to a local parent support session – if they want it – focussed on parents with learning disabilities if possible*
6. *Commission peer support (buddy) that is provided via local community based services with timescales dictated by the parent e.g. NCT, third sector*
7. *Option to access easy read materials – midwife to know they are available and offer the option*
8. *Social workers to follow health and make resources easy read now – use NHS England accessible information standard as the lever*
9. *Commission and create local support groups for parents with learning disabilities. Explore who will run these and how they will be managed and funded*
10. *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*
11. *Commission and provide specific services for fathers who have a learning disability as they reported they felt excluded from existing services and valued peer support*

Resources we found during the project have been included and will be made available on our website. We hope that we will add to this as an ongoing resource. Two areas worthy of further investigation are:

- *more extensively and systematically audit the resources that are in use today and make these widely available - who is using/ not using and why and what are the barriers*
- *explore more widely examples of what is working well and share these – for example where are the parenting groups and what do they do, what other examples of good practice are in place and where*

We have written this report in a simple informal style, co-working with a mum who has a learning disability. It is also available in an easy-read accessible format.

Introduction and Background

Introduction

CHANGE AND PEN worked together supported by NHS England to give a platform to the seldom-heard voice of parents with learning disabilities. The partners worked in collaboration to gain a better understanding of the maternity experience of care for parents with learning disabilities. The end goal of the work is to support both commissioners to ask the right questions of their service providers and service providers themselves in this important area in order to improve the maternity experience for parents with learning disabilities.



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.

Background

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.

Learning Disability is defined as “a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence); with a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development”. (Department of Health, *Valuing People* 2001)

A learning disability affects the way a person understands information and how they communicate. This means they can have difficulty:

- understanding new or complex information
- learning new skills
- coping independently

A learning disability can be mild, moderate or severe. Some people with a mild learning disability can talk easily and look after themselves, but take a bit longer than usual to learn new skills. Others may not be able to communicate at all and have more than one disability.

A person with an IQ of less than 70 can be diagnosed as having a learning disability. CHANGE advised that for parents usually their IQ will be above 70 and you rarely find a mum whose IQ is below this.

Our approach embraced the fact that people with learning disabilities are unique individuals with their own likes and dislikes, history and opinions, and have the same rights as anyone else (RCN, 2013).

There is a huge range in estimations of the prevalence across the UK, however, The British Institute of Learning Disabilities (BILD) estimates that 1,198,000 people in England have a learning disability i.e.2% of the population. (Feb 2011). This is complicated – not everyone knows they have a learning disability, and not everyone wants to be “labelled”.

There has also been a shift in people’s attitudes to this group, however, the change is slow and many people still feel “cared for” rather than “supported with”.

According to Best Beginnings around 7% of adults with a learning disability are parents. In reality most have a mild to borderline impairment, which may make it difficult to identify them as usually they will not have a formal diagnosis. Often professionals do not want to ask and not all parents want to be asked.

In the maternity setting there is still a very long way to go for this group – who feel marginalised and discriminated against. Many parents with learning disabilities face stereotyped beliefs that:

- they could never be good enough parents
- that any parenting difficulties are automatically linked to their learning disability without considering other environmental or social factors.

Estimations vary but it is thought that between 40% and 60% of parents with a learning disability do not live with their children. According to Best Beginnings the children of parents with a learning disability are more likely than any other group of children to be removed from their parents’ care.

Experience shows that some women with learning disabilities may avoid maternity care because of:

- lack of confidence
- negative staff attitudes
- lack of clear explanations of what is going on
- inaccessible leaflets
- fear of the involvement of social services

This information was sourced from Best Beginnings and our work supports this view.

We saw evidence that supported the view that parents with a learning disability can improve their parenting skills with additional support tailored to their needs – this was particularly evident in our focus group in Bath. For example childcare skills can be taught through behavioural modelling, using visual manuals and audiotaped instructions, and using simple behavioural instructions. Parents learn more effectively where they are given praise and feedback, and where complex tasks are broken down into simpler parts.

Parents with a learning disability face extra scrutiny of their parenting ability, but receive inconsistent advice from different professionals on what constitutes good parenting. They feel they are often told what NOT to do but receive insufficient guidance on what TO do.

“I felt like I was invisible and not being listened to.”

Parents with a learning disability may be reluctant to ask for support with parenting issues because of fears that this will raise child protection concerns. Many will have already had a previous child removed into care. Some parents will not be eligible for support from adult learning disabilities teams because their learning disability is not severe enough to qualify.

Researchers at the Norah Fry Centre at Bristol University – a leading centre of research on services for learning disabilities – estimate that parents with learning disabilities are up to 50 times more likely to be involved in care proceedings.

What We Did

Professionals Survey

Over a six week period we invited professionals to take part in an on-line survey. In this survey we asked a series of questions to help us understand the maternity experience in general and specifically for parents with learning disabilities. 107 professionals took part. Their comments and feedback are included in this report.

