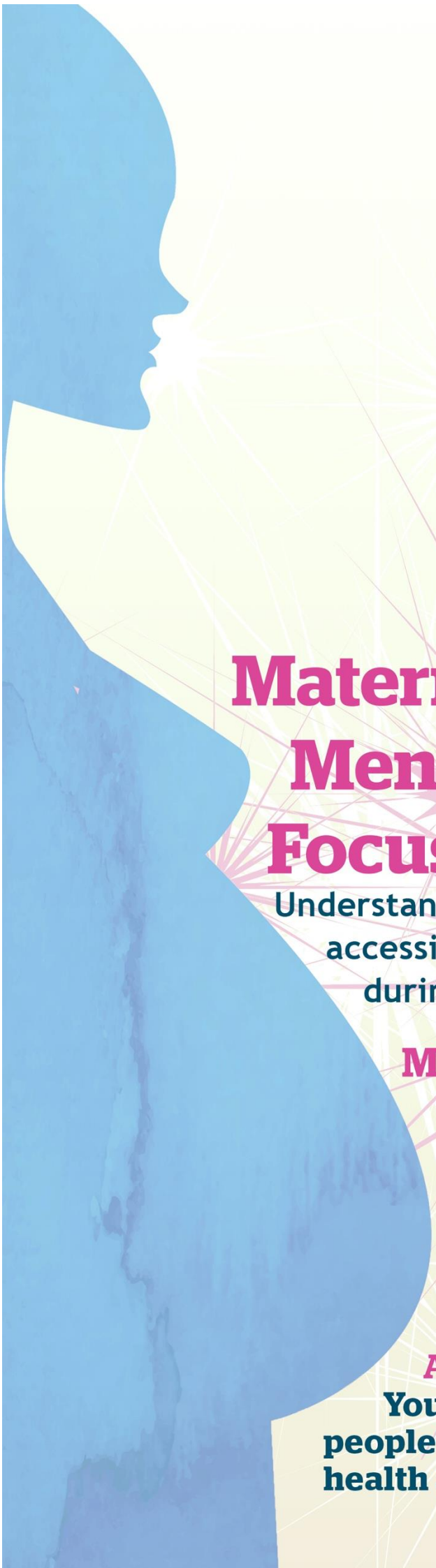
healthwatch Leeds



Maternity and Mental Health Focus Groups

Understanding people's experiences of accessing mental health support before during and after pregnancy

March 2019

About Us

Your independent watchdog ensuring people's voices are at the heart of shaping health and care services in Leeds

Background

In 2016 Healthwatch England started a project to find out about people's experiences of using mental health services. The aim of this work was to help inform mental health policy and practice by creating a strong evidence base about people's experiences of mental health care at different stages of life. Over 34 000 people shared their views and experiences of using mental health services with Healthwatch England. More information about the project and the report is available on the Healthwatch England website at https://bit.ly/2uqkhoa.

Following the information gathered by Healthwatch England, four main areas of mental health were highlighted as those that people talked about the most. These included primary care, crisis care, community treatment and children and young people's services. Healthwatch England decided to look at all these areas in more detail and started with the mental health support available to people planning on having a child, who are pregnant or new parents.

Why we did it

As many as 1 in 5 pregnant women and new mums experience some form of mental health challenge. 1 in 3 new dads also report concerns about their mental wellbeing.

Mental health is a key area we are focusing on this year and as part of this, Healthwatch Leeds was keen to do some work around maternity and mental health.

We were one of 5 local Healthwatch who were selected to work in partnership with Healthwatch England to get the views of new and expectant parents through a range of methods. These included an online survey, focus groups and a visit to The Yorkshire and Humber Mother and Baby Unit based at the Mount Hospital in Leeds. Healthwatch England will produce a full report of the findings from all 5 Healthwatch taking part in this project.

What we did

We organised five focus groups over the course of two months in February and March 2019.

Two of these took place as part of an existing focus group where women were feeding into the design of a new maternity support app. At these we spoke to six women who had either had a child within the last three years or were pregnant.

Three focus groups were held at Mencap's Leeds base and involved a total of 18 women. All 18 had at least one child with a learning disability.

In our conversation with the women, we focussed on four key questions:

- Who supported you with your perinatal mental health problems?
- If you did not get support, what were the reasons for this?
- What was good about the support you got?
- What could have made your experience better?

What we found

The general picture

Of the 24 women we spoke to all of them had experienced some level of mental health problems, however only eight told us that they had accessed specific perinatal mental health support.

While most of the women had not specifically accessed support for their mental health problems many of them told us that they had received support from health professionals such as GP's and health visitors. However the majority of women talked about 'other' services such as Mencap being their key source of support.

Several women reported the following experiences and observations over the course of the five focus groups:

Women who have a difficult experience during or immediately after their pregnancy are not systematically offered support.

We spoke to women whose mental well-being was disrupted by traumatic birth; their child's diagnosis with a learning disability; or domestic violence and homelessness. Although all these circumstances were known to health and/or social services, this did not automatically lead to the women being offered mental health support.

Health professionals' interactions with women can lead to a breakdown in trust.

