

Mothers with a learning disability:
access, information provision and
ongoing engagement in antenatal care.



**A pilot project: developing an antenatal
appointment resource.**

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The Polyanna Project

We are a health access and information consultancy, specialising in client centered communication and access for disadvantaged communities.

We use art to convey identity driven health messages between service providers and users.

We are a not for profit organisation, working to research as well as develop information and education resources. The name Polyanna reflects the ethos of the group...optimism. The Polyanna Project comprises of a diverse group of professionals who work together and includes a consultant midwife, anthropologist, artist, barrister, health psychologist and an IT technician.

Acknowledgements

We would like to acknowledge and thank the parents who gave their time and trust to talk to us. We would also like to thank the following people:

In London:

Estelle Bloom, Senior Accessibility Officer, Mencap; Andrew Lee, Director People First; Chris Gillbanks, Joy Palmer and Lynne Ferdinando Parenting Officers Barking & Dagenham Mencap; Candice Prentice, Community Based Advisor, Mencap; Jackie Loveridge and Debra Kober, Tower Hamlets Advocacy Project, Mencap.

In Cornwall:

Christine Bateman, Senior Advocate; Becki Shepstone, HOPE project; Debbie Hunter, Paul Thomas and staff at Cornwall Special Parenting Service; Sue Miner, Operations Manager FalCare CiC Ltd.

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Project Summary

This was a small pilot project, conducted in London and Cornwall, assessing the information and communication needs of antenatal women with a learning disability. The perspectives of women together with support and advocacy groups and providers both National and local were also sought. Advocates in the third-sector, notably from People First, Mencap; and Parenting Support services were consulted.

As a pilot project the aim was:

- To develop and test a picture based resource informing women and their partners about local individualised appointment sheets for antenatal care.
- To consult with women and their partners who have a learning disability about their experience of antenatal care.
- To consult with 3rd sector support and advocacy organisations about their perspective on access and engagement during pregnancy for mothers with learning difficulties.
- To write a report about the process and findings, including suggestions for improving care and recommendations for further work.

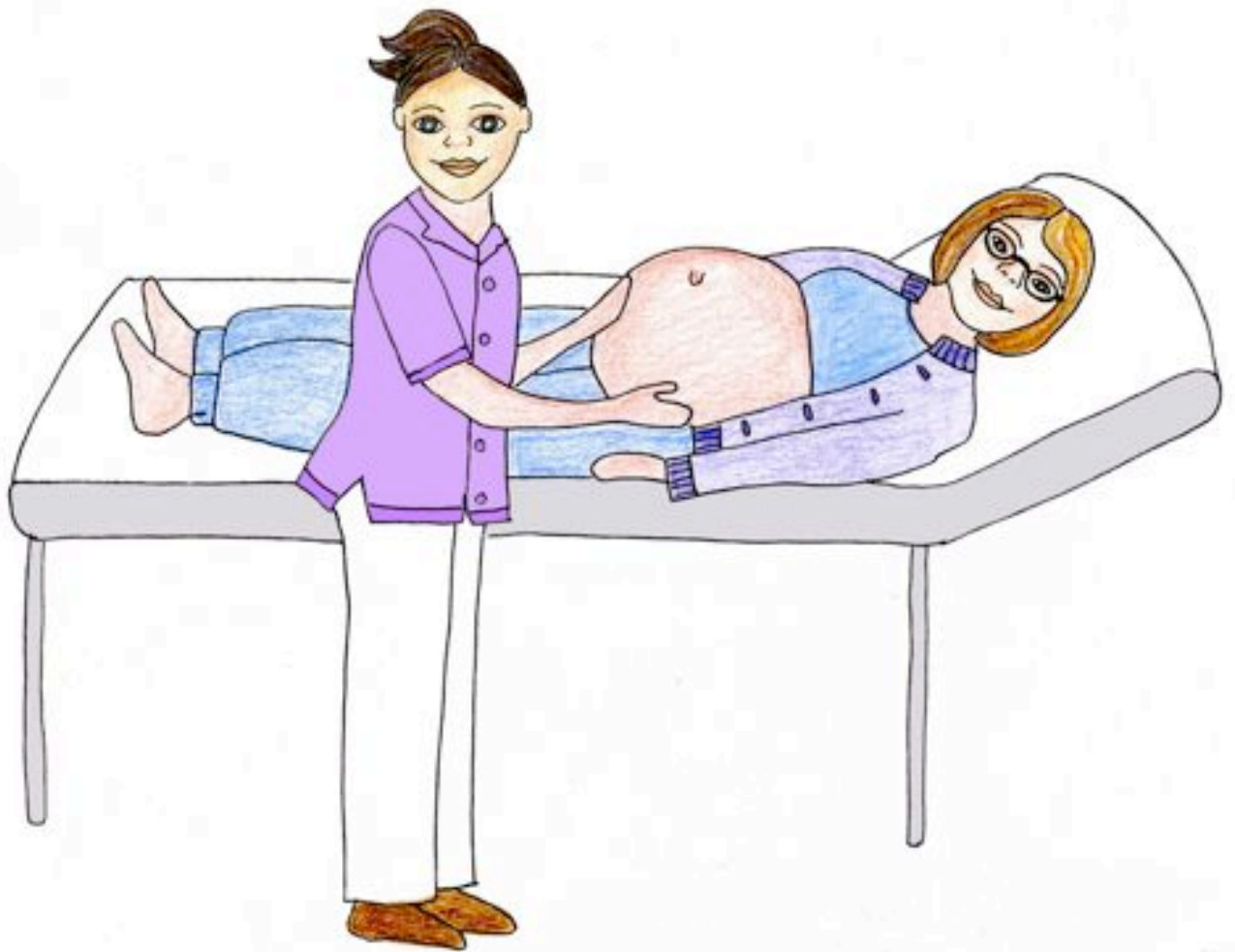
Maternal and child health and wellbeing are important outcomes of better access and engagement during antenatal care (Lewis 2007); however people with learning disabilities have more unmet health needs and require specific, enhanced services, including better communication (Michael 2008).