Focus Groups

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. The first focus group in Leeds was a Steering Groups giving us guidance on how to shape the subsequent four sessions. We also spoke with some relatives of parents with a learning disability in two of the sessions.



Mothers and fathers with learning disabilities were invited and in total we met 34 parents from across the country. Some have their children living with them, many did not; some brought their children with them! For some their child was yet to be born (and one left to go to the maternity unit!) and for some their child was now an adult.

In each focus group we invited parents to share their experience and their hopes with us. In many of the groups we were joined by interested professionals e.g. student midwife, local midwife, student social workers, other researchers and by advocates.

Parents seemed to really value the opportunity to come together and realise they had so much in common – these were sharing and emotional conversations – tissues were needed on many occasions. Some already knew each other but others did not, but for all the connection was powerful.

The key findings from the focus groups are covered later, but in summary there seemed to be a huge variation in the experience for parents across the country – there are pockets of great practice where parents feel supported – both those who have kept their child and those who have not, but more often they felt the “system” had judged them and treated them unfairly.



Where parents felt supported they had access to quality advocacy services by advocates who they trusted, professionals (midwives, nurses) who understood them and their needs and good local providers. Where they did not the opposite was true.

What became clear is that when parents do “lose” their child i.e. have them taken away there is a system-wide lack of compassion and understanding. Ultimately this is a devastating situation for any parent and no “bereavement” type support seemed to be available for these parents.

Parents often blamed themselves and found it difficult to get answers that they understood.

Parents Survey

To support the focus groups we invited parents across the country to take part in an easy read accessible survey. We have included the feedback from these parents in the report. These surveys reinforced what we heard in the focus groups.

Maternity Experience Survey

What is this survey all about?

- PEN and CHANGE are working with NHS England's Patient Experience Team to write a report about people's experiences of maternity services.

We would really like to have your views and welcome you being involved.




Desk Research

We also undertook some desk research to understand the resources, papers and materials available more widely. These have been included as appropriate.

“I think midwives should be trained in how to deal with people who have learning disabilities because I just feel as though, when someone hears the word disabled or learning disability, people don't understand what it is and just think that you're stupid or label you and treat you as though you don't exist.”

Ladder of Power

In each focus group we discussed a range of people involved in the maternity experience – using a ladder of power. Using this we asked each group to discuss each type of person involved in their experience of parenthood and how much power they felt they had over them as parents and their experience of maternity. Each type of person was added to the ladder depending upon how much power they felt they had – the most at the top of the ladder – the least at the bottom.

As we introduced each new type of person we discussed how the parents felt about that person and why, what their concerns and experiences were and where they placed these people on the ladder of power. Each group ended up with their own ladder of power.



Leeds



Coventry



Newcastle



Bath



London

Using the insights from these focus groups over the page is the typical ladder of power with comments from parents. Where possible have used the words of our parents:

Ladder of Power

Social
Worker

Social worker was always at the top: Most parents had a bad experience “as they have the power to take your children off you” Comments ranged from: “*they have all the power*”, “*they decide, you have to prove you are good enough to look after your child*”, to “*mine wasn't that bad*” In many cases parents did not feel they had a reasonable explanation of why their child was taken away. The concept of neglect is a difficult one to understand.

Hospital
Midwife

Hospital midwife can be very impactful and in terms of power was often above the Consultant. Feedback was very mixed: For some parents they are *helpful* “*when I was upset she was there to help*” but most commented they felt judged “*you can't carry your baby – you may drop her*”, “*she removed my baby and would not let me see her*”, “*she assumed I would not want my child*” and “*she kept waking the baby up – I did not know why*”. There seemed to be little compassion for parents who they know will lose their child and often they were “*skewed and alarmist*”.

Health
Visitor

Health Visitor was mixed – some felt they were very powerful others less so. At times they were very helpful: “*she helped me get a nursery place*” or “*she got me safety gates*” “*I knew she was just a phone call away*” – for others they were not so positive “*I felt the dad was pushed away*”.

Obstetrician

Obstetrician were rarely reported to be involved but when they were they were quite powerful. The different kinds of Consultants were not understood e.g. Gynaecologist, Paediatrician.

Community
Midwife

Community midwife was seen as more powerful than the GP- partly because “*they actually come into the home to check you*”. Although feedback was mixed as a rule these were felt to be more sympathetic than the hospital midwife.

Receptionist

Receptionist was more powerful than the GP – they are the gatekeeper to whether you get an appointment or not – for others where they did not have a problem they were close to the bottom of the ladder of power. “*you can tell their attitude on the phone*”, “*I'd like them to listen more*”.

GP

GPs “*do not have the power to take children away but do make important decisions*” and overall the parents did not have much to say about the GP. “*I smiled at the doctor but I didn't really understand them – I think I should have really disagreed and made a bigger effort*”.

