



Women with Learning Disabilities and Maternity Services in Leeds: initial issues

Information of results to Healthy Leeds

February 2010

CHANGE is a user-led organisation working for the equal rights and full inclusion of all people with learning disabilities

The research team for this project follows the model of co-working at CHANGE, in which people with learning disabilities and people without learning disabilities work equally together on a project. Under the supervision of CHANGE's Director, the following two researchers have worked on this project:

Ana Laura Aiello

Ana Laura is an international human rights lawyer. Ana Laura is also an experienced consultant regarding disability and human rights. She has conducted several projects for organisations like Amnesty International or Mental Disability Rights International (leading mental disability rights organisation based in the United States of America). In addition to her work, Ana Laura is currently undertaking part-time PhD research at the Centre for Disability Studies (University of Leeds). Ana Laura also has a personal experience with respect to learning disability: her only sister is a person with a learning disability.

Catherine Carter

Catherine is a mother with a learning disability. Her personal experience as a disabled person and as a mother has contributed to make the voices of people with learning disabilities more legitimately heard in this report.

Acknowledgements

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1. Context of the research

This has been a four months and a half project, conducted in 40 working days. The researchers worked two days per week, from 28/09/2009 to 17/02/2010.

The project has been funded by Healthy Leeds.

In consideration to the extremely tight deadline for this research, the proposal advanced that the possible findings would not reach to large scale conclusions about maternity services but would highlight some of the issues of maternity services within the Leeds area.

While implementing the proposal and following a case-study approach, the research team gathered in-depth qualitative data about the experiences of some women with learning disabilities as users of maternity services in Leeds. Interviews and recordings were employed with this purpose. The main issues that arose from these women's experiences have been presented and analysed under the light of human rights standards and the social model of disability (section 2). Following the research proposal, an example of accessible information which contains some of the crucial findings of this document has been attached (Appendix 1). This Appendix has been elaborated with easy words and with pictures from CHANGE picture bank. Finally, and as the research proposal determines, this piece of accessible information has been sent to the research participant for her member checking.

In the course of this project, the impossibility of finding the maximum number of research participants established in the research proposal has revealed as an unexpected and challenging research issue in itself. This issue is explored in section 3.

CHANGE's Director has been supervising the project. Also the organisation has been interacting with the funder during the course of the research. In the context of this last interaction, the need of this research has been highlighted and supported by the Commissioning Manager for Maternity-NHS Leeds.

In connection with this research, on 15 December 2009 CHANGE hosted a day for maternity service professionals. The aim of this day was to explore how maternity professionals in Leeds can meet the needs of women with learning disabilities in better ways. The Commissioning Manager for Maternity-NHS Leeds attended this event. Also professionals from the following areas attended this day: midwifery, nursery, doula service, breastfeeding counselling, outreach work and research. Through presentations and exercises, the debate highlighted the importance of giving women with learning disabilities appropriate support. Key ideas which resulted from this day's debate enriched the research analysis.

In addition, this research project has been registered by the researchers on the Parenting Pilots and Pathfinders Digest (Parenting Unit, South Leeds Family Learning Centre) and the project has been included in the January 2010 Pilots and Pathfinders Digest Update.

Finally, the overall findings of this document will be presented in an accessible format at a suitable event by people with learning disabilities. This event will be funded with the budget already granted to these effects.

2. Experiences of some women with learning disabilities as users of maternity services in Leeds

In order to find women with learning disabilities who are users of maternity services in Leeds, the researchers appealed to contacts with at least 200 key stakeholders.¹ As a part of these contacts, the research was advertised in major websites; also a leaflet and accessible letter were broadly distributed.

In accordance with the provisions of the Mental Disability Act 2005, the researchers evaluated if each of the women with learning disabilities interested in participating in the project had capacity to give consent. With the purpose of assisting these women to reach to a fully informed consent, the researchers gave each woman an accessible participant information sheet and consent form. Before the potential participants signed the consent forms, the researchers met with them at CHANGE's offices, explained the participant information sheet to them, and answered their questions about the project.

While working with these women, the researchers found that the proposed methodology was difficult to implement exactly as proposed. Sometimes, the interviews had to be cancelled and re-arranged, and also the common feature was that the researchers had to collect the data in the women's houses rather than at CHANGE's offices. Secondly and in relation with the proposed recordings, although the participants initially agreed to record themselves, they finally did not. Then the researchers had to record the women while conducting the interviews. And thirdly, finally the researchers could not accompany the women to visits to maternity services. This was because the researchers did not have ethical approval to do this. The lack of ethical approval was determined basically because of the very tight deadlines for this project (40 days of work), the consideration of the standard

¹ This approximate number responds to the following key stakeholders: people with learning disabilities, voluntary organisations and research centres.

timings for obtaining ethical approval² and the final decision by the organisation of not going for ethical approval³. This project has been then focused on women with learning disabilities recruited privately and with capacity to consent, because no ethical approval is required in this case.⁴ The findings of this report must then be interpreted with these limitations in mind.

Following, the women's experiences are exposed and analysed under the light of human rights standards and the social model of disability. Complying with ethical guidelines, the real names of the participants have been anonymised in this report.

2.1. Jane's experience: 'They only knew that I had a learning disability, but they didn't know how to deal with me'

The researchers interviewed Jane on 22 December 2009. In the context of this interview, the researchers recorded images.

Jane is a 27 year-old woman born in Leeds.

She affirmed that she has a learning disability and that she communicates to people that she has a learning disability. Because of her learning disability, Jane said that she finds hard,

² From NHS contacts, finally we have been informed by the REC Co-ordinator (Leeds West Research Ethics Committee) that the process for ethical approval can take *a minimum* of a few weeks.

³ Decision taken after writing to the funder explaining the situation and asking for more time and funding, obtaining a negative answer.

⁴ Confirmation obtained from the NHS REC Co-ordinator (Leeds West Research Ethics Committee).

Computer work, reading, writing, my [her] concentration ... social workers ...

Jane assumed that she needs extra support because of her learning disability. For example, she referred that she is in contact with the organisation People in Action⁵ and that they are providing her, among other things, with advocacy.

At the moment of the interview and recording, Jane was not working. She referred that she worked for Morrisons in the last year. She worked there as a sales assistant, however, she had this job only for a few months, because as Jane referred,

... I could not concentrate, I went through a lot of stress, family problems, and that caused me to leave early ...

Jane has a partner. They are engaged at the moment. With this partner, Jane has four children. All of these children are in foster care. Very recently, she was pregnant again but she had a termination after sixteen weeks of being pregnant.

When asked about this termination in different parts of the interview, Jane seemed to be very angry and consternated. She repeatedly affirmed that she was not given any other choice rather than to have the abortion, and that she wanted to have her baby. She explained that she wanted to know if she was going to be able to keep this baby but that she received no answers.

She told us that the termination took place in St James Hospital.

⁵ <http://www.peopleinaction.org.uk/> (last accessed on 3 February 2010).

