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# Down syndrome in maternity care: Mothers’ experiences of mental health support

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## Table of Contents

# 1. Summary

Pregnancy and the postpartum period are times of significant change, often characterized by an array of emotions and expectations. This period is considered a sensitive phase when individuals may be more susceptible to mental health challenges. There is considerable evidence of the impact that perinatal mental health can have upon not only the mother but also on child development. Recognising and meeting the mental health support needs of expectant and new parents is seen as a vital part of maternity healthcare provision.

When the arrival of a child is accompanied by a Down syndrome diagnosis, this can uniquely shape the emotional landscape for parents, demanding a nuanced approach to mental health support. The news can evoke a range of profound emotions, necessitating support to help parents adjust to the diagnosis and understand what it means. However, there is very little evidence about mental health support for new and expectant parents when they find out their child has Down syndrome.

We conducted a survey about the maternity experiences of mothers of a young child with Down syndrome who was born in England, Scotland or Wales from 2019 to 2022. The survey was designed in collaboration with Positive About Down Syndrome (PADS), an initiative of the charity Down Syndrome UK (DSUK), and was developed from a previous survey conducted by DSUK in 2018 (DSUK, 2019; see also Enoch, 2019). 317 mothers responded to the online survey and answered questions about their experiences of prenatal testing, diagnosis, and maternity care. This report focuses on what they told us about their experiences of support for their mental wellbeing during and after their pregnancy.

The majority of mothers reported that there was not enough support available for their mental wellbeing either prenatally or postnatally. Over half (56.5%) of mothers felt that there was not enough support for their mental wellbeing during pregnancy, while almost two thirds (63.8%) advised that there was not enough support after their baby’s birth. Less than a third of mothers (31.4%) felt they were given enough reassurance about the future, while 37.6% felt that their mental wellbeing had been negatively affected by healthcare professionals’ attitudes towards their baby having Down syndrome.

In written responses, many mothers described needing support to help them process, discuss, and learn more about the significant news, but that this was often not available. Some mothers who received prenatal news about Down syndrome felt that healthcare professionals assumed they did not require support because they had declined further testing, or chosen to continue their pregnancy. Meanwhile, an important feature of positive prenatal support highlighted by several mothers was having their decisions respected by healthcare professionals.

Respondents who received a postnatal diagnosis highlighted that a lack of support at this time made them feel alone or isolated. There were a number of interactions recounted when healthcare professionals displayed insensitivity or inconsideration for respondents’ emotional wellbeing. Support after birth that was described positively, on the other hand, was often characterized by healthcare professionals displaying kindness and compassion for parents as they processed the news.

Concerning mental health support both during and after pregnancy, respondents highlighted the importance of being able to connect with other families of a child with Down syndrome. This alleviated feelings of isolation and provided access to positive narratives and hope for the future.

These connections were largely facilitated by charities and frequently as a result of mothers’ own research to find organisations online, often later in their journey than they would have liked. Indeed, a consistent feature of respondents’ written accounts was the impetus being on them to research and find their own support, since healthcare practitioners did not provide or signpost to this.

The Care Quality Commission (CQC) conducts an annual national Maternity Survey of women receiving NHS maternity care in England, which includes a question about mental health support during pregnancy. In 2022, 85% of women surveyed felt they had received enough support for their mental health during their pregnancy (CQC, 2023). The comparative figure from the current survey of mothers of a baby with Down syndrome, excluding respondents who answered ‘Not sure,’ was 38.1%. This highlights a substantial discrepancy in the extent to which the mental health support needs of mothers of a child with and without Down syndrome are being met.

# 2. Introduction

## 2.1. Background and rationale

### *2.1.1. The Down syndrome diagnostic pathway*

Prenatal testing for Down syndrome is a feature of many healthcare systems, though the technologies and processes involved vary across countries, and have expanded over recent decades.

In England, Scotland and Wales, prenatal screening for Down syndrome is offered to all pregnant women as part of their NHS maternity care. Initial screening tests comprise a blood test and an ultrasound examination, which together are referred to as the 'combined test.' If parents receive a 'higher chance' result from this initial screening, they are offered further testing.