Although the women interviewed had all accessed their care via their General Practitioner (GP) it was not clarified if this was in a timely way. All the women had engaged with some if not all their antenatal care. The barriers to attending appointments were explored including; knowing the time and venue of the appointment, understanding the purpose of the appointment, feeling prepared for the consultation, communicating and feeling reassured and supported during and between appointments. Antenatal appointment sheets were shared with those interviewed and were, with slight modifications, proclaimed helpful and pertinent.

Many of the people interviewed were able to illuminate positive examples of supportive communication. They shared their ideas and experiences of what facilitated a 'better conversation' and improved understanding. Improved awareness and use of specialised support and advice services for both mothers and professionals were highlighted as key issues.

The findings from interviews with both advocates and mothers highlighted barriers to on-going engagement with antenatal care including difficulty with travelling to appointments, contacting a midwife to change appointments and feeling bewildered during consultations due to a lack of time or language used. The picture based appointment resources were received well, particularly as they were designed to be literal, for example, a photo of the maternity notes, picture of the hospital and the midwife adorned in the correct uniform colour. The importance of using time well to engage and involve women in their care was highlighted, for example filling in the appointment sheets and talking about the next appointment, when, where and why with them rather than just giving them a piece of paper was highlighted as best practice.

Background



Defining what is meant by learning disability and rationale for the project.

The Department of Health's report Valuing People (DH 2001) defined a person with a learning disability as presenting with:

- a significantly reduced ability to understand new or complex information and/or to learn new skills.
- a reduced ability to cope independently, which started before adulthood with a lasting effect on development.

The White Paper (DH 2001) begins with the pronouncement that people with a learning disability are people first. The White Paper states that the focus, should be what people can do with support rather than what they cannot do, and their right to marry and start a family. Deinstitutionalism with a greater opportunity to live in the community has led to more people with a learning disability forming sexual relationships that in turn means maternity services need to consider how their needs can be best met. It is estimated that in 2005, 7% of people with learning disabilities in the UK were parents (Emerson et al 2005). In 2007 both the Royal College of Midwives (RCM) and the Royal College of Nursing produced guidance for midwives and nurses providing care for this group of pregnant women. Both reiterate the premise of individualised care according to need, working flexibly and making adaptations to keep the woman central.

People with a learning disability may have more complex health needs; experience greater inequalities in health and have more unmet health needs than are present in the general population (Gibbs *et al* 2008, Mencap 2004, 2007, 2012). In 2008 an

independent inquiry, 'Healthcare for all' (Michael 2008) found that people with a learning disability have higher levels of unmet needs in accessing health care than the general public. In maternity services their physical needs may be hidden, the need for regular high quality antenatal care is therefore key for positive health outcomes for both mother and baby. The Disability Discrimination Act (2005) and the Mental Capacity Act (2005) lay out a legal structure for the delivery of equal treatment for people with learning disabilities. However the independent inquiry (2008) found that this framework was not adhered to. It learnt that there was insufficient attention to make reasonable adjustments such as facilitating family access and help, appointment times at quieter times and for longer periods, and more accessible information.