She said that only her partner went with her to the appointment. The rest of her family and friends, she referred, did not supported her through this pregnancy because,

... nobody knew [apart from her partner], I wanted to keep it secret until I knew what was going to happen

According to Jane, the doctor pressured her to decide on termination,

... because he said ... it was not going to go right ... I can concentrate, you know ... it was not good for my health to go through my pregnancy ... and that it would end up in the same way than the others ... [the baby was going to be taken away]

The researchers asked her why the doctor said that the pregnancy was not going to be good for her health. Jane referred that it was,

Because I was going through a lot of stress ... and what with the others was going [her other children in foster care] and everything ... And I was under a lot of stress through the social worker ...

And she also said that,

... he just said ... because I am asthmatic ... that causes me a lot of panics attacks ... He did not give me any explanation, he did not say this could damage the health of the baby ... He didn't say why, he just said it is not good for your health and that's it

When asked if she had to sign something for going ahead with the termination, Jane referred that,

Yes, a form which says that you are determined to go ahead with it. But I was not. And they said well, this is the best option. And I said you do not know me, I am not thinking that I am doing the best when I am doing this ...

The referred uncertainty regarding if she was going to be able to keep the baby with her or not, seems to have influenced Jane to finally sign the form,

... and I did not know whether the baby was coming home or going to be taken into care, nobody was telling me anything so basically I did not have any choice

In effect, Jane spoke about the lack of information from social services in relation to what could happen with the baby after the delivery. When the researchers asked her if social services or social assistants have been involved in this pregnancy, she said that,

Yes. I put a complaint in against my other social worker ... And I spoke to the complaints officer and somebody else from social services. And I thought it would be the same social worker all the way through, but it wasn't. She came to see us, and I told her about the pregnancy and I asked whether I was able to keep the baby, and she didn't give any answers. They gave me no options, she wasn't telling me what I wanted to hear ... She got me mad...

When the researchers asked Jane if she asked any questions in her appointment with health services, she referred that,

Yes, I asked what does it entail [the process for termination], how long was it ... What is the pain like ... I was not getting anywhere and not knowing what was happening ...

This unclear picture of what happens with a termination may have influenced Jane's decision of going ahead with the termination.

After the signature of the form and inclusively after the process of termination was put in progress, Jane was still not convinced about the termination,

... So I took the first tablet and I came on and I still was not hundred percent ... and when I went with the third ... the last ... of tablets ... which is inserted through the vagina really, I was saying I am not going ahead with it, I can not go ahead with it, I was upset and the midwife, well, the nurse or whoever ... turned around and she said, you can't go home, you have to get through the whole thing, because ... if you go ahead with the pregnancy it will turned out with all sort of problems ...

Jane also complained in the interview about the attention that she received during her stay at the hospital,

Well, I went through a lot of entire things, I didn't want to do it ... No one just sat down and talked to me and listened to what I was saying ... They just went ahead and did what they

needed to do. Only they were saying it's too late now ... When I was in pain, I asked for some painkillers and they didn't give me anything ...

Jane also said on this regarding that in nine hours she only saw a midwife. She also referred that she saw more than one midwife in her last termination process,

Because they were changing over, when I was at the hospital going through termination they had shift change

When the researchers asked her if it would have helped if she had the same midwife, Jane said that,

Yes, it would. If you have the same midwife all the way through and she went with everything with you clearly ... Rather than you go through everything by your own ... and not giving you anything, tell you what's happening ...

When asked again about what happened when she said that she wanted to keep the baby, Jane said that,

They just said, well this thing is not going to happen ...

Asked about what she would say to the doctor, to the social worker, or to the midwives if she had to say how a woman with a learning disability could feel supported, she answered,

I think they should give them options, rather than telling you only have the option of an abortion. You have to give her enough time to think ... nobody can decide in 24 hours what he wants to do ... I didn't ...

And she stated regarding doctors or midwives in her last termination process,

They only knew that I had a learning disability, but they didn't know how to deal with me

Asked again about what she thinks that is the right support, she answered,

Well, somebody who knows what you are going through ... like your learning disability. And who help you through your pregnancy, and through your birth, and through your labour ...

When the researchers asked if she was meaning only one person or more than one, X said,

... obviously you need a midwife ... the same midwife ... rather than passing you on to the hospital ... and the hospital has five or six midwives or doctor or whoever ... in your room and you do not know what is going on

In relation to her experience with the termination, Jane finally stated,

... that was I felt like, that anybody gave a shit about my learning disability ... they treat everybody the same but they should treat people with learning disabilities different. Slightly different but a bit more better. Like they do with others

Jane also referred to her experience regarding her previous pregnancies. In general, it seems that her experience around these was good because she felt supported in more than one time,

... The midwife I had last time [she is referring to the pregnancy of her last born child] ... She went through everything with me ...

Regarding the information that this midwife gave to her, Jane says that,

It has pictures ... The midwife explained clearly, so I understood ...

Also when she was referring to her experience with her last born child and answering the question regarding if the doctor or midwife explained to her that she can have special support because of her learning disability, she said that,

... The midwife I had was trained in that department

Asked in another part of the interview if she understood information given to her by the health services, she said that,

Yes, because there were more pictures than words

When asked about her understanding of ante-natal or parenting classes that she attended, she said that,

Some of them I did. But it was all words, and the writing was too small. So I asked if I could have it in pictures, basically, with big writing ... and she gave me a copy with words and pictures

Finally, when asked if she visited the labour ward before the birth of her child, she explained that she did but that the staff only showed her the room without any explanation. The researchers then asked her if this staff knew about her learning disability; she answered positively but clarified that,

... they did not understand about it ... she showed us basically ...

From Jane's experience, the following concerns arise:

- Lack of information: it is clear from different parts of this interview how Jane felt that she was not receiving information from health and social services;
- Non-accessible information: when being given information, Jane referred in many times that she did not understand it;
- Pressure for terminating with her pregnancy: from Jane's interview, it seems clear that the doctor did not give her any argument regarding the substantial negative effects that her pregnancy could provoke on her health or on the baby's health. Stress is not usually considered by health workers as a reason to advise on termination. It seems also clear that Jane signed the aforementioned form while she was going through considerable uncertainty, stress and pressure. She affirmed that social services did not give her answers about what was going to happen with baby

after the birth. The researchers consider that all of these conditions prevented Jane from giving free and informed consent.

The organisation has also been aware of other cases of women with learning disabilities who have been pressured for having terminations of their pregnancies. In this last sense, the charity Life Pregnancy Care (Leeds office)⁶ informed the researchers by phone that they have been supporting at least two women with learning disabilities who have went through this situation. The researchers could not obtain more information because of the lack of women's consent to speak about their experiences.

2.2. Mary's experience: '... They just said ... if you need help, help is there'

The researchers interviewed Mary twice. The first time was on 3 December 2009, just before Mary's due date for giving birth. The second time was on 13 January 2009, after Mary's delivery. In this second time, the research team recorded beautiful images of Mary with her baby.

Mary has a speech impairment. This impairment affected the complete understanding by the researchers of Mary's interview.

Also and according to the researchers views, Mary seemed to answer the questions in a general or vague way. And, in some occasions, her answers were contradictory. Maybe, these facts are associated with Mary's learning disability.

⁶ <http://www.lifecharity.org.uk/> (last accessed on 3 February 2010).