Nurse in GP

Nurse in GP – parents like to be seen by the same person “*it really matters if they are not the same person. They do not pass information on and I do not like being passed from pillar to post*”. “*Nurses can spout a lot of information – they are proper annoying.*”

Advocate

Mum with
learning
disability

Advocate – in the majority of cases the advocate was seen as hugely supportive; in a couple of cases the relationship was not working so well. They were seen as an enabler – and for some they wanted “*more advocacy before having the baby – it can be very scary*”.

Mum with learning disability was at the bottom – just above the dad in most cases. This is not where they felt they should be - “*the mother should have the most power – she should have a voice*”. They felt they were “*treated like they were daft, stupid or a two year old*”, “*they made you feel horrible*”

Dad with
learning
disability

Dad with learning disability was usually right at the bottom as they “*do not get a say*”. They are often told they cannot come to see their baby being born. The exception was where the relationship was abusive or the Dad was manipulative in other ways. “*The father can walk off and leave the mother with the baby*”. “*If the mother has a LD then social services require an assessment – it is not the same if the Dad has a LD*”.

Four additional stakeholders/ groups of people with power were mentioned:

- The families of the parents with a learning disability – their mums and dads, aunts, sisters, who could make the difference between keeping their child at home or nearby – “my parents knew mum and baby had to be together so they moved closer to help us”
- School – who could be supportive or on occasions could be extremely unhelpful – “they called me in over a silly bump on the head”
- Work colleagues – several of the mums found their work colleagues were extremely supportive and helpful giving them useful guidance
- Family Support Workers – some mums had access to these and they were felt to have been very helpful

What We Found - The Pregnancy Experience

In the focus group we asked the parents to describe their experience from the moment they found out they were pregnant until they were at home. We have captured what they said in their words in the following pages across their experience. There are a few great examples of when it is been a good experience, but this is far exceeded by the examples of what has not been a good experience for this group of parents.

Overall the parents felt what worked well were:

- access to the community midwife
- where buddy schemes existed these were well received
- the advocacy provided
- support groups e.g. Georgie Mums, Camden People First

Overall areas the parents felt did not work well were:

- being judged all the time
- attitude of staff
- conflicting information (people telling you different things)
- not supported to breast feed
- if in pain not supported by the midwife
- most Dads did not feel welcomed during birth
- no support when babies taken away
- encouraged to have an abortion without being told why
- ability to get appointments at the GP.

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

Before

| | When I found out I was pregnant | What happened next | What information was available |
|---|--|---|--|
| 😊 | <p>"I was very happy when I found out"</p> <p>"I had a pee test and it told me I was one week and a half pregnant"</p> <p>"The pregnancy was unplanned for my first, all other pregnancies were planned"</p> <p>"I have had three pregnancies and have seen the same midwife for all three. She made me feel more relaxed/confident"</p> | <p>"I went to the doctors and was introduced to the midwife"</p> <p>"Barnado's did parenting classes in the home – they were very helpful"</p> | <p>"My mum explained a lot to me – I had people around who could explain things to me"</p> |
| 😞 | <p>"I did not find out until I was 6 months pregnant as I was having injections"</p> <p>"I new something was wrong because I had no periods"</p> <p>"I tried several pregnancy tests"</p> <p>"For my second baby I was confused – I still had blood – but knew something was wrong. I felt the baby move at 6months and knew I was pregnant"</p> <p>"Nervous and worried. As well as having a learning disability I also have cerebral palsy. I wasn't allowed to have my baclofen throughout the pregnancy."</p> <p>"I was very nervous. My disability makes it difficult for me to talk to people"</p> | <p>"I was nervous going to the doctor"</p> <p>"I had to go to the hospital for ante natal care for my kidneys, and never got to my appointed doctor – I saw different people every time "</p> <p>"The nurse mumbles – she is not English and uses big words I do not understand"</p> <p>"My doctor understood my learning disability and I felt I was listened to."</p> | <p>"The book was not easy to read but it did explain. I was showed videos and I went through all the information"</p> <p>"The colour of the uniforms can be confusing"</p> <p>"I can not read or write – pictures work well for me, but I also need someone to explain it several times too"</p> <p>"The midwife was friendly but didn't give me any information, I just looked on the NHS website. I had no ante-natal classes and wasn't informed about them even though I asked."</p> |
| 😞 | <p>"I was shocked at being pregnant at 16 years"</p> <p>"Social services did not like the fact that I was living with my partner because he was violent to me"</p> <p>"I felt mortified because I was in a difficult situation with my other children"</p> <p>"I was nervous and scared – I was worried that my child would be taken away"</p> | <p>"Because I was 16 they said I would need extra help"</p> <p>"I felt judged – people kept asking me 'are you sure you want his baby', 'what if it has Downs Syndrome'"</p> <p>"I was bleeding at 11 weeks and had to ring 111 - the midwife did not give me this information"</p> <p>"At 24 weeks I found out I had E. Coli infection in my kidney"</p> <p>"At 25 weeks I got beaten up and went to get checked up"</p> | <p>"I did not have any information"</p> <p>"When I had my second child I forgot all the signs – the midwife assumed I remembered everything"</p> |