Equity and Excellence: Liberating the NHS (DH 2010) highlights that central to the White Paper is the principle of shared decision making with increased control and choice by the service user: "No decision about me without me" (DH 2010: 13). Core to the paper is the ideology of the central role of the receiver of care, prominence being given to individuals taking more responsibility and exercising greater control and choice over their care. It recognises the public health opportunity that pregnancy offers and the possible implications in engaging women and their families from all sections of society. It argues that providing women and their families with information, support and advice through pregnancy and at the start of life may influence long term health needs and reduce inequalities in health. The paper encourages people to take responsibility for their own health.

Recent national guidance 'Pregnancy and complex social factors' (NICE 2010) outlines that women with complex social factors are likely to have particular needs and may be faced with barriers to care and understanding their choices. Although the guidance does not offer an example of women with learning disabilities it is still relevant for these women, in particular the recommendation for improving ways of communicating with

women so that they can make appropriate choices. The guidance also recommends listening to women about their experience of maternity services and eliciting their views on how services could better meet their needs (NICE 2010).

The last two Confidential Enquiries into Maternal Deaths (Lewis 2007, CMACE 2011) makes for somber reading. It reported that five women with a learning disability or mental health problem died from a thrombo-embolic disorder; four of whom it concluded had substandard care. It relates the poor pregnancy outcomes to inappropriate access and poor care provision. One anxious woman with a learning disability died from pre-eclampsia, whilst she had received 'kind' care the authors conclude that it was inappropriate for the women to have midwife only care . Although the incidence of severe learning disability occurs across the whole population, mild or moderate disability are higher where there is poverty in areas of deprivation or urban settings (Michael 2008). Understanding and adopting healthy lifestyles, diet and exercise are more challenging for this group who have a tendency to lead more sedentary lives with poor diet due to a lack of awareness, culinary skills, financial resources and access. This means they are more likely to be overweight, a risk in its' own right (Michael 2008)

The need to ensure that the woman understands who the appointment is with and why and what will happen are key, careful reminders, and if necessary accompanying the woman to appointments may help. This project's remit was based on this need; to design and develop clear antenatal appointment sheets for various consultations with different health professionals in maternity services:

“Directors of midwifery services should develop resources in partnership with experts and disability advocates in different formats appropriate to need” (RCM 2007: 1).

Methodology



Ethics

The researchers for this project are members of the Social Research Association and work within its guidance for ethics.

A project summary (including an easy-read version) was written and discussed with both advocates and parents with a learning disability (appendix 1). Subsequently, following advice from advocates in Cornwall a proforma of outline questions was prepared (appendix 2). The ethics and process for recruiting women was agreed between The Polyanna Project and the advocates.

Women were recruited with and through their known advocates. The project was explained to the parents, including the purpose of the project, their role, that the information would be anonymous and that they could change their mind or leave the project at any time.

During the interviews, active listening techniques were employed so that comments were sometimes reflected back to enable meaning to be more accurately noted.

The project took place in two primary locations: London (North and East) in the boroughs of Tower Hamlets, Barking and Dagenham, Havering and Redbridge and in Redruth in Cornwall. Ten face-to-face interviews were conducted with staff from National campaigning, advocacy and support organisations for people with learning disabilities and eight parents with learning disabilities were interviewed. Seven women, one with her husband, none of the women were currently pregnant. Although one woman had a previous child adopted, all had their children currently in their care. The

women all had mild to moderate learning disabilities.

Process

The initial part of this project centered on talking with staff working in campaigning, advocacy and support organisations for people with learning disabilities. Initial contacts were made by telephone and the project summary was sent electronically. Individual interviews with representatives within the key national campaigning and advocacy charities, People First and Mencap were conducted. The aim was to identify barriers to access and engagement, communication needs and suggestions for improving the experience of women with a learning disability within maternity services.

The proposal was to assess whether people within these organisations were able to contribute to the project either with their own knowledge and expertise or by helping to recruit women and their partners.