Mary is a 38 year-old woman, born in Leeds.

When the researchers asked Mary if she went to the school, she preferred not to answer this question.

Currently, Mary has a partner. She referred that she feels happy with him. She told the researchers that they are engaged.

Mary has two children. Her eldest child is sixteen years-old and is in foster care. Mary had this child with a former partner and it seemed for her, that this past experience was very painful. Very recently, Mary had a baby with her current partner. The questions of these two interviews were directed to find out about this last experience.

When asked by the researchers if she has a learning disability, Mary's perceptions did not seem to be uniform. In this sense, first she said that she has,

A tiny birth, that one [the researchers understood that Mary was speaking here about her self-perception as a tiny premature baby]

But in the second interview, she referred that what she has

... it's just a mild learning disability

Asked if she tells people that she has a learning disability, Mary first answered that

I think that some people trust services and some people might have learning disability but in my mind it is just a tiny birth [again, the researchers understood that Mary was speaking here about her self-perception as a tiny premature baby]

Later in the interview, she said she did not tell her doctor that she was a premature baby. In the second interview, however, she referred that she told the midwife that she has a learning disability.

When asked about what her tiny birth means for her, Mary answered,

Just ... support and all that lot

After Mary found out that she was pregnant, she referred to the researchers that she

... got some legal advice from a solicitor ... she put me on the right track. She made me feel positive about me and the baby

Asked more questions about her experience with the health services, some interesting answers arose. For example, Mary referred that she received a letter from the hospital, regarding an ultrasound scan test. The researchers asked her if she could read this letter and she replied positively. Also she clarified that this letter did not include, for example, pictures. After in the interview, she referred that she also received a pregnancy book. She told the researchers that she could read it, however, she responded affirmatively to the question regarding if she found this book long-winded. And replying to the question if she preferred information with pictures or short sentences, Mary stated,

No, it would be better to have all the writing there because I can understand it all

Mary referred that she didn't receive advice on what foods to eat or on what to buy after the baby is born. She referred on this last regarding,

I always knew about what to buy and all that lot

Mary didn't receive information about what a birth plan is and also did not have one. On this regarding, she reply to the question about if the doctor or the midwife explained to her what a birth plan is by stating that,

Not really, because I went through birth one time ...

Mary was not given information about the possibility of attending ante-natal classes. She told the researchers that

... They didn't tell me anything about that ...

This participant did not attend these classes.

Mary referred to the researchers that she was not asked about if she wanted to visit the labour ward before her baby's birth. After in the interview, she referred that,

... I already knew what a labour ward was ... [because she gave birth before]

Asked if she knew she can choose how she would like to feed her baby, for example, that she can breast-feed or bottle-feed, she replied,

I understand all of that ... They discussed with me during my previous pregnancy ... I prefer to bottle-feed rather than breast-feed

However, in the second interview she replied to the question about if she would breast-feed if she were shown how to do it,

Yes, I would do, yes

Mary also referred to the researchers that she saw a midwife at her home, after the baby's birth. When asked in the second interview if the midwife was teaching her something, for example, how to change nappies, Mary stated that

... I have done it before. It is in there, all of that is still in there

Asked about if she would ask if she did not understand or that perhaps she needed to understand better the information she was given, she said

No ... I have been through it once and I have got that in mind ...

With respect to the role that social services played in this pregnancy, Mary said that

... they have been asking a lot of questions

When the researchers asked her about what sort of questions social services were asking, Mary answered,

About assistance, about all that

Then she gave us more details about the role of social services here, by explaining that social services are supporting her

By these family aid people, coming twice a day ... checking if we are both OK

The researchers then asked her if social services are, for example, teaching her parenting skills. M answered negatively,

No, they just come in and check upon us

Later in the second interview, the researchers understood that she was referring to social services when she said that

... they just ... a bit of concern about what happened to my first child

She also clarified that

... they just have concerned about me coping and all about that

When the researchers asked her about if social services said that they were going to help her, Mary replied,

Yes. That [they] are going to help us to make sure that we keep her, a family instead of taking the child away from us

The research team then asked Mary if she felt that social services helped her. Her answer was,

Ehm ... If I really asked for help, I will ask for it ...

We asked if she feels she didn't receive help because she did not ask for help, Mary clarified,

No, they just said ... if you need help, help is there

Mary did not receive any support from her own family regarding this pregnancy experience. She clarified that the support that she received came from

... just my partner, his family

After in the second interview, Mary detailed that,

... I can't trust my own family because ... my sister I don't believe her and all about that ... I saw my first daughter heartbroken [she is referring to her sixteen-year-old daughter] because of my own family didn't want to know, didn't want to know me and all that lot so I thought I got something different this time

Asked about if an advocate explained or supported her in the pregnancy, firstly she denied it but just after that she referred that

I have somebody from Leeds Advocacy⁷

It is interesting that when Mary was asked about if she felt supported during her delivery, she only made reference to her partner by stating that,

Yes, was my partner, yes. He was there all the way through

From Mary's experience, the researchers would like to highlight the concerns which follow:

⁷ <http://www.leedsadvocacy.org.uk/> (last accessed on 3 February 2010).

- How a user of maternity services is identified as a woman with a learning disability and the consequences regarding her receiving support: from this interview it arises that Mary exposed at least two different self-perceptions in relation to the question about if she has a learning disability. Also it arises that Mary recognised that she needs support, and at least in one time, Mary did not communicate to the health worker that she has a learning disability. The lack of identification or knowledge, by the health worker, of Mary as a woman with a learning disability, has serious consequences regarding the support that she needs. In other words, if the health worker does not identify Mary as a woman with a learning disability, and therefore as a woman with special needs, the health worker won't be able to support Mary in the way that she requires;
- Lack of information: it is more than clear that Mary did not receive information about crucial issues, for example: a birth plan or ante-natal classes. From her answers it would appear that she did not miss this information, because of the knowledge that she would have as a product of her first experience as a pregnant woman. It can also be interpreted that the services relied on her first experience as a mother, in terms of not giving essential information to her. However, the first experience of Mary as a pregnant woman was from sixteen years ago and in this considerable length of time many things have changed (and Mary might not be aware of them). Also it seems that Mary did not ask for information or help, but this fact does not exempt the services of their obligation of being proactive in addressing the specific needs of women with learning disabilities;
- Lack of accessible information: Mary did not receive accessible information at any time; however, she affirmed that she was not having problems in accessing the information that she was given. Support to women with learning disabilities must be given on a case-to case basis, and the document Valuing People Now: A New Three-Year Strategy for people with learning disabilities: 'Making it happen for everyone' establishes as a key policy objective for 2009-12, that people with learning

disabilities should 'have support to develop person centred plans'.⁸ It seems that Mary did not need support with her access to information. But the findings of this interview lead to the interpretation that, if Mary did not receive accessible information, it is very probable that other women under her same situation also are not receiving accessible information. Regarding this, and as it was affirmed in the previous point, the services should be proactive in supporting women with learning disabilities. At least these services should ask the women if they need accessible information, and if it is the case, services should offer accessible information.