Birth

| | What kind of birth I had | What happened next | What information was available |
|---|---|--|---|
| 😊 | <p>"I had high blood pressure so I had a caesarean to be on the safe side"</p> <p>"I was offered a caesarean but I wanted to push my baby out so I was given the choice"</p> | <p>"My midwife was really caring, I could not fault her. I would like to have had the same midwife all the way through"</p> | <p>"The consultant explained the caesarean very well"</p> <p>"I got good info off the teen midwife about labour"</p> |
| 😐 | <p>"I was told I had to have a caesarean"</p> <p>"I had a natural birth"</p> | <p>➔ "The baby popped out in 9 minutes!"</p> | <p>➔ We went through the birth plan and they explained everything e.g. epidural and we stuck to the birth plan"</p> |
| 😞 | <p>"I was treated very badly. I was told I could have a natural birth but then I was told I had to have a planned caesarean. They wouldn't explain why and I was very scared during the caesarean."</p> <p>"They shout at you and treat you like you are daft or stupid, they make you feel horrible!"</p> <p>"Not good – they didn't have time for me"</p> | <p>➔ "I had high blood pressure and the doctors said I was exhausted, the midwives put on my notes I had post-natal depression. When my son was born they took him away for 2 hours and nobody would tell me where he was. I had him for 5 minutes before they took him away."</p> <p>"The midwife shouted and was nasty because I was too tired to push"</p> <p>"The dad was told he could not come to see the baby being born – he was told to go home"</p> <p>"They didn't believe me when I said I was in pain. When I was sick they told me not to mess the floor up"</p> <p>"It came out crying – I was shocked"</p> | <p>➔ "They didn't explain why I couldn't have a natural birth and they didn't explain whether I had exhaustion or not etc. There were no ante-natal classes and I was only allowed to look around the ward the day before the caesarean. I was that scared and shaking they allowed my husband in for the whole caesarean. normally they would have to wait outside first and then come in. I read a bit on the NHS website but it wasn't an easy read and I was still very scared. I was shaking that much with fear I was asked if I was cold."</p> <p>"No one told me how painful it would be"</p> <p>"When it was born at 29 weeks I did not expect it to have arms and legs – I did not understand how babies develop"</p> |

Afterwards

| | Back on the ward | What happened next | What information was available |
|---|---|---|--|
| 😊 | <p>“One nurse in the hospital spoke to me horribly, she was very mean. I wanted to walk around and do things because that’s how I am. I have autism.”</p> <p>“The midwife could see I could look after my baby”</p> | <p>“She kept telling me off, until she found out about my disability. then she was very nice to me and a lot more understanding”</p> <p>“I was left on my own”</p> | <p>“Social workers wanted me to be under social services, but the midwife said I was OK to go home”</p> |
| 😐 | <p>“I did not want to wake her and feed her but I was told I had to”</p> | <p>“They were much more helpful at home than at hospital”</p> <p>“Why did they prick his feet?”</p> <p>“It took more than 2 hours to do the checks before I was allowed home”</p> | <p>“There were no clear rules – every one said something different – it was very confusing”</p> <p>“I have to read the information five times to understand”</p> <p>“I had to teach my partner to feed him, change his nappy etc.”</p> |
| 😞 | <p>“Why are some midwives and nurses so pushy and keep waking you and the baby up?”</p> <p>“They snapped ‘When did you last feed that baby? Did you write it down in the rota?’”</p> <p>“I got told off – it felt really unfair”</p> <p>“I felt very small – they looked down on me”</p> <p>“The midwives kept telling me he would be removed after 4 days”</p> | <p>“The father was not allowed in”</p> <p>“They told me I had a choice - stay with my partner and lose my baby or leave my partner and keep my baby”</p> <p>“I felt they were treating me differently – I was told I would drop her – other mums were allowed to carry their babies”</p> <p>“They made me feel like the baby was not mine – it was horrible!”</p> | <p>“No one showed me how to bottle feed”</p> <p>“I was not supported to use the knowledge I had so I lost confidence”</p> |

Breastfeeding

| | Breastfeeding | What happened next | What information was available |
|---|--|--|---|
| 😊 | <p>"I had a good experience with breast feeding"</p> <p>"I did not think I could breastfeed – I have epilepsy so I thought I couldn't because of the medication, but the community midwife said I could"</p> | <p>➔ "The midwife helped me to latch on and showed me how to feed"</p> | <p>➔ "She wrote a good report about me"</p> <p>"The specialist LD Nurse took photos and showed me these photos so I could understand – how to hold, how to feed etc."</p> |
| 😐 | <p>"I had a caesarean so was never told about breastfeeding"</p> <p>"I did not feel confident or comfortable to breastfeed"</p> | <p>"I wanted to breastfeed but I couldn't"</p> <p>"I had problems breastfeeding – I did try but I got very sore"</p> | <p>"I was taught how to bath the baby, but not how to breastfeed it"</p> |
| 😞 | <p>"Mums with a learning disability are often not supported to breast feed – it is seen as a bonding exercise so it is not encouraged because they may not keep the baby"</p> <p>"The baby was taken away and two days later they sent someone to help her express – the family had to deal with it"</p> | <p>"I felt useless because I tried and tried and always felt in the wrong"</p> | |