Until recently, the only further test available was an invasive diagnostic procedure - an amniocentesis or chorionic villus sampling (CVS) - carrying a small risk of miscarriage. However, between 2018 and 2021, a new screening test known as Non-Invasive Prenatal Testing (NIPT) was introduced into NHS practice. NIPT is a maternal blood test offered to mothers who receive a higher-chance result from initial screening. Although more accurate than initial screening, it is not definitive, and so parents who receive a high-chance NIPT result are still offered invasive diagnostic testing to confirm whether their baby has Down syndrome.

A large proportion of expectant parents who receive a prenatal Down syndrome diagnosis in Great Britain go on to have a pregnancy termination. National statistics for England show that in 2019, 88.0% of pregnancies with a prenatal Down syndrome diagnosis ended in termination (Public Health England, 2021a). In 2019, there were 685 live births of babies with Down syndrome recorded in England, and 588 (85.8%) of these were diagnosed postnatally (Public Health England, 2021b). This means that the majority of parents of a child with Down syndrome have received the diagnosis postnatally.

### *2.1.2. Perinatal mental health and Down syndrome diagnosis*

Mental health difficulties during and after pregnancy are common. Around 1 in 5 women globally are estimated to experience prenatal or postnatal depression (Hahn-Holbrook et al., 2018; Yin et al., 2021). Anxiety disorders are estimated to affect 15% and 10% of women during and after pregnancy, respectively (Dennis et al., 2018). Prenatal and postnatal mental health difficulties can have adverse effects on both mothers and infants (Howard & Khalifeh, 2020). For example, maternal depression has been associated with slower learning of language skills, both in children without disabilities (Clifford et al., 2022) and in children with Down syndrome (D'Souza et al., 2020).

Research indicates that the majority of parents raising a child with Down syndrome love their child, are proud of them, and consider them to have positively impacted their life (Skotko et al., 2011; Bertrand, 2019). However, receiving unexpected news about an unborn or newborn child can have a profound emotional impact (Nelson Goff et al., 2013; Clark et al., 2020). Mothers of a child with Down syndrome may hence be particularly at risk of experiencing mental health problems during and after pregnancy. Research demonstrates that:

- Receiving a higher-chance initial **prenatal screening** result is associated with increased maternal anxiety (Lou et al., 2015) and depressive symptoms (Hippman et al., 2009) during pregnancy
- Maternal anxiety remains high after receiving a high chance result from **Non-Invasive Prenatal Testing (NIPT)** for Down syndrome (Van Schendel et al., 2017)

- Receiving a **prenatal diagnosis** of a fetal condition is associated with increased anxiety and depressive symptoms in women continuing their pregnancy (Koc et al., 2023)
- Many mothers feel anxious or frightened after receiving a **postnatal diagnosis** of Down syndrome (Skotko, 2005) and experience elevated psychological distress six months after giving birth (Nes et al., 2014)

Support for mothers' mental health is a vital part of supporting maternal and family wellbeing. In the UK, the National Institute for Health and Care Excellence (NICE, 2016) highlights the role of maternity healthcare professionals in supporting maternal mental health and recommends that women are asked about their mental wellbeing during each routine maternity health contact. This is intended to allow appropriate prenatal and postnatal support to be provided where necessary.

Support from maternity healthcare professionals can positively impact the mental health of mothers of a child with Down syndrome:

- Women receiving higher-chance **prenatal screening results** identify that relevant information can help to reduce their anxiety (Sagi-Dain et al., 2022)
- Receiving prenatal counselling after **prenatal diagnosis** of a congenital condition is associated with reduced anxiety (Morokakis et al., 2016)
- Receiving positive information about Down syndrome with a **postnatal diagnosis** is associated with increased optimism (Skotko & Bedia, 2005)

However, there is very little evidence about the experiences that mothers of a child with Down syndrome have had of mental health support in maternity care.

This report contains findings from a survey of mothers of a child with Down syndrome born in England, Scotland, or Wales between 2019 and 2022. The survey asked detailed questions about experiences of maternity care in relation to prenatal testing and diagnosis. This report focuses only on data we collected about mothers' experiences of mental health support in maternity care. Other findings from the survey will be reported elsewhere.