2.3. An analysis under the light of human rights standards and the social model of disability

The analysis of Jane and Mary's experiences has reflected a number of concerns.

When looked under the light of human rights standards, these concerns are transformed into human rights violations to the women with learning disabilities. The detection of human rights violations, on its turn, leads to the identification of responsibilities for these violations.

Disability is a human rights issue. The perception of disability as a human rights issue is very recent, and this fact is reflected in the perceptions that people have and in the work that is done in the area. However, a number of international and national standards recognize the human rights of disabled people and establish obligations that the authorities must comply with. Among the international human rights standards, the United Nations Convention on

⁸ Valuing People Now: A New Three-Year Strategy for people with learning disabilities: 'Making it happen for everyone', available at

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_093377
(last accessed on 3 February 2010).

the Rights of Disabled People and its Protocol⁹ is essential. With respect to national standards, in the United Kingdom, for example the Human Rights Act 1998¹⁰ is fundamental.

The understanding of disability as a human rights issue is also connected to the philosophy of the social model of disability. According to Barnes and Mercer, in the 'socio-political model of disability', disability is 'the outcome of social barriers and power relations' and not the result of an 'individual pathology'.¹¹ Priestley states, in a similar line, that 'social scientists have increasingly come to view disability as the product of complex social structures and processes, rather than as the simple and inevitable result of individual differences or biology'.¹² Basically, the social model of disability considers that disability is not the result of the individual limitations of a person. This model stresses that disability is produced by the society because the society does not provide adequate services or support for disabled persons. Finally, it can be argued that the social model of disability respects the difference represented by disability and stresses the duty of the society to adapt to the needs of all of its members.

As part of the vulnerable group of disabled people, women with learning disabilities are protected by these human rights standards. In addition, women with learning disabilities are part of the vulnerable group of women. In other terms, women with learning disabilities are vulnerable under at least two different conditions: as persons with learning disabilities, and

⁹ The Convention on the Rights of Persons with Disabilities and its Optional Protocol was adopted on 13 December 2006 at the United Nations Headquarters in New York (hereinafter, the United Nations Disability Convention). The United Kingdom ratified this convention on 8 June 2009 and therefore the provisions of this convention are mandatory for this country.

¹⁰ The Human Rights Act 1998 allows rights under the European Convention on Human Rights to be enforced directly in the United Kingdom's domestic courts. The European Convention on Human Rights was adopted in Rome on 4 November 1950.

¹¹ Barnes, C. and Mercer, G. *Disability* (Cambridge: Polity Press 2003) p 12.

¹² Priestley, M. *Disability: A Life Course Approach* (Cambridge: Polity Press 2003) p 12.

as women. Also these multiple vulnerabilities are linked to the multiple discriminations that women with learning disabilities can suffer.

Having the preceding considerations into account, it is time to make reference to the human rights violations that were detected through an analysis of Jane and Mary's experiences. Especially, the number of international standards is very high. Therefore, the following considerations will only use examples of the most relevant and current human rights standards.

In first place, it was referred that from Mary's experience arose the concern regarding her lack of identification as a woman with a learning disability and then her consequent lack of support. The lack of support for a woman with a learning disability contravenes rule 4 of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities,¹³

States should ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to increase their level of independence in their daily living and to exercise their rights...

In second place, the lack of information was a concern regarding the experiences of the two women interviewed. This absence of information is violating the article 21 of the United Nations Disability Convention. In effect, the right to access to information is ignored when the services do not inform women with learning disabilities about crucial health and social issues that are affecting them.

¹³ A/RES/48/96, 85 th plenary meeting, 20 December 1993.

In third place, and intrinsically linked with the preceding considerations, human rights standards determine that the information given to disabled people must be accessible. In the cases of Jane and Mary, non-accessible information was pointed as a concern. Looked under the light of the United Nations Disability Convention, this concern is transformed into the violation of the human right to accessible information (article 9). This essential article determines that,

1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas...

At a national level, the non-accessible information for women with learning disabilities is contravening the Disability Discrimination Act 1995. In effect, the non-provision of accessible information constitutes accordingly to this law a discrimination against this group of people.¹⁴ CHANGE in fact regularly hears from parents with learning disabilities who have struggled to have access to information. CHANGE has worked for almost a decade with the government and parents with learning disabilities, to improve access to information for parents with learning disabilities. As well as helping to develop the Good Practice Guidance - Supporting Parents with Learning Disabilities¹⁵ we have worked with health care practitioners from across the UK to develop a unique and comprehensive series of illustrated, easy read books about Pregnancy, Birth and Parenting. Among these publications, there are: You and Your Little Child 1-5; You and Your Baby 0-1; and My

¹⁴ Disability Discrimination Act 1995, Part III, 19 Discrimination in relation to goods, facilities and services.

¹⁵ This publication can be obtained from CHANGE at

<http://www.changepeople.co.uk/productDetails.php?id=1736&type=4> (last accessed on 3 February 2010).

Pregnancy, My Choice.¹⁶ In a number of occasions, these publications have been bought in bulk by services. For example, it is in the Good Practice Guidance in Scotland that every parent with learning disabilities receives the CHANGE parenting books. Here is a sample of who has recently bought multiple copies of the accessible parenting books from CHANGE: The Family Nurse Partnership in Waltham Forest; Newham PCT; Manchester City Council; Calderdale PCT; Middlesbrough Council; NHS Fife; Plymouth City Council; and Family Action London. Moreover, Australia is also buying the parenting books in bulk.

In fourth place, it has been said that the researchers consider that Jane's termination was produced after her lack of a free and informed consent. This situation seriously contravenes human rights standards. Article 23 of the United Nations Disability Convention recognizes the right of persons with disabilities 'to decide freely and responsibly on the number and spacing of their children'.¹⁷ On its part, article 25 of the United Nations Disability Convention,

(d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care...

And the Human Rights Act 1998 establishes in its article 8 the 'right to respect for private and family life'. Moreover, the Center for Reproductive Rights,¹⁸ principal independent non-governmental organisation working on this issue, has established on this regarding that,

¹⁶ All of these publications can be obtained from CHANGE at <http://www.changepeople.co.uk/catalogue.php?type=3> (last accessed on 3 February 2010).

¹⁷ United Nations Disability Convention (n 9), article 23 (1.b).

¹⁸ <http://www.reproductiverights.org> (accessed on 18 January 2010).

Women with mental disabilities should be involved in decision-making about their reproductive rights to the fullest extent allowed by their capacities. To the degree that a woman can give her informed consent, she is entitled to do so. At the same time, women with mental disabilities may possess particular vulnerabilities that entitle them to heightened protection from sexual abuse and other forms of exploitation.

Sexual freedom must not be unduly restricted, and reproductive health services, particularly contraception, sterilization, and abortion, must not be forcibly or coercively imposed. In the course of the provision of health services for all women with disabilities, the right to receive care also includes the right to refuse it...¹⁹

[this text has been highlighted by the researchers]

¹⁹ Center for Reproductive Rights, 'Reproductive Rights and Women with Disabilities: A Human Rights Framework- briefing paper', available at, http://reproductiverights.org/sites/crr.civicaactions.net/files/documents/pub_bp_disabilities_0.pdf (last accessed on 18 January 2010). It must be also clarified here that the Center for Reproductive Rights' paper considers women with developmental disabilities as part of the concept of women with mental disabilities. On its turn, the concept of developmental disabilities has been used, in many occasions, in the same way as the concept of women with learning disabilities.