Staff able to contact parents for the study were supplied with a proforma of the question scope. This was for ethical reasons, to aid transparency and to acknowledge and use their expertise as to the relevance and acceptability of the questions. The question areas related to:

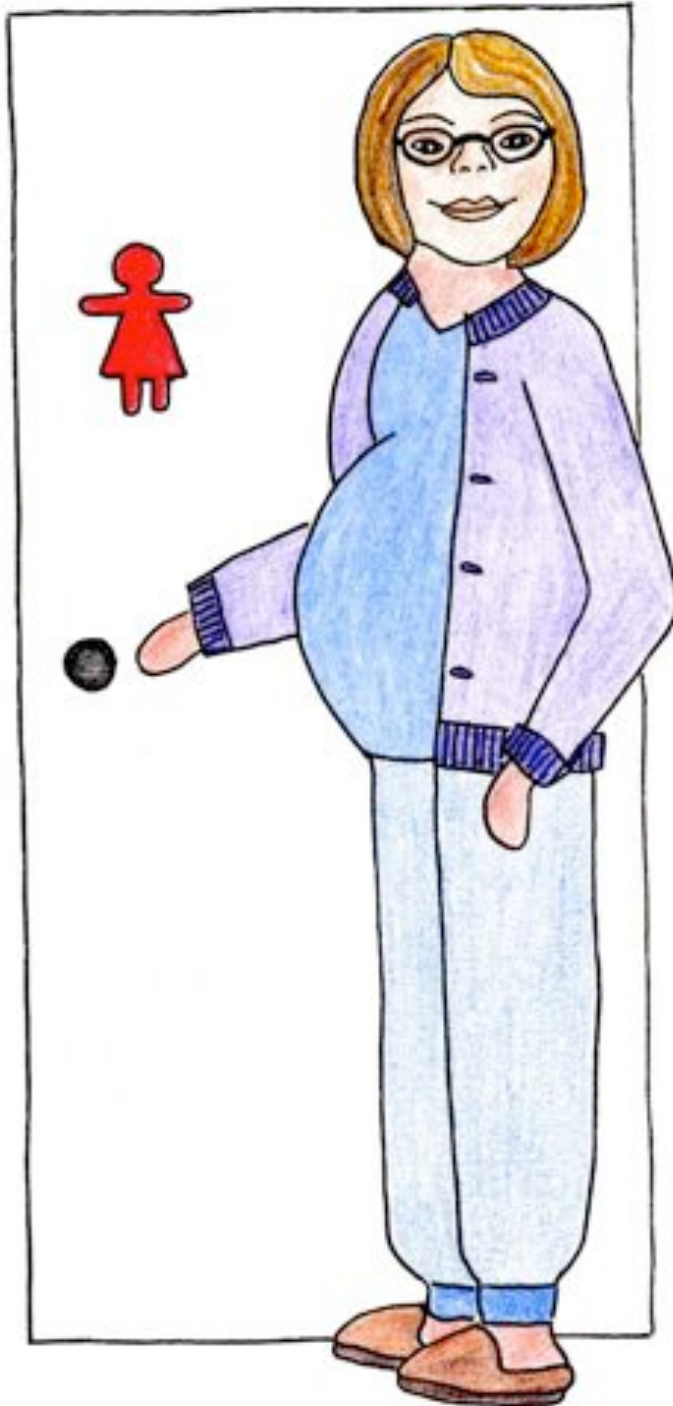
- How the women initially accessed antenatal care
- The women's expectations of antenatal care
- What helped them understand and ask questions during the antenatal appointment

- Their understanding of the clinical aspects of care including blood-pressure measurement and urine testing
- What support networks were helpful
- Information and learning preferences (written; verbal; use of computers and technology)

Cornwall advocacy recruited one mother who was interviewed at home with her advocate. The Special Parenting Support service made the easy read versions available (primarily at their college group) but did not recruit participants directly; instead the researcher was invited to the group to explain the project.

Six mothers and one father in the group wished to take part. One mother in the group declined. The researcher introduced the project to the whole group and invited them to participate in individual interviews. At the beginning of each interview verbal consent was gained and the option to withdraw or not answer was reiterated.

Findings



Parenting Issues

The majority of advocates and mothers interviewed voiced their concerns about parenting issues.

The Director of People first began his interview with the statement:

“The first thing is to challenge the starting point that services will take your newborn baby away from you...are others perfect parents because they don’t have a learning disability...it would be refreshing to have people ask, what do people with a learning disability need to keep their families together? being asked, what do you need?”

One advocate for Mencap said:

“...some women with a learning disability are scared even before accessing care and they know they have more hurdles to jump and therefore they may delay seeking care.”

The choice to start a family is hampered for women with a learning disability by poor support, funding, diverging agendas, prejudice, inadequate professional support and a lack of education (Porter *et al* 2012). In 2004 approximately 40-60% of babies born to parents with a learning disability were removed from their care and placed permanently outside the family home (Tarleton, 2006). The polarisation of the rights of the parents and rights of the child are not under discussion as part of this project but it is important to acknowledge that for the mothers, fathers and advocates we interviewed it was

never out of vision.