## 2.2. Brief study methods

### *2.2.1. Questionnaire*

Researchers from the University of Warwick collaborated with leaders of Positive About Down Syndrome to create a questionnaire about the maternity experiences of mothers of a child with Down syndrome. This was adapted from a previous survey study conducted by Positive About Down Syndrome (DSUK, 2019). The questionnaire asked participants about the experiences they had of maternity healthcare in relation to screening and diagnosis. The questionnaire addressed experiences of healthcare and communication at each stage of the diagnostic pathway, from initial screening, to NIPT, diagnostic testing, and receipt of pre- or post-natal diagnosis. Participants were then asked questions about their overall maternity care experiences. Among other questions, this included: whether participants felt there was enough support for their mental wellbeing during and after pregnancy; whether they felt they were given enough reassurance about the future for themselves, their baby and their family; and whether the attitude shown by healthcare professionals towards their baby having Down syndrome had a negative impact on their mental wellbeing. Participants were also given the option to describe anything that particularly helped them when they discovered their baby had Down syndrome, and to tell us what would have improved their experiences. Finally, participants were asked for information about their sociodemographic characteristics.

The questionnaire was hosted on the online survey platform Qualtrics. It was open between August 2022 and February 2023. The majority of questions were multiple-choice, with some open-ended questions, giving participants the option to elaborate upon their responses, should they wish to. Participants took differing pathways through the questionnaire, depending upon their answers to questions about their prenatal testing experiences and choices. All questions could be skipped, except for the consent and eligibility questions at the beginning.

### *2.2.2. Participants*

Respondents were eligible to participate if they were the biological mother of a child with Down syndrome who was born between 2019 and 2022 and was at least 2 months old at the time of participation. Participants must have been living in England, Scotland or Wales during their pregnancy with their child with Down syndrome, and had to be over 18 years of age at the time of participation.

Recruitment for this study was conducted primarily by Positive About Down Syndrome, an initiative of Down Syndrome UK, which is a charitable organisation supporting parents of children with Down syndrome. Recruitment was also supported by Cerebra, a charitable organisation supporting children with neurological conditions and their families. Recruitment took place between August 2022 and February 2023 via online networks of parents on social media websites (Facebook) and email mailing lists. There was no renumeration available for taking part.

### *2.2.3. Ethical review*

Ethical approval was granted by the University of Warwick Health and Social Sciences Research Committee (reference 121/22). The survey was anonymous and began with presentation of an information sheet followed by consent questions, to which participants were required to agree before they could proceed to the main survey. Details of organisations supporting parents of children with disabilities were available at the beginning and end of the survey.

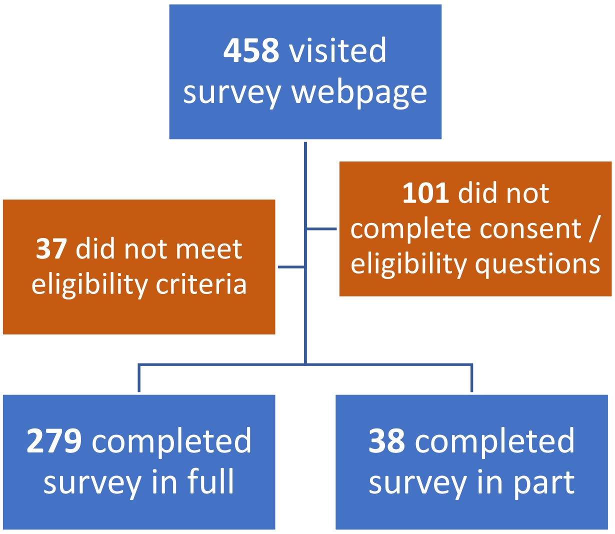
# 3. Findings

## 3.1. Who took part in the survey?

Because recruitment took place via online advertisements, we were unable to calculate a response rate. However, 458 people visited the introductory page of the survey, of which 101 did not complete the initial consent and eligibility questions. There were 37 people who completed the eligibility questions but did not meet the inclusion criteria to participate. There were 38 people who passed the eligibility questions but did not reach the end of the survey, and 279 people completed the survey in full. This resulted in a total of 317 respondents and a completion rate (from initial interest) of 60.9%.