3. Why women with learning disabilities who are users of maternity services in Leeds are hard to find: preliminary answers

There are no statistics about mothers with learning disabilities in Leeds. For example, the document Leeds Primary Care Trust, Disability Equality Scheme only establishes statistics in relation to people with learning disabilities in Leeds (2,000), but not regarding mothers with learning disabilities.²⁰ This lack of local statistics in relation to mothers with learning disabilities is repeated, at a national level, in the survey Adults with Learning Difficulties in England 2003/2004.²¹ In Leeds the allocation of more economic resources regarding people with learning disabilities has been an priority,²² and references in key policy documents regarding people with learning disabilities appear.²³ However, there is much to be done for addressing the specific needs of mother with learning disabilities.

²⁰ Leeds Primary Care Trust, Disability Equality Scheme (Working document), Leeds-NHS-Primary Care Trust, available at <http://www.leedspct.nhs.uk/attachment/e7b2c3bb40c3f78be49766a9c0e35f6f/16babd8a63b16b52f6ed78a299a72b2a/> (last accessed on 4 February 2010). This document establishes on this regarding that most of the information in the section (Appendix A: National and local statistics) has been taken from the 2001 census and the Disability Rights Commission.

²¹ Adults with Learning Difficulties in England 2003/2004, available at <http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/adults-with-learning-difficulties-in-england-2003-2004> (last accessed on 4 February 2010).

²² The Leeds Primary Care Trust's Annual Report and Accounts April 2008-March 2009 has established as a priority (in third place among priorities) that in 2009-2010 resources were going to be focused on increasing investment for those with learning difficulties (document available at,

<http://www.leedspct.nhs.uk/attachment/e7b2c3bb40c3f78be49766a9c0e35f6f/24454c655b586dab5cc81916f81e7853/NHS+Leeds+Annual+Report+FINAL.pdf> -last accessed on 8 February 2010, p 42).

²³ These references are mainly about the difficulties that people with learning disabilities have in accessing to health services, especially, to health screening (Measuring the Gap: Tackling health inequalities, A report by the Leeds Joint Public Health Information Group with the support of the Yorkshire and Humber Public Health Observatory December 2007 –available at,

There is no precedent, specifically in Leeds, about research into the experiences of women with learning disabilities as users of maternity services. At a general level, this lack of local research also is repeated at a national level.²⁴

Our experience with this new research showed us that finding 6 women²⁵ for this research was an unexpected and challenging research issue in itself.

It is true that the fact of having ethical approval for appealing to the help of services (for example, midwives) to find a higher number of women could have helped. However, and with independence that the search for women through services would not guarantee to find all of the women proposed, the considerations that follow are product of our contacts with mainly the voluntary sector and demonstrate interesting preliminary findings about the

<http://www.leedspt.nhs.uk/attachment/e7b2c3bb40c3f78be49766a9c0e35f6f/8c8474d76f93b5832fad79a7538615c7/Inequalities+report.pdf>, last accessed on 8 February 2010); NHS Leeds Strategy: For Better Health for All, available at, <http://www.leedspt.nhs.uk/attachment/e7b2c3bb40c3f78be49766a9c0e35f6f/7b1795005ff073baba8a129045caa213/Leeds+PCT+Strategy+2008.pdf>, last accessed on 8 February 2010).

²⁴ The following are examples of research conducted about mothers with learning disabilities: Booth T., Booth W. (2003). Self-advocacy and supported learning for mothers with learning difficulties. *Journal of Learning Disabilities*, 7(2), pp 165-193; Feldman M.A., Varghese J., Ramsay J., Rajska D. (2002). Relationships between social support, stress and mother-child interactions in mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15 (4), pp 314-323; Kroese B.S., Hussein H., Clifford C., Ahmed N. (2002). Social support networks and psychological well-being of mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15 (4), pp 324-340; Llewellyn G., McConnell D., Cant R., Westbrook M. (1999). Support network of mothers with intellectual disability: an exploratory study. *Journal of Intellectual and Developmental Disability*, 24 (1), 7-26; Maternity Alliance (1996) Right from start: maternity services for women with learning disabilities. *Disability, Pregnancy and Parenthood International*; 16:6. DPPI Website: freespace.virgin.net/disabled.parents/; Tymchuk, A., Andron, L. (1990) Mothers with mental retardation who do or do not abuse or neglect their children. *Child Abuse and Neglect*; 14:3 pp 313-323.

²⁵ Number of research participants established in the research proposal.

general invisibility of women with learning disabilities who are users of maternity services in Leeds and about their attitudes to services.

3.1. Difficult identification of women as women with learning disabilities, and consequent support

It was advanced in this document that the absence of identification of a woman as a woman with a learning disability is related to her lack of support. The limited findings of this current small piece of research replicate more general research findings. In this sense, a recent review of the research highlighted that ‘mainstream services (like antenatal [sic: ante-natal] and midwifery need to be better equipped to identify and support parents with learning disabilities’.²⁶

This lack of identification, and support, are also related with obstacles for finding these women for a project like this.

The following reasons, not exhaustive, can explain the difficult identification of a woman as a woman with a learning disability.

One reason seems to be the complex and not uniform content of the category ‘learning disability’. For example, CHANGE considers that a woman who has difficulties in reading, or in memorising, might have a learning disability. But for some people this might not be the case.

²⁶ Llewellyn G., McConnell D., Cant R., Westbrook M. (1999) Support network of mothers with intellectual disability: an exploratory study. *Journal of Intellectual and Developmental Disability*, 24 (1), pp 7-26, quoted in Ward L, Norah Fry Research Centre, University of Bristol, Supporting parents with learning disabilities and their children: A review of research p 5.

Another reason for this is that sometimes the woman herself does not say that she has a learning disability. The negative effects of historical prejudices associated with learning disabilities, seem to be among the motives that determine a woman with a learning disability to avoid her identification as a person who is part of the vulnerable group of people with learning disabilities. In fact the prejudice faced by people with learning disabilities was mentioned in the debate that took place at CHANGE's offices on 15 December 2009. Moreover, the Annual Report of the Director of Public Health in Leeds 2009: Making a Difference-People and Places suggests that not all people with learning disabilities in Leeds are registered with GPs because of, among other reasons, fear of discrimination.²⁷

For one reason or another, the lack of identification is linked to the lack of support needed by a woman with a learning disability. It was published that the support for pregnant women with learning disabilities varies in terms of where these women live or who provides the support.²⁸ As it was demonstrated, support is not only a need that a woman with a learning disability has, or a favour that services can give to this vulnerable group of persons. Support is an essential human right and services are then compelled to provide it. And support for parents with learning disabilities is a governmental key policy objective for 2009-12.²⁹ This issue of support was raised by the workshop participants on 15 December 2009. The participants stressed the crucial need for support to these women from the beginning. The participants also highlighted that these women should be asked what their needs are, and recognised that there is a need of training for workers and professionals in order to understand what the women's needs are.