This was particularly the case for women whose children had been diagnosed with additional needs, but it was not exclusive to this group. Women's relationships with health professionals were sometimes negatively affected when they felt their concerns about their children's health was being dismissed. One woman told us how her first experience with the health visitor had been so negative the trust between them had never developed.

This breakdown in relations with health professionals can have the double effect of making women feel isolated and making them less likely to access mental health care.

Women find it difficult to recognise mental ill health in themselves and to start conversations with health professionals about their mental well-being.

Women told us they feel ill-informed about the difference between "baby blues" and mental illness. They commonly feel that the conversations they have with their health visitors about their well-being are "tick-box" exercises, rather than real prompts to reflect on and disclose their feelings. It was very rare for conversations with health visitors to act as a starting point for accessing mental health support.

Peer-support groups provide useful support.

There was general agreement that speaking to and socialising with other mothers provided much-needed reassurance. Examples include support groups at Mencap, breastfeeding groups and mother and toddler walking groups.

What we found

Mencap service users' experiences

We led three focus groups with attendees of Mencap Leeds' Hawthorn family support service, parents and carers of children aged 0-3 with additional needs. While much of what they reported tallied with the general findings already highlighted in the report, they also discussed specific difficulties with access to mental health support linked to their children's health conditions.

There was universal praise for the support offered by Mencap.

The women we spoke to found the peer support that the Hawthorn service provided very beneficial, but they also appreciated the practical help it offers such as accompaniment to meetings with health professionals. However, it appears that parents of children with additional needs are not systematically signposted to organisations such as Mencap by health professionals. One woman found out about Hawthorn through a friend, while another only knew about it because she worked with adults with learning disabilities.

Women feel that very little specialist support is offered by the health service.

Very few women we spoke to were able to access a health visitor with specialist training in learning disabilities. Many felt that their standard health visitor was "out of their depth", and as a result it was impossible to build up any kind of relationship with her. This left the women feeling isolated.

"No-one ever asks how you are."

Mothers of children with additional needs often come into contact with health professionals frequently over a long period of time. However, many of them told us that these health professionals rarely asked them how they were coping during this particularly stressful moment in their lives. This contributed to their reluctance to talk openly about their mental health, a topic which some felt was still stigmatised.

It was common for women to feel they had to "soldier on" and focus solely on their child, rather than themselves. (One respondent commented that at no point did any health professional call her by her name: she was always referred to as "K's mum".) Some women also felt that, because they were looking after their child, time pressures were too great for them to access support. Self-referring for counselling, for example, can feel like one job too many when you are caring for a young child with additional needs.

The way health professionals talk to parents about their child's additional needs can affect their well-being.

It was commonly felt that health professionals focussed on the problems associated with their children's health conditions, rather than viewing them as a positive addition to parents' lives. This attitude can be emotionally unsettling for parents at a very vulnerable moment in their lives; it can also reduce their trust in health professionals, who appear to sometimes lack insight into or empathy for the experience of having a child with additional needs.

Although mental health support is difficult to get, once accessed it can be very helpful.

With a few exceptions, the women we spoke to who did receive specific mental health support found it useful. However, two women found that, when a treatment option such as counselling did not suit them, they did not know where to go next. Moreover, the treatment the women received did not always take a holistic look at their lives and how having a child with additional needs could impact upon mental wellbeing.

Our messages / recommendations

General recommendations

- Provide information and support for new parents who may need additional support in a range of formats suitable to each person's needs and requirements
- Review the mechanisms in place for offering parents mental health support if their circumstances make them particularly vulnerable, for example if they have experienced a traumatic birth or their child is diagnosed with a disability. If no mechanisms are in place, consider how they could be implemented.
- Look at training and support for health professionals so that they are able to highlight and deal with mental health issues and signpost when needed.
- Consider how all health professionals who come into contact with parents and expectant parents can be encouraged to ask the question "how are you?" and to make this meaningful and backed up with support if needed.
- Ensure that all health visitors and other professionals are in a position to signpost service users to peer support groups and specialist services.
- Review the current provision for perinatal mental health support, including for those parents who may need additional support to ensure it meets the need.

Specific recommendations for when working with parents of children with additional needs

- Review what proportion of parents of children with additional needs are offered specialist support, for example a specialist health visitor.
- Review the extent to which health professionals, including those working in mental health, are aware of how the process of securing a diagnosis for a child might affect service users' emotional and mental well-being.
- Ensure that signposting to specialist local organisations is done systematically.

Next Steps

The report will be shared with the service providers and commissioners in Leeds.

We will agree with them the next steps to be taken in response to our recommendations and work with them to ensure any agreed actions are followed through and implemented. We will undertake any follow up work required to ensure there are real changes made to the service so that it is a good experience for everyone.

We will also share the report with Healthwatch England to feed into the national project, and with the Care Quality Commission.

The report will also be published on the Healthwatch Leeds website.

Thank you

This report has been written by Anna Chippindale, Sessional Project Worker at Healthwatch Leeds, in collaboration with Sharanjit Boughan, Community Project Worker.

We would like to thank the women that took part in the focus groups and shared their personal stories with us.