When something goes wrong

| | When something goes wrong | What happened next | What information was available |
|---|--|---|--|
| 😊 | <p>"The nurses were nice to me in the hospital I was in there for 4 days because of complications and I was poorly"</p> | | |
| 😐 | <p>"When we found out our son's bowels were growing outside his body they walked outside and someone came back and looked at the scan."</p> <p>➔</p> <p>"She saw the baby had fits and she listened to me"</p> | <p>"They walked out again leaving us worried. They then pushed us into the reception until someone explained. We were crying."</p> <p>➔</p> <p>"She explained about the blood tests and what they were for"</p> | <p>"Knowing more info about my son's condition. I had to look on my PC to find out. They told us to leave and come back in a couple of days"</p> |
| 😞 | <p>"I didn't understand when he got jaundice what was going on – there were tubes out of his nose and everything!"</p> <p>"I got an infection in my placenta and needed a C-section"</p> <p>"They said I couldn't go home – I needed to be assessed"</p> | <p>"There as no explanation of what the infection was – only that it could kill me, my baby or both"</p> <p>➔</p> <p>"It was very stressful. I have to pack with a new baby- and go into a new environment and I was watched on camera 24 hours. Nothing I did was right"</p> | <p>"When you have a premature baby why can't you stay in the same room as them? This was not explained to me"</p> |

At home

| | Back at home | What happened next | What information was available |
|---|--|---|--|
| 😊 | <p>"She was very nice and helpful"</p> <p>"Social worker now is good - she understands and makes sure I know when I have done a good job"</p> | <p>"My baby has an allergy to milk – she got me some other milk"</p> | <p>"I am a look and learn person – she drew pictures and left them on the fridge e.g. sterilising"</p> |
| 😐 | | | |
| 😞 | <p>"There was no hand over from the hospital midwife to the community midwife – they do not share information"</p> <p>"Social services said I was too affectionate with my babies and too protective"</p> <p>"They just took my child away – and did not give me any support or counselling. I was told to go to the GP"</p> | <p>"My child lived with us until he was 3, then he was removed. Then they moved and I lost contact for 6 years"</p> <p>"I did not understand what was happening – we went to court"</p> <p>"They use neglect as an excuse in court"</p> <p>"They put me on depression tablets – I blamed myself"</p> <p>"They took my daughter away on 5th November – I was saving up for Christmas"</p> | <p>"No one explains what neglect is – I still do not really understand why they were taken away"</p> |

Other Observations and Concerns

During our conversations we heard of other areas of concern/ observations:

1. **Judged** – When speaking with the parents what became clear is they experience much of what other parents experience, the same concerns, the same questions and emotions, but this is often amplified for the parents with a learning disability as they feel judged at every point – they have to prove they are good enough to be a parent; other parents simply do not have this external additional pressure
2. **Care act** – there is a perception that people with a mild disability will no longer have access to their much needed advocacy support
3. **Breadth** – the parents we met represented the full breadth of social circumstances with many examples of rape, abuse, paedophile predators, teenage pregnancies, multiple fathers, through to parents in long term loving relationships
4. **Difficult births** – it appeared that there were more caesarean births and difficult births e.g. premature, complications etc. than is the norm, but we do not have statistical data to support this
5. **Empathetic** – this is an audience who are highly empathetic in many cases, and so extremely tuned into nuances and attitudes
6. **Challenges** – often these parents themselves have children with learning disabilities and indeed their own parents have a learning disability making their circumstances more challenging and requiring the right support
7. **Abortions** - CHANGE hear a lot about pregnancies where abortion is recommended but not fully explained
8. **Bereavement** – when their baby or child is taken away there seems to be a total lack of support – this for many is like a bereavement and they have no coping infrastructure to support them. These were incredibly difficult and emotional conversations as understandably parents find this a difficult topic to discuss
9. **Social worker** – the relationship with the social worker was rarely a good one – making this a stressful topic for all – one parent had to leave because they were so upset. This is hard to address as their role is a critical one but in its current approach is not working for the parents

“I am always fearful that they will take my child away.”