²⁷ The Annual Report of the Director of Public Health in Leeds 2009: Making a Difference-People and Places, available at <http://www.leedspct.nhs.uk/phar/2009-PHAR.pdf> (last accessed on 4 February 2010), p 30.

²⁸ When parents have learning difficulties: Given positive support, people with learning difficulties can make capable parents. Nicky Richardson. April 26 2001, Volume 97, No 17 Nursing Times p 40

²⁹ Valuing People Now: A New Three-Year Strategy for people with learning disabilities: 'Making it happen for everyone' (n 8).

CHANGE aims to support professionals who work in pregnancy and maternity support services (for example, midwives, health visitors or outreach workers) to meet the needs of women with learning disabilities in better ways. We want to work with maternity service professionals to identify any current good practice and areas that can be improved. As well as guidance from parents with learning disabilities, health professionals have always been key to supporting us to develop our work. Parents Training for CHANGE provides realistic and insightful training developed and delivered by parents with learning disabilities themselves.³⁰ In this way, CHANGE is contributing to the achievement of the crucial Department of Health Strategy User Group or Nothing About Us Without Us' goals: this strategy has established that 'staff training should include people with learning difficulties as trainers'.³¹ Moreover, we are also helping to make the governmental key policy objective for 2009-12, established in relation to services, a reality:

'The workforces across services are given the appropriate support and training to equip them with the values, skills and knowledge to deliver the *Valuing People Now* priorities for all people with learning disabilities'³²

In order to offer a better support for mothers with learning disabilities, the key stakeholders that participated in CHANGE's workshop stressed the need for communication between services. On this regarding, outreach workers expressed the importance of having a link with midwives. The 'considerable evidence of the lack of communication, coordination and collaborative working across children's and adult services, and health and social services'

³⁰ <http://www.changepeople.co.uk/training.php> (last accessed on 16 February 2010).

³¹ Department of Health Strategy User Group or Nothing About Us Without Us, available at <http://www.publications.doh.gov.uk/learningdisabilities/access/nothingabout/index.htm> (last accessed on 3 February 2010).

³² Key policy objective 3. for services, *Valuing People Now: A New Three-Year Strategy for people with learning disabilities: 'Making it happen for everyone'* (n 8).

was stated.³³ Among the measures for overcoming this lack of communication, coordination and collaboration between services, the creation of pathways and protocols are crucial.³⁴ In the case of Leeds, the NHS Operational Plan (2009/10) established as a key objective to develop 'an improved focus on learning disabled clients with protocols which reflect the need for admissions to be client appropriate'.³⁵ In addition, in 2009 the Leeds Learning Disability Strategy 2009-2012 was launched.³⁶ It is affirmed in the strategy that it 'will provide a clear strategic direction for the support and services for people with learning disabilities'.³⁷ In this way, it is expected that after three years of this strategy first implementation, the communication, coordination and collaboration between services will improve. Finally, in the Leeds Maternity Matters Strategic Action Plan, it appears as a strategic objective to 'develop care pathway for disabled women (physically disabled and learning difficulties)'. The researchers have been informed by the Commissioning Manager for Maternity-NHS Leeds that 'due to limited resources and other competing priorities, the decision was made to make the development of a care pathway for pregnant women/parents with a learning disability a priority for 10/11'.

3.2. Few instances where women with learning disabilities can have their voices heard

³³ Tarleton et al, 2006 quoted in Ward L, Norah Fry Research Centre, University of Bristol, Supporting parents with learning disabilities and their children: A review of research (n 26).

³⁴ For example, the following pathway was created to address the specific needs of women with learning disabilities: Care Pathway for Pregnant Women with Learning Disabilities, Stockport Primary Care Trust, Stockport Social Services and Stockport NHS Foundation Trust. Contact information, denise.monks@stockport.gov.uk

³⁵ NHS Operational Plan (2009/10), available at, <http://www.leedspt.nhs.uk/attachment/e7b2c3bb40c3f78be49766a9c0e35f6f/b47f174160351b782992a82ffb1b567/Operational+Plan+-+One+Year+-+0910.pdf> (last accessed on 4 February 2010), p 32

³⁶ Leeds Learning Disability Strategy 2009-2012, available at, [http://www.leeds.gov.uk/files/Internet2007/2009/27/ld%20strategy%20full%20version%20june%202009\(1\).pdf](http://www.leeds.gov.uk/files/Internet2007/2009/27/ld%20strategy%20full%20version%20june%202009(1).pdf) (last accessed on 4 February 2010).

³⁷ Leeds Learning Disability Strategy 2009-2012 (ibid) p 3.

Until very recently, CHANGE itself has been hosting a group where parents with learning disabilities could meet.³⁸

Also the organisation People in Action hosts 'Families in Action', a project where advice and support is offered to parents with learning difficulties and disabilities.³⁹

However, more specific instances for support and advocacy are missed in Leeds, where women with learning disabilities who are mothers or mothers-to-be could meet and could have their own voices heard.

A positive example on this regarding is the group 'Middlesbrough mums'. This group meets weekly and is supported by a social worker, a community nurse and support workers from the community learning disability team. The group offers support and information to the mums. Guest speakers are invited, specialist equipment and resources are at the mum's disposal, and include instructions in pictures/easy to understand format.⁴⁰

A similar example, but in North Tyneside, is constituted by the group Special Mothers in North Tyneside (SMINT).⁴¹ This support group for example train students and professionals regarding the way of working with people with learning disabilities.

Also in Hull there is a doula's⁴² project which supports disadvantaged women, among them, women with learning disabilities.⁴³ A project worker told CHANGE that they have been trying to implement this project in Leeds but have not been able to find funding.

³⁸ This was the Parents Network. Currently, this network is not in place, because the project finished. In any case, information about the project can be found at <http://www.changepeople.co.uk/showPage.php?id=17> (last accessed on 3 February 2010).

³⁹ <http://www.peopleinaction.org.uk/activities.html> (last accessed on 3 February 2010).

⁴⁰ <http://www.middlesbrough.gov.uk/ccm/content/health-and-social-care/2disabilities/2learning-disabilities/middlesbrough-mums.en?page=5> (last accessed on 3 February 2010).

⁴¹ http://www.northtyneside.gov.uk/serviceitem.shtml?p_ID=2821 (last accessed on 3 February 2010).

⁴² Doula UK's website refers that,

'Doula' (pronounced 'doola') is a Greek word meaning 'woman servant or caregiver'. It now refers to an experienced woman who offers emotional and practical support to a woman (or couple) before, during and after childbirth. A doula believes in 'mothering the mother' - enabling a woman to have the most satisfying

The existence in Leeds of instances where these women could be specifically supported would help them to have a more active profile, would address their special needs much better and, of course, would make it easier to reach to them. And as the Good Practice Guidance - Supporting Parents with Learning Disabilities stresses, the access to advocacy and self advocacy by parents with learning disabilities will contribute to raise their self confidence.⁴⁴

3.3. Persons who act as gatekeepers, and women's own fears of contacting services because of past bad experiences

The researchers found in the course of the project that some persons seem to act as gatekeepers in relation to the access to women with learning disabilities as users of maternity services in Leeds. In a number of cases, and after knowing of a possible research participant, CHANGE's researchers were not allowed to speak directly with the woman.