**Figure 1**

*Survey responses*



Of 317 respondents, 251 (79.2%) provided at least one written response to an open-ended question. The written responses shared in this report are those which relate to mental health support and come from 85 different respondents. Throughout the report, quotes separated by speech marks within each text box come from different respondents.

Sociodemographic information about respondents is shown in Table 1. The majority of respondents were between 35 and 44 years of age (n= 208; 65.6%) and were living in England while pregnant with their child with Down syndrome (n= 277; 87.4%). Most were married or in a civil partnership and living with their partner during their pregnancy (n= 177; 64.1%), and a large majority described their ethnic group as white (n= 261; 93.9%). The majority of respondents were university-educated, either to undergraduate (n= 108; 39.0%) or postgraduate level (n= 82; 29.6%). The majority (n= 175; 62.5%) had given birth prior to having their child with DS. Most respondents identified themselves as non-religious (n= 164; 59.9%) while a large minority were Christian (n= 104; 37.6%).

**Table 1**

*Sociodemographic characteristics of respondents*

| **Sample characteristics (N = 317)** | ***n*** | ***%*** |
|---|---|---|
| ***Age (years)** | | |
| 18 – 24 | 3 | 0.9 |
| 25 – 34 | 89 | 28.1 |
| 35 – 44 | 208 | 65.6 |
| 45 - 54 | 17 | 5.3 |
| ***Country of residence during pregnancy** | | |
| England | 277 | 87.4 |
| Scotland | 28 | 8.8 |
| Wales | 12 | 3.8 |
| ***Year of birth of child with DS** | | |
| 2019 | 79 | 21.8 |
| 2020 | 68 | 21.5 |
| 2021 | 117 | 36.9 |
| 2022 | 63 | 19.9 |
| **Sex of child with DS** | | |
| Male | 160 | 57.1 |
| Female | 120 | 42.9 |
| **Marital status during pregnancy** | | |
| Married / civil partnership and living with partner | 177 | 64.1 |
| Living with partner (but not married or in civil partnership) | 77 | 27.9 |
| Single / Divorced / Separated / Widowed / Not currently living with partner | 22 | 6.9 |
| **Number of previous children born** | | |
| None | 105 | 37.5 |
| One | 106 | 37.9 |
| Two | 36 | 12.9 |
| Three or more | 33 | 11.8 |
| **Ethnic group** | | |
| White | 261 | 93.9 |
| Mixed / multiple | 7 | 2.5 |
| Asian | 4 | 1.4 |
| Black | 4 | 1.4 |
| Arab | 2 | 0.7 |
| **Religious affiliation** | | |
| No religion | 164 | 59.9 |
| Christian | 103 | 37.6 |
| Muslim | 4 | 1.5 |
| Hindu | 1 | 0.4 |
| Any other religion | 2 | 0.7 |
| **Educational attainment** | | |
| University degree or higher | 190 | 68.6 |
| No degree | 87 | 31.4 |
| **Economic situation** | | |
| Living comfortably / Doing alright | 197 | 71.1 |
| Just about getting by / Find it quite or very difficult | 80 | 28.9 |
| **Ability to raise £2000 in emergency** | | |
| Could raise easily / Could raise with some sacrifices | 169 | 61.5 |
| Would have to do something drastic / Could not raise | 106 | 38.5 |

#### *3.1.1. Which prenatal tests did respondents have? What were their results?*

*Initial screening*

Details of screening tests offered to and taken up by respondents are shown in Table 2, along with their screening test results.