Professionals Survey - Examples of what is working well

Below are some examples shared in the professionals' survey of what is working well in their organisation. This is taken from the survey that 107 professionals took part in. Interestingly the key themes highlighted by the professionals mirror those raised by the parents. One question asked specifically about examples of good practice related to the maternity experience for parents with learning difficulties or other vulnerable, hard to reach or disabled families. All the examples put forward are included below. Full results from this survey are available in a separate report: ***Celebrating the Best of the Maternity Experience of Care with a focus on parents with learning disabilities*** available from PEN.

Good use of Multi-disciplinary working using BSL Interpreters, Adult SW, Hospital staff to allow extra explanation for a profoundly deaf woman with LD who requires Gynae Surgery. Used Hospital communication book to explain what would happen after surgery.

We have 2 public health midwives working in Knowsley who provide care to vulnerable women which includes women with learning disabilities and other vulnerable groups. They link in with many services to provide tailored care e.g. obesity pathways and links with slimming world and other groups.

We did work very closely with all agencies involved with a patient recently who had a learning disability and had frequent multiagency meetings throughout her pregnancy and following delivery which enabled us to all support the family more effectively. We aim to make this the norm in all cases in the future. This lady did have a very effective support system already in place.

1. Traveller families Invited by family to record their experience as users of the service. This was then shared with providers. This reflected the following insight - mainstream services appear too wary of large groups attending the unit in support of their family member and are struggling to provide the reception desired. A work in progress.

2. Young mums and mums to be Invited personally to attend a community event in a local church in the centre of Chester city to be pampered free of charge. Nails, make up etc . A one stop shop was created in this pop up session for one afternoon. The young mums met future staff and signed up to groups such as parenting sessions; one agreed to retry to lactate with her baby following contact with breastfeeding Hv specialist.

The Hospital has a dedicated Safeguarding Midwifery team.

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

We have a number of initiatives for vulnerable families including

1. **Case loading** of women in prison including safeguarding, pregnancy support and scanning at the prison, mother and baby unit in prison with parenting skills taught. Two safeguarding midwives caseload the prison women and babies.
2. **Perinatal Mental Health Midwife** with a focus on community based care and liaison with mental health agencies.
3. **Birth Reflections Service** for women and partners suffering following difficult birth, birth trauma, depression and needing counselling.
4. **Bereavement midwifery team** - giving support follow stillbirth and pregnancy loss.
5. **Enhanced postnatal pathway** for women and vulnerable families requiring extra support, help, advice and observation.

If any women has a disability she will be offered a home visit to assess and plan for any additional needs she may have with regard to maternity care.

Mainly through individual care plans and working with the services already in place for the mother.

Mainly the community midwife is aware of a family's problems and will endeavour to secure adequate support for them through the appropriate channels. These can sometimes be difficult to access due to communication with the LD team.

We have a dedicated team of 3 specialist midwives who care for the most vulnerable 2% of our local population offering enhanced, individualised care to meet each family's needs.

During time on Community was instrumental in organising & running AN class for vulnerable mothers i.e. No English, disabled, teens, anyone in need. Set up leaflets in other languages in conjunction with council run assoc. Teenage pregnancy Midwife & team. Specialist Midwives in all vulnerable areas.

I was a part of the recent care of a woman with a learning disability in my position as Midwife For Long Term Conditions. I made sure I was available to see her when she came into hospital for antenatal appointments, so she always saw a familiar face. I worked with the woman, her partner and mother to produce an individualised plan of care to ensure her experience of our maternity services was a positive one.

Myself & my colleague run a service of extra advice & support to young people, which includes those with learning difficulties.

Development of pathway-aids staff in directing to appropriate care & support which improves service user's experience. We have a 'One stop antenatal clinic' for those with substance abuse We work closely with the following working with vulnerable groups:- NSPCC and alongside their 'Baby steps programme' Integrated Care Pathway (ICP)- a preparation for parenthood programme in the Children Centres Involved with Family Link workers (FLAN). Work with the Family Nurse Partnership Programme (FNP) Bradford about to start the 'Better Start Programme' Ties with 'Here we are group', newly started 'Birth Choices group' and work closely with the Bradford & Airedale 'Maternity Partnership' group. 1:1 Parent Education is offered with Specialist Midwife in Parent Education together with HFN/support worker to prepare those with LD or any specific needs for the rest of their pregnancy, forthcoming birth & becoming parents. Visits to Labour Ward, Birth Centre & wards all offered & undertaken to help reduce anxiety of coming into a new/strange place. Consideration given to involving a doula for birth support & possibly post birth.

Community midwives routinely ask about learning difficulties / disabilities for all women and refer to the Specialist Midwives for additional support and planning. Joint pregnancy and birth planning with appropriate agencies as soon as possible to ensure appropriate support provided to women and their families to meet their individual needs. All vulnerable, hard to reach and women with disabilities are referred as above and pregnancy and birth planning undertaken if appropriate for the individual.

We have a Disability action and awareness group which has service users and staff as members. We have a folder available for each midwifery team with resources available. We employ a Disabled Public Health Midwife

Both parents would stay in the postnatal ward to ensure parenting skills etc. resulted in the family being equipped to take baby home. We have baby showers for hard to reach parents. Planning grandparent event in hard to reach areas.