The research team were given the following reasons for not being allowed to speak with the possible participant:

- That the woman definitely does not want to get involved, and after the researchers insistence for knowing why, they were told that she was afraid of social services;

and empowered time that she can during pregnancy, birth and the early days as a new mum. This type of support also helps the whole family to relax and enjoy the experience (Doula UK, <http://www.doula.org.uk/content/duk/about/default.asp> -last accessed on 3 February 2010-).

⁴³ This project's website is: <http://www.goodwindoulas.org/aims+and+objectives> (last accessed on 3 February 2010).

⁴⁴ Good Practice Guidance - Supporting Parents with Learning Disabilities (n 15) p 41.

- That at the moment, the person would be dealing with too many things and that it would not be good for her to collaborate, and when the worker was asked about why she thought that it was better for this mother not to participate in CHANGE's research, this worker said that she was not in contact with the mum anymore and that this mum would be involved with social services;
- That it was not possible to have direct contact with the mother because another person, who spoke with the worker that gave us this information, suggested not to contact the potential participant;
- That the potential participant is very reluctant to engage in activities;
- Finally, among the reasons that we were given on this regarding, a worker told CHANGE that she heard back from the organisation that supports the potential participant that this potential participant is having a difficult time at the moment and that it would not be a good idea to contact her.

The preceding results of the contacts with these persons prove the absence of own decisions by these mothers with learning disabilities. CHANGE is convinced that the fact of speaking with the mothers directly, and talking to them about what the organisation was trying to do, would have represent an opportunity for the mothers to make their own decision as to whether they wanted to be involved or not in the project. Moreover, the mothers would be able to exercise in this way their 'full and effective participation and inclusion in society'.⁴⁵

Also some of these reasons given by the persons especially evidence the fear of some women of being in contact with CHANGE because of their experiences with social services.

⁴⁵ General principle established in article 3 of the Convention for the Rights of Persons with Disabilities (n 9).

This reluctance on part of these women seems to be connected to the reality that women with learning disabilities who are mothers or mothers-to-be face in the United Kingdom. The review of the research about parents with learning disabilities and their children already mentioned stressed that,

A high proportion of parents end up having their children removed from them. Estimates of the proportions ... vary, but a figure of 50% seems common (Tarleton et al, 2006; Elvish et al, 2006). The national survey of adult with learning difficulties in England found that one in 15 of the 2898 adults interviewed were parents (Emerson et al, 2005). 40% of them were not living with their children (Emerson et al, cited in Morris, 2007)⁴⁶

These are the facts that these women are facing. However, the workers and professionals that were part of CHANGE's workshop recognised that in general for the child is better to stay with the parents rather than being in foster care. CHANGE would like to stress that parents with learning disabilities have the right to support for being parents. And on this last regarding, the mentioned Department of Health Strategy User Group or Nothing About Us Without Us also establishes that 'Social services must have a policy about support for disabled parents with a subsection on proper support for people with learning difficulties'.⁴⁷

⁴⁶ Supporting parents with learning disabilities and their children: A review of research (n 26).

⁴⁷ See n 31.

4. Conclusions and recommendations

The experiences of women with learning disabilities as users of maternity services in Leeds analysed for this report do not reach to large scale conclusions about the response given by maternity services in Leeds.

However, these experiences highlight initial issues for concern that seriously contravene basic international and national human rights standards:

- The lack of identification of a woman with a learning disability and therefore her lack of support;
- The lack of information about crucial health and social issues that affect a woman with a learning disability;
- The non-accessible information given to a woman with a learning disability;
- The grave concerns with respect to the lack of a free and informed consent for deciding a termination that have been evidenced with respect to a woman with a learning disability.

In addition, the project found interesting preliminary findings about the lack of active presence of women with learning disabilities in the context of Leeds maternity related services, and about how these women think about these services. For example, the research found that:

- In Leeds, there is a lack of instances where these women can have a voice;
- Third persons decide on behalf of women with learning disabilities and these women have a fear of services (especially of social services).

In order to overcome all of these initial issues and to provide women with learning disabilities as users of maternity services in Leeds with an attention respectful of their human rights, CHANGE would like to make the following recommendations to the services:

- Services should try to identify women with learning disabilities in order to give these women the support that they are entitled to. In order to achieve this, appropriate training to the services workers about the specific support needs of women with learning disabilities is crucial. A coordinated work between services is also fundamental. And as part of an appropriate support for these women, CHANGE recommends that services should offer to the woman with a learning disability the possibility of having only one health professional, for example a midwife, that could support her through all of the stages of her pregnancy, delivering, and initial months with her baby;
- Services should provide women with learning disabilities with accessible information about crucial health and social issues that concern these women. A uniform strategy inserted in the services' relevant policies seems to be the most effective way for complying with this goal. For example, the services can determine in their policies that publications, such as the ones produced by CHANGE, will be mandatory distributed among women with learning disabilities users of maternity services in Leeds;
- Services should respect mothers with learning disabilities' reproductive rights. Further investigation about the cases mentioned in this research is needed;

- Services should consider the creation of specific instances for providing mothers with learning disabilities with support and advocacy;
- Services should take into consideration women with learning disabilities own voices. This consideration would constitute the first step for building trust in their communication with this vulnerable group of people. The involvement of users in the decision-making of services is crucial.

CHANGE hopes that these initial findings will help mothers with learning disabilities to have a legitimate voice. The organisation also expects that these findings will guide services to make the premises of the social model of disability a reality and to build better pregnancy and maternity support services for these women in Leeds.

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APPENDIX 1: JANE'S EXPERIENCE

Who we interviewed:

	<p>We talked to Jane, a 27 year old woman from Leeds.</p> <p>She tells people she has a learning disability.</p> <p>We contacted her through People in action, Leeds.</p>
	<p>She said she finds doing computer work, reading, writing and focusing hard.</p> <p>She needs extra support because of her learning disability.</p>



She has trained as a chef.

At the moment, she is not working.



She worked for Morrison's as a sales assistant for a few months.

She found it hard to focus on her job.

She had a lot of stress and family problems and had to leave her job at Morrison's.

	<p>She is engaged and very happy with her partner.</p> <p>They have 4 children.</p> <p>All of these children are in foster care.</p>
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Her Story:

	<p>Recently, she became pregnant again.</p> <p>She didn't want anyone to know about this until she knew what was going to happen.</p> <p>Her family and friends did not support her through the pregnancy.</p>
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She told her social worker that she was pregnant.



She wanted to know if she was going to be able to keep the baby.

The social worker didn't give her any answers.



She was very angry and confused.

The social worker just got her mad.



Social services didn't give her information in relation to what could happen with the baby after the delivery.

She felt she was not given any other choice than to get rid of her baby.



She thought it would be the same social worker all the way through but it wasn't.



She said that she put a complaint in against one of her social workers.

She spoke to the complaints officer and somebody else from social services.