**Table 2**

*Uptake and results of screening tests*

| **Did you have the combined or quadruple screening test for Down syndrome?** | **n** | **%** |
|---|---|---|
| Yes | 190 | 59.9 |
| No | 83 | 26.2 |
| Not sure | 44 | 13.9 |
| Total responses | **317** | **100** |
| | | |
| **What was the result of your combined or quadruple screening test?** | **n** | **%** |
| The test indicated a higher chance of my baby having Down syndrome | 108 | 60.0 |
| The test indicated a lower chance of my baby having Down syndrome | 70 | 38.9 |
| Not sure | 2 | 1.1 |
| Total responses | **180** | **100** |
| | | |
| **Were you offered Non-Invasive Prenatal Testing (NIPT) for Down syndrome as part of your NHS maternity healthcare?** | n | % |
| Yes | 96 | 31.6 |
| No | 195 | 64.1 |
| Not sure | 13 | 4.3 |
| Total responses | **304** | **100** |
| | | |
| **Respondents offered NIPT in the NHS (n= 96): Did you have NIPT for Down syndrome?** | | |
| Yes – had NIPT in NHS | 67 | 69.8 |
| Yes – had NIPT privately | 5 | 5.2 |
| No | 23 | 24.0 |
| Not sure | 1 | 1.0 |
| Total responses | **96** | **100** |
| | | |
| **Did you access privately-funded (non-NHS) maternity healthcare in order to have NIPT for Down syndrome?** | **n** | **%** |
| Yes | 36 | 11.9 |
| No | 267 | 88.1 |
| Total responses | **303** | **100** |
| | | |
| **What was your NIPT result?** | n | % |
| The test indicated a higher chance of my baby having Down syndrome | 88 | 86.3 |
| The test indicated a lower chance of my baby having Down syndrome | 12 | 11.8 |
| The test was inconclusive | 2 | 2.0 |
| Not sure | 0 | 0 |
| Total responses | **102** | **100** |

*Prenatal diagnostic testing*

Fifty-six respondents (19.1%) reported that they received a prenatal diagnosis of Down syndrome for their baby. There were a further 24 respondents who completed only part of the survey so it was unclear whether they received a prenatal or postnatal diagnosis. Of 237 respondents who received a postnatal diagnosis, 88 (37.1%) had received a higher-chance result from prenatal screening (initial screening and/or NIPT), while 149 (62.9%) had not received any prenatal result indicative of Down syndrome.

## 3.2. What were respondents' experiences of mental health support during and after pregnancy?

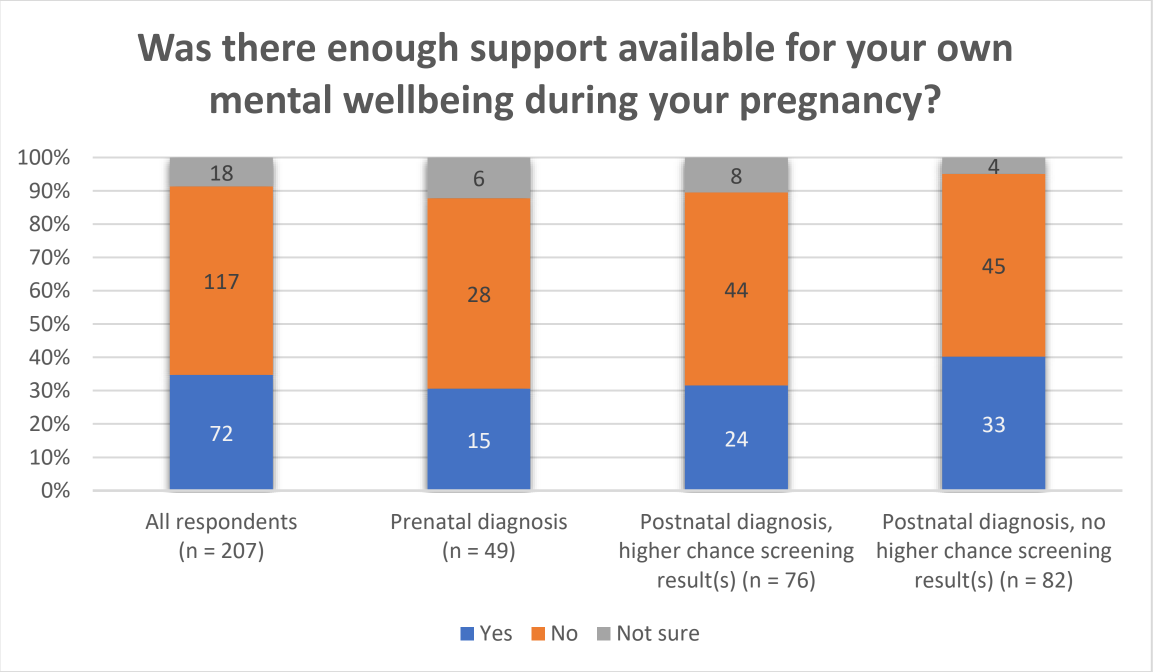
### *3.2.1. Support during pregnancy*

***"Someone talked about the fact that I had chosen to continue my pregnancy and therefore I should be fine with having a child with Down syndrome even though I was really struggling with the diagnosis. They didn't seem to appreciate that continuing the pregnancy doesn't mean that you are okay, it's a lot to process."***