We have a team of midwives providing additional support for women from vulnerable groups, providing continuity throughout the pregnancy episode. This team link closely with safeguarding team and social care services.

Mother with Friederichs Ataxia wheelchair bound care provided by Vulnerable team midwife in her area. Birth planned for another site with antenatal birth plan multi-disciplinary meeting to plan birth and postnatal care in hospital. Breastfeeding support and parenting support planned and implemented after the birth. MDT discharge planning meeting held with handover of care back to original vulnerable team midwife. Postnatal care at home.

What We Would Change

We asked the parents to consider what they would do to change the experience. Clearly every parent's experience is different as is what they are looking for from their experience, however there are some core areas that they did put forward:

Process improvements:

- One point of contact throughout the process – someone we trust and can understand
- Buddy scheme – with a parent who does not have a learning disability
- Communication – ensure information is shared more effectively across the different professionals
- Parenting classes – offer parenting classes that cater for this group of parents

People improvements:

- Provide training – of how to work with parents with a learning disability (both midwives and social workers)
- Attitude and behaviour – particularly people on the wards and in the GP practice
- Communication – many parents struggle with literacy or have a short attention span so provide resources that will help e.g. easy read/ DVDs/pictures and be happy to repeat important messages

Physical improvements:

- Cleanliness – ensure wards are hygienic
- Temperature – make sure wards are not too cold
- Uniforms – colour of the uniforms can be very confusing

“It feels like a crime to have a baby – people who drink and take drugs have babies, why shouldn't a person with a learning disability have a child?”

Recommendations and Next Steps

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.

“Treat me properly, treat me right, be nice”

“They talk to you like you are stupid, or a child and they undermine you”

- 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.

Philipa Bragman of CHANGE says learning disabled parents often feel they are put under unfair scrutiny, driven by an assumption that if they have a learning disability they cannot be a good parent.

“These parents are often judged in ways that other parents are not,” she argues.

“They are the only group with a perceived risk from the start. They go through a process where they have to prove they can parent rather than an assessment of what support they need to parent. They feel they are set up to fail,” she says.

Bragman believes many of these issues stem from miscommunication between parents and practitioners.

“The parents are often seen as being difficult when they can’t quite understand what is required of them. There is an assumption when communication breaks down that they don’t care, but very few parents are deliberately difficult.”

Acknowledgements

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.

Mums with Learning Disabilities

*I've an IQ of less than 70 and I'm going to be a mum,
 Take some time to get to know me – I'm not the only one,
 Stuff that really helps me is continuity of care –
 seeing a friendly midwife, someone who really cares.
 Getting information that is accessible for me,
 it gives me a bit of power so I'm a partner – that's the key!
 Yes, breastfeeding may take a bit more time, but it's worth the fuss!
 Challenging the stigma, really is a must!
 So next time when you have the privilege to care
 for a mum who's got LD –
 please invest the time and care....*

Appendices

Word Bank

PEN co-worked with CHANGE and during this process we have prepared a word bank of complex words:

Focus Group: group of people who are invited to take part in the research

Gynaecologist: special doctor who looks after women

Insight: useful information

Obstetrician: surgeon that delivers the child

Paediatrician: special doctor who looks after children

Qualitative Research: research that helps understand issues

Quantitative Research: research that involves lots of people

Survey: a set of questions that is used in research in a questionnaire

Resources

Please find below lists of various resources we have found as part of this project. This is by no means exhaustive and would love to hear of any additional examples to share. Please send these to r.evans@patientexperiencenetwork.org These will be hosted on our website: www.patientexperiencenetwork.org under Resources.

List of advocacy services

During the process we have created a list of advocacy services and other support groups. At the time of writing there are 193 entries. If you would like access to this list please contact Catherine Carter at CHANGE or Ruth at PEN.

Papers

[British institute of Learning Disabilities \(BILD\) Fact Sheet: Learning Disabilities Ken Holland Feb 2011](#) Useful fact sheet about learning disabilities

[Community Care: Parents who feel set up to fail Louise Hunt September 2011](#) A Kent project is proving that proper support for parents with learning disabilities can lead to fewer children being taken into care

[Department of Health: Valuing People 2001](#) This is the first White Paper on learning disability for thirty years and sets out an ambitious and challenging programme of action for improving services

[Department of Health Valuing People Now: Summary Report March 2009 - September 2010](#) This report shows how providing clear and transparent information can enable local people to look at progress and improve services at a local level.

[RCN Learning Disabilities](#) A review of learning disabilities and repository of papers and references.

Resources for Parents

Baby Steps Programme at NSPCC:

<http://www.nspcc.org.uk/services-and-resources/services-for-children-and-families/baby-steps/>

Baby Steps is an NSPCC ante-natal programme helping vulnerable parents cope with the pressures of having a baby.