Visiting her GP:



She felt her doctor pressured her to decide on getting rid of her baby.

The doctor said it was not good for her health, and that the baby going would go into care, the same as her other children.

The doctor said that she was going through a lot of stress.

She said she was under a lot of stress because of the social worker.



The doctor did not say that going through with the pregnancy would damage the health of the baby.

He just said it's not good for your health, and left it like that.

Agreeing to an abortion:

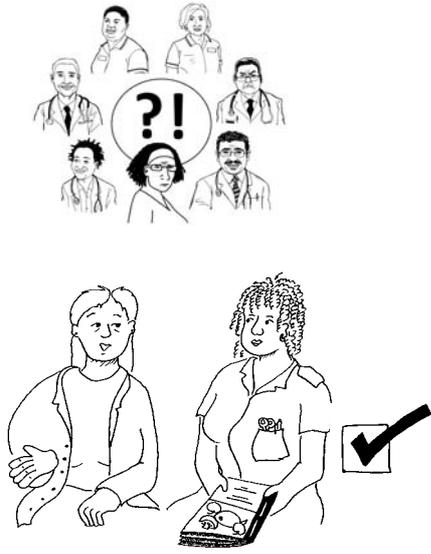
 	<p>She had to sign a form to say she wanted to go ahead with an abortion.</p> <p>She seemed to sign the form because she was uncertain if she was going to be able to keep the baby with her or not.</p> <p>She did not know whether the baby was coming home or to be taken into care.</p>
	<p>Nobody was telling her anything. She felt she did not have a choice.</p>
	<p>She asked questions about having an abortion.</p> <ul style="list-style-type: none">• She asked how long does it take?

	<ul style="list-style-type: none"> • What happens? • What is the pain like?
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The Abortion at St James’s University Hospital, Leeds:

	<p>She was not convinced about having an abortion, even after signing the form.</p>
	<p>Even after taking the first tablet, she was still not sure about having an abortion.</p>
	<p>She felt she still did not want to go through with it when she went for the third part of the tablets, which are inserted through the vagina.</p>

	<p>She was upset.</p>
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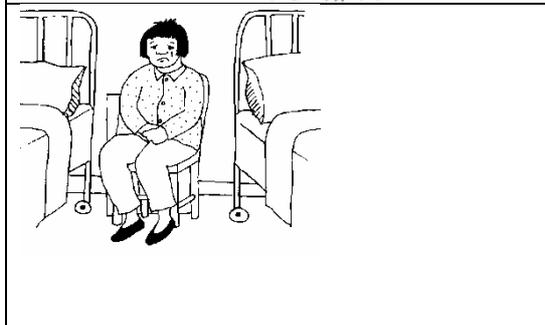
	<p>She said the hospital has 5 or 6 midwives or a doctor in your room and you do not know what is going on.</p> <p>She said that it would have helped to see the same midwife all the way through.</p>
	<p>One midwife said 'you can't go home, you have to go through the whole thing'.</p> <p>And 'if she went ahead with the pregnancy, the baby will turn out with all sorts of problems'.</p>



When she said that she wanted to keep the baby, they said that is not going to happen.

At the hospital, no staff sat her down and talked to her and listened to what she was saying.

When she was in pain, she asked for some painkillers. They did not give her any.



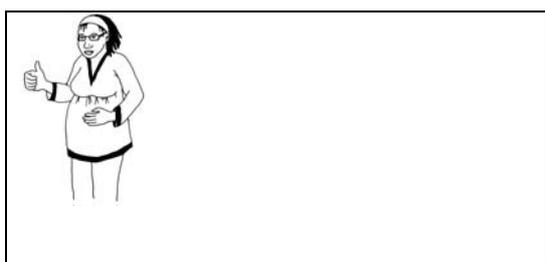
Midwives were changing shifts when she was at the hospital.

It was nine hours before she saw a midwife.

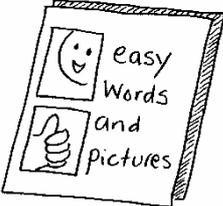


The staff already knew that she had a learning disability but they didn't know how to deal with her. She felt she was on her own and not told what was happening.

Past Experiences of Services:



Most of her experiences with her other pregnancies were good.

	<p>During the pregnancy of her last born child, the midwife she had went through everything with her.</p>
	<p>The midwife gave her information with pictures. The information had more pictures than words.</p> <p>The midwife explained clearly to her so she understood.</p> <p>The midwife she had was trained to work with people with learning disabilities.</p>
	<p>She attended ante-natal or parenting classes.</p> <p>She understood some of these classes, but it was all words and the writing was too small.</p>
	<p>She asked if she could have it in pictures with big writing and they gave her a copy with words and pictures.</p>



She visited the labour ward before the birth of her child.

But the staff only showed the room without explaining to her what everything was.

Recommendations:



We think she did not get information in a way she understood.

She felt that she was not given enough information from health and social services, and often the information she did get was not accessible.



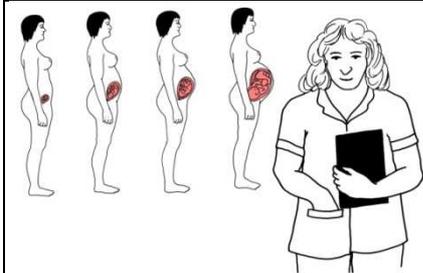
Health staff and social services should treat people with learning disabilities differently.

They need extra support.



Doctors, midwives and social workers should support women with learning disabilities:

- By giving them options, rather than telling them the only option is the ending of a pregnancy
- They should give them more time to think



The right support for a woman with a learning disability is seeing the same midwife all the way through and who knows about supporting a woman with learning disabilities.

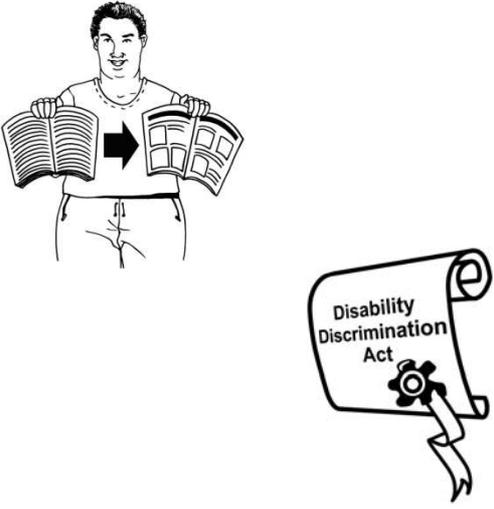


Women with learning disabilities have human rights.

The Government has to respect the human rights of women with learning disabilities

Services should not force women with learning disabilities to have a termination.

This is seriously against human rights standards.

	<p>Women with learning disabilities have the right to accessible information about important health and social issues that are affecting them.</p> <p>If women with learning disabilities do not get accessible information it is against the Disability Discrimination Act of 1995.</p>
	<p>Women with learning disabilities should take part in all decisions that affect them.</p>

	<p>We heard about other women with learning disabilities in Leeds who went through the same situation.</p> <p>We were not able to get permission to meet with these women.</p>
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