Information preferences

A couple of the mothers commented that some of the leaflets they had been given were not helpful, with four women highlighting that they had lost the information leaflets provided. One woman commented that a midwife had used pictures on a computer along with explanations in the appointment and that she had found this helpful.

Another woman described looking through a picture based pregnancy book with her mother, she recounted how her mother had explained things and repeated things until she understood.

Three women liked receiving information from popular television programs such as 'One Born Every Minute; others found such dramas off putting or couldn't recall what they had seen. Advocates emphasised that modeling from watching others was often a good learning mechanism.

All but one parent had access to a computer and used them to access information, for example, films on 'You Tube' however they had not been directed by the midwife or other professionals to more reliable sites for information.

Having support from family members, friends, partners or advocates at appointments is highlighted in best practice (Michaels 2008), however several women interviewed talked about the impact of being seen alone without family support:

“...times when no family there, there was a big difference and I was more scared.”

Advocates in London and Cornwall all emphasised that they or a Learning Disability nurse could attend appointments with women to support them if necessary.

Views on the antenatal appointment sheets

The antenatal resources were also shown to advocates for comment and six of the parents. The resources were appointment sheets with pictures and easy read text including space for the midwife to fill in any other details, for example the time of the next appointment (appendix 3, 4 & 5).

The draft resources were received positively from both advocates and mothers and women said they liked the idea of a midwife filling in the appointment sheet with them. They said that it was important that the appointment sheets were used to reinforce information given verbally. This was seen as more inclusive and helpful than just being given a pre-written appointment card. They liked the fact that the pictures gave insight into what to expect at each appointment. Having printed information that could be shared with advocates and family, re-read and reiterated was seen as very important.

Everyone said they liked the appointment sheets and all but one said that they liked the combination of words and pictures. They all thought that they were clear and they all understood them. The picture of blood being taken received most discussion with

several women saying that they didn't like it or were afraid of needles, or pain. Their immediate emotional response to the picture showed its value as a tool to aid communication and discussion.

Women also liked the picture of the hospital on the sheet, showing where they had to go. This was seen as sensible and reassuring, because it took away some uncertainty. The theme of reassurance was significant, with some concerned that they would not understand, not remember, get lost or not know what was going on.

The women all recognised the urine sample and scan pictures and conversation quickly went on to their stories of pregnancy. Several women talked about losing sheets and paperwork, or accidentally throwing them away. The design of the sheets allows them to be secured in the maternity notes and therefore less likely to be misplaced.

Respect and Integrity

For the Director of People First, an organisation run by and for people with a learning disability a primary issue was:

“...not what is said but how it is said, [with people usually] coming from a presumed ‘can’t do’ perspective rather than one to support needs”

He reflected on a personal experience he had experienced with his wife:

“Supporting people with a learning disability is very complicated and tests the health professionals. If you go to an appointment as a couple and the health professional says ‘who is your carer?’ immediately trust is broken and a golden opportunity lost...”

For one mother, timekeeping became a signifier of power and control:

“You are scrutinised, but the health professionals are not, you can’t be late, but they are often late” (Mother).

And another mother talked of lack of choice:

“With Social Services you feel like you have no choice, you have to do what they tell you, or it may be like the last time and you lose the kid” (Mother).

Access and ongoing engagement with maternity services

Women in this small pilot project had all been referred via their General Practitioner to maternity services. One woman, married with three boys, recounted a positive experience of antenatal care. She thought that things were explained well, she made an appointment for the next visit with her midwife and she was confident of the purpose. She was happy with her care and spoke about how she could go to see her midwife or GP if she had any worries and that they would see her straight away. Between appointments the midwife would call her on her mobile phone. However an advocate expressed her concern that this wasn't always women's experience:

“Women with a learning disability are less able to express themselves, ask questions, speak up or complain...they worry that they will be judged or thought difficult and fearing the consequences, stay quiet.” (An advocate, Mencap).

The women shared the reasons why they had not attended all their antenatal appointments:

1. Transport difficulties

One of the major obstacles was planning journeys. In Cornwall, women were reliant on a skeleton rural timetable that often made attendance difficult. In addition there was the added stress of waiting before or after an appointment or indeed of missing the last bus because the appointment was delayed. Confidence in asking and using different

modes of transport affected access, for one woman ringing for a taxi was too difficult. For another woman, agoraphobia or anxiety about when and how to get on and off the bus were inhibitors. One mother explained that using buses was very stressful, that she didn't understand money and although she would have been eligible for a bus pass found that she had to pay. She was entitled to have her fares reimbursed but again this was 'another thing to do' and was too complicated.