We asked all respondents whether they felt there was enough support available for their own mental wellbeing during their pregnancy. Of all 207 respondents who answered this question, 72 (34.8%) reported that there was enough prenatal mental health support available, while 117 (56.5%) felt there was not enough support, and 18 (8.7%) were not sure. When looking only at respondents who received a prenatal diagnosis, or higher-chance screening result(s) during pregnancy, the proportions who felt they received enough prenatal support fell to 30.6% (15 respondents) and 31.6% (24 respondents), respectively.

**Figure 2**

*Perceptions of support available during pregnancy*



In written responses to open-ended questions, several respondents who received a **higher chance screening result** highlighted that they were **not given the opportunity to talk about this** with healthcare professionals**:**

*"When the outcome was high, my husband was asked to discuss with me about having an abortion and was told this was the option most expectant mothers would choose… This result was given on a Friday afternoon with no option to talk to anyone, no support, no guidance."*

*"The wait from the result showing a high chance to the wait for the confirmed blood test was unbearable and so were the initial weeks after our son's diagnosis was confirmed. We desperately needed someone to talk to, a counsellor and kept being told this was possible but it never happened. Counselling is essential when going through this to support the parents mental health and provide support at such a difficult time."*

*"No support after having the results of 1-12 chance."*

*"Results given via phone then the call ended. We felt abandoned with the news and had no idea where to go next/ what was going to happen now."*

Similarly, respondents highlighted a **lack of support following a prenatal diagnosis:**

*"The doctor was quite dismissive with a response of "Have you decided to terminate or keep the baby?" and a scribbled website on a scrap of paper that she disappeared from the consultation to get. No empathy/sympathy, considering I was in floods of tears". …*

*"I got told over the phone during covid 19… wanted to know more but felt like it was more I'm so sorry your baby has down syndrome sort of convo and given my option at 34 weeks for termination or to carry on was mind blown at the lack of support and resources felt like got left to own devices I was the one doing all the research and wanted to talk with doctors etc none provided proper counselling and info"*

*"The Fetal medicine practitioner who rang me with the results said She was so sorry and that I must be devastated. She reminded me I had options. She booked an appointment with a genetic counsellor for the following week via zoom. That person … knew nothing about any of the questions we asked. She could not signpost us to any support groups"*

*"We had our results after an amino at 34 weeks…. we never actually received any information or support regarding the diagnosis…. Every midwife/health professionals all were asking us if we have found anything ourselves as they didn't know where to point us."*

*"I had to keep asking for information about DS, and hardly anything was given to me. I specifically asked if I could be connected to any families who had children with DS but they were not able to sign post me to any. This made me feel even more alone and that I had made the wrong decision to continue with the pregnancy."*

*"There was no emotional support at all in the pregnancy or birth for my baby's diagnosis or when making the decision to continue with the pregnancy"*

*"Received the phone call when home alone was straight to the point about the showing my baby having Down syndrome and offered a termination wasn't offered any kind of support even sign posted to support"*

*"I struggled with my mental health during pregnancy and my midwife referred me to prenatal mental health services but I was rejected as "I didn't need any support with my eldest son" (who was my first pregnancy and is neurotypical) and it's common for prenatal DS diagnosis to need time to come to terms with it"*

Some respondents highlighted a sense that **their decision not to have further testing or a termination meant they were not offered support:**

*“I was very upset but because I then declined further testing, I had no follow up counselling… [My experience would have been improved by] More support during pregnancy for my mental well-being. Felt like they didn’t care after I had turned down the amniocentesis.”*

*“In pregnancy, once I had declined an amniocentesis, it was as though I was therefore “fine” with the knowledge my baby might have Down Syndrome, despite my maternity notes showing I had depression before. I would have appreciated a midwife or the genetic counsellor reaching out and checking that I was ok.”*

*“We were clear from the outset that termination wasn’t an option for our family, which I feel resulted in us