Best Beginnings:

<https://www.bestbeginnings.org.uk/parents-with-learning-disabilities> and their Baby Buddy app which helps and supports mothers by having information in bitesize chunks, with simple and clear language so that a mother with a reading age of 11 can understand.

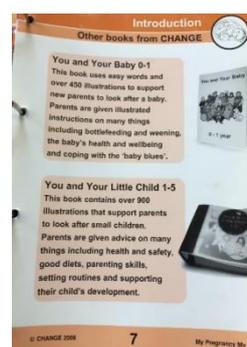
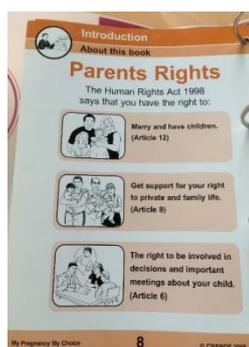
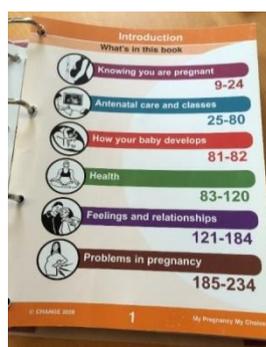
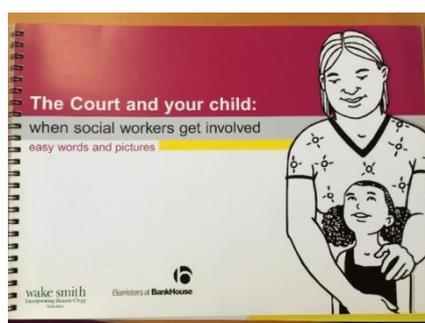


CHANGE:

www.changepeople.org have a series of resources available in easy read format. These include:

- My Pregnancy, My Choice
- You and Your Baby 0-1
- You and Your Little Child 1-5

Photographs from these resources are shown below:





Shared Lives South West:

<http://sharedlivessw.org.uk/about-us/> - a Charity that pairs adults with learning disabilities or, sometimes, dementia, with trained people who are committed to the idea of sharing their homes, families and lives, either short or longer term

Sure Start Project:

<http://www.nidirect.gov.uk/sure-start-services> a government programme which provides a range of support services for parents and children under the age of four, who live in disadvantaged areas across Northern Ireland.

Resources for Professionals

- Being a Parent, Buckinghamshire Interagency Protocol, working with Parents with Learning Disability
- Hospital Passports are widely used (see PENN2013 Northumbria NHS Foundation Trust – Joint North Tyne Hospital Passport
- Inclusive Support for Parents with a Learning Disability
- Inequalities Sensitive Practice Initiative, Maternity pathways – Women with Learning Disabilities Greater Glasgow and Clyde
- **Kent Project:**
<http://www.communitycare.co.uk/2011/09/23/supporting-learning-disabled-parents-to-keep-their-children/> – an interesting project in Kent Valuing Parents Support Service that is working hard to ensure more children stay at home with their parents
- Leeds Maternity Strategy 2015-2020 pages 5 and 23 specifically focus on parents with a learning disability
- **Norah Fry Research Centre at Bristol University:**
<http://www.bristol.ac.uk/sps/research/centres/norahfryresearch/> who are a leading national centre of excellence for applied social research and teaching, making a positive difference to the lives of disabled people. Their website has some easy read resources
- Parenting with learning disabilities – Response and Recognition – Department for Education Parents with Learning Disabilities in Bristol - A brief overview of local evidence: Lesley Russ: Public Health: Bristol City Council lesley.russ@bristol.gov.uk
- What Works for Parents with Learning Disabilities? – Summary - Susan McGaw, 2000 Barnado's



My Poem by Suzie Fothergill

*I'm a woman who has talent
That they can't take away.
They tried with drugs
And needles to dope me every day.*

*Institutions stink,
They make you want to puke,
The doctors think they're it
And they'll read you like a book.*

*I was kicked around and used
Insulted and abused;
They messed my mind right from the start
Treated me like a dirty tart.*

*But it was them that did that,
It was them that scarred my mind,
It was them that corrupted my innocence,
And left me feeling that no one cared.*

*They shoved me in a hostel
As a guest of the Salvation Army,
With the company of drunks and punks
It was enough to send a poor lass barmy.*

*I wonder why it had to be that all my life
No one to love me
No one to care
No one to see
No one to listen properly.*

*So now my second life begun -
A new chance to live life through my son;
A reason for living I have found
And it's going to be better second time round.
So now I tell you*

*I've got a voice
I've got a right to make a choice.
I'm not a toy for you to abuse
I'm a woman of spirit and now I'll refuse...
To take that abuse anymore.*



From *No Going Back*
Forgotten Voices from Purdhoë Hospital
Written by Tim Keilty and Kellie Woodley

For further information please contact:

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