2. Competing demands and difficulty in changing/cancelling appointments.

For some competing demands meant that they were unable to attend their appointments. Telephoning to change appointments caused anxiety and difficulty for half of the mothers interviewed. This was either because they found ringing too complicated or because they were greeted by impatience and indifference. Although mobile phone credit was a problem for some, all the women interviewed thought that texting was a good way to communicate.

3. Support, reassurance and explanation

Issues around support, reassurance and explanations were common topics of discussion. Participants, both mothers and advocates commented that understanding why they had different appointments and remembering where to go was difficult. Women said they used their mobile phones and calendars to remember their antenatal appointments but they did not always feel prepared for the range of appointments for example obstetric reviews, scans, blood tests. Within appointments they did not always

understand what was happening and why, why they were having their blood pressure taken or why they were asked to bring a urine sample or what the purpose of a scan appointment was.

During consultations mothers expressed that they found it difficult to understand some conversations, this was especially the case if there were several professionals present, for example where an obstetric opinion was sought and the language became more specialised. These mothers said this made them feel bewildered and overwhelmed. Asking questions and interrupting flows of conversations was too difficult and that the appointments were often too rushed. One mother explained that she was aware that she has learning difficulties and found things more challenging but that during her appointments the professionals were often impatient. She recalled how they would explain things once or twice but still used complicated medical terms. She went on to say:

“They ask if I have understood and I say yes, otherwise they would be there all day”

She thought having information to take away to show to relatives, friends and advocates would be helpful. One woman described a clear example of ‘does she take sugar?’ when she recalled how the midwife turned to her mum and talked to her instead.

Recommendations



Advocates and mothers, through their experiences highlighted a number of factors that could help to improve engagement with antenatal care for women with a learning disability. Many of their thoughts reflected those of earlier and larger reports (Michaels, 2008; RCM, 2007; RCN, 2007.) although those relating to the draft antenatal appointment resource were new.

1. Antenatal Care

Beginning with place, and time of the antenatal appointment, they suggested providing antenatal care, where feasible in the home. Where hospital or community clinic visits were necessary, these should be made at the start or end of the clinic to avoid a busy waiting room. Having appointments with an extended time frame was also thought to be good practice.

Appointment systems where people need to take a ticket with a number on and are then seen on arrival order may be challenging for people with a learning disability. Advocates suggested that careful explanation or the option to by-pass this system would be advisable.

Realistically women with a learning disability will have a number of professionals providing care and support. Coordinated meetings and appointments and transparency between professionals and the parents are important. Continuity from a named midwife/team of midwives would help engender trust, transparency and individualised

care. This would also enable improved communication between appointments, professionals and support networks:

“Midwives with limited knowledge and experience in caring for disabled women should seek advice and guidance from disability advocacy organisations and from disabled women themselves, who are often the best source of information” (RCM, 2007: 2).

For midwives, the Mencap helpline can be a source of support. Through the helpline, people with a learning disability, their families and professionals can get advice, be referred to local agencies for help, be informed of rights and be allocated a case worker where necessary. Early and ongoing engagement with maternity services is enhanced by concurrent support from parenting support services or advocacy service, GPs and Social Services.

2. Communication

During consultations a number of areas became evident to enable enhanced communication in the antenatal period. Advocates also said that in dialogue, midwives needed confidence to wait and listen for answers. People often needed time to process what was said before answering and that waiting rather than prompting would be most helpful. Again, enough time during appointments would be needed to facilitate this.

Using literal terms and avoiding idioms and acronyms would also help understanding, as these would not be understood and may cause distress. Commonly used expressions such as “in a minute” could cause anxiety when taken literally.

One advocate recommended keeping appointments simple, addressing fewer things and conveying fewer messages at one time, as this would help understanding. They suggested that the midwife should check that messages are understood, perhaps by getting the woman to repeat back to her. Paying attention that language is simple and sentences were short so that there is one message per sentence. Writing down information, drawing, referring to maternity notes, appointment sheets and pictures were also considered helpful for women. It is imperative to be mindful that 'one size does not fit all' and that care should be structured around individualised ongoing assessment of need to what is appropriate at any given time. This would invariably mean that the schedule of care would require more appointments.

Communication needs to be two ways, communication may be given differently but it is also important that the mother is given time and the means to communicate. Inviting the partner, other family member or advocate to appointments can help to reinforce messages.

3. Resources

This project was a pilot project. The antenatal appointment sheets were received positively. There is scope to develop further resources that are attractive, locally literal and pertinent for women who have a learning disability. Printed information that can be added to maternity notes means that they are less likely to be lost. Mobile phone apps may also be appropriate as all the women in the project used this technology as a means of communication; however the research would need to be expanded. CHANGE develops resources for and with people with a learning disability but there is a need for

local information. For a mother with a learning disability an appointment card or leaflet with the hospital displayed and the midwife wearing the correct coloured uniform is more literal and pertinent and therefore more likely to be taken notice of, referred to and used.

Communication demands on the midwife are high, and support for them might also include additional resources such as:

- E-learning and 'class-room' education for professionals, for example the education offered by Mencap in Barking and Dagenham (and elsewhere) where parents with a learning disability share their experience with midwives
- Using maternity notes to their full potential to record women's individual needs
- Text and telephone reminders for appointments
- Simple reminders of key points and signposts to other support and resources
- Discussion prompts to give to and use with women, for example those produced by CHANGE and The Polyanna Project

Conclusion

Much of what we learnt during this project was reflective of other reports, notably the Independent Inquiry (Michaels 2008). The recommendations made in the report echoed the guidance issued by the RCM (2007) and RCN (2007) and implicit in the Nursing and Midwifery Council Code (2008). This project was collated and written up under the shadow of the Francis Report (2013) which underlines the need to improve transparency, competency and care across the board. What is undoubtedly true is that if you improve the care and provision for the most vulnerable in society the majority will benefit.

The Government launched the Compassion and Caring strategy in 2012 with a vision based around six core values: care, compassion, courage, communication, competence and commitment. Core to this document and vision are the underlying premise of attitude and education to promote and enhance these basic values. Much of the substandard care we heard about during this project would not have happened had the 6C's been everyday practice. The strategy offers the opportunity to revisit some core values, ones that all who provide care for this group of vulnerable adults need to embrace.

Women with a learning disability may feel under scrutiny; the emphasis being placed on parenting issues early on in a pregnancy can overshadow antenatal care aimed at monitoring the health and wellbeing of both mother and child. Professionals working within a climate of shared decision-making and shared autonomy rely on women to self

report any problems or concerns. However this way of working may have serious flaws for a woman with a learning disability as she may wish to please, endeavor to give the right answer or simply not recognise when things are not right. For some, a lack of transparency of care left advocates, women and their families confused and uncertain.

This project has highlighted that there are issues to be tackled around communication and making adjustment to meet the individual needs of these women. Midwifery is a profession that prides itself on offering individualised care. If it is to lay such a claim it needs to be mindful of the most vulnerable individuals that access care.

The appointment resources were received positively and the fact that they are designed to be integrated (tag-tied) into the maternity notes which the mother brings to each appointment means that they are not so easily mislaid as more traditional appointment cards. Depictions of what to expect at an appointment clearly opened up conversations and added transparency and offered something to show to family and advocates. They are efficacious, and delightful to look at and aid recognition and orientation. They also have literal authority, for example, the midwife wearing purple and the picture of the hospital entrance. The appointment sheets were adapted easily for each hospital site demonstrating their transferability to other units, in Cornwall and elsewhere.

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Appendices



Appendix 1



Proposal

Developing an appointment resource / discussion tool for midwives to use with parents who have a learning disability or self reported learning difficulty.

The Polyanna Project

We are a health access and information consultancy, specialising in client-centred communication and access for disengaged communities

We use art to convey identity-driven health messages between service providers and users

We are a not for profit organisation, working to research as well as develop information and educational The name Polyanna reflects the ethos of the group...optimism. The Polyanna Project are a team of professionals who work together: a consultant midwife, anthropologist, artist, health psychologist, barrister and IT technician.

A Feasibility Study - Aspects of Antenatal Care

The aim of this project is to consult with women and their partners who have a learning disability to develop a picture based appointment resource.

This will inform them about local individualised provision of antenatal care and what to expect.

The resource would complement, rather than replace the CHOICE resource (CHOICE, 2006). It will be in a format that will enable the women and their partners to refer to the resource between visits and to bring it with them to antenatal appointments.



The Background

In 2010 the coalition Government published Equity and Excellence: Liberating the NHS (DH, 2010). Central to this White Paper is the principle of shared decision making with increased control and choice by the service user:

“No Decision About Me Without Me” (DH,2010: 13)

Core in the paper is the ideology of the central role of the receiver of care, prominence being given to individuals to exercise greater control and choice over their care. It recognises the public health opportunity that pregnancy offers and the possible implications in engaging women and their families from all sections of society. It purports that providing women and their families with information, support and advice through pregnancy and at the start of life may influence long term health needs and reduce inequalities in health. The overarching principle is one of improving information and facilitating informed choice.

The ‘information revolution’ proposed would ensure that all people have the information they need to make informed choices, presented in a way they can understand. The consultation paper asserted:

“...choice has an important role in promoting equality and reducing inequalities by helping people from different backgrounds to access the highest quality of service” (DH, 2010 b.1)

Furthermore the imperative of information and choice for everyone is underlined:

“...access the information they want through a range of means to ensure that no individual or section of the community is left out” (DH, 2010.15)

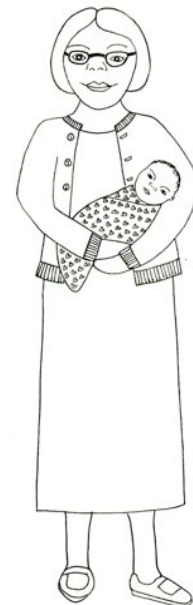
The Disability Rights Commission (2006) stated that information about options of treatments, procedures and appointments should be in a format that is accessible.

NICE recommends that:

“Pregnant women should be offered information based on the current available evidence together with support to enable them to make informed decisions about their care” (NICE 2008.5)

A recent report by the King's Fund (Coulter and Collins, 2011) describes this shared decision making as an ethical imperative and fundamental to good care and outcomes, ensuring the correct individualised care.

The recent publication: Pregnancy and complex social factors (NICE, 2010) outlined that women with complex social factors, including parents with a learning disability are likely to have particular needs and may be faced with barriers to care and understanding their choices. The guidance recommends improving ways of communicating to women so that they can make appropriate choices. NICE recommends involving women in their antenatal care, not just their current pregnancy but listening to their views about their experiences and their thoughts on how services could adapt to serve their needs.



The Development

This pilot study is being self funded by the Polyanna Project, however we are hoping to build on and develop the resources produced with future funding.

To enable us to carry out the pilot project we are seeking to consult with people with a learning disability. The consultation will be either on an individual basis or in a focus group. We are also interested to meet with advocates and providers of services. for their advice and comments This will enable us to adapt the resources so that they are accurate, useful and pertinent.

We will be commencing this innovative project in mid February 2012. If you are unable to offer us advice at this time and would like us NOT to contact you would you be so kind as to e-mail us by 25th February 2012.

Our previous work can be viewed on: www.thepolyannaproject.org.uk

Please contact us via e-mail: info@thepolyannaproject.org.uk

References

Coulter and Collins (2011) Making Shared Decision-Making a Reality. No decision about me, without me. The Kings Fund
Pregnancy and complex social factors. (2010) national institute for Health and Clinical Excellence

Department of Health, (2010) Equity and Excellence: Liberating the NHS. The stationary Office.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353

Department of Health (2010b) An information Revolution: a consultation on proposals
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_120598.pdf

Appendix 2

Learning Disability antenatal Project

Interview Guide/proforma

1. Who did you go and see when you were first pregnant?

- Did you know what each appointment was about and what was going to happen?
- What helped you understand information in the appointment, was it pictures, reading or time to ask questions? What would you have liked more of?
- Was there anything that made you feel nervous or that you did not like?
- Did you have anyone with you at the appointment?
- Did you understand why your Blood Pressure and urine was tested?

7. Did you understand why you were having blood tests?

8. Who can answer your questions in pregnancy?

9. How do you like to learn about things, by reading, the computer, having a go? Talking to friends?

10. Do you use a computer, smart phone, Twitter, Facebook? Do you play videogames?

Appendix No 3

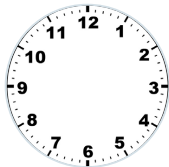
Antenatal appointment: midwife



Please come to see
your midwife

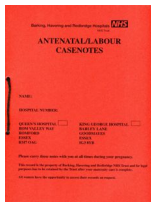


At: Antenatal Clinic
(women's outpatients)
Queen's Hospital

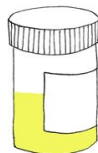


Date:

Time:



Bring your notes



Bring your urine sample

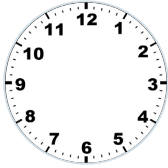
Antenatal appointment: midwife



Please come to see
your midwife

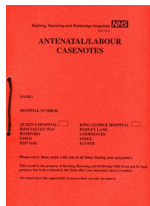


At: Antenatal Clinic
King George Hospital

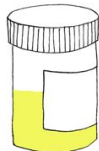


Date:

Time:



Bring your notes



Bring your urine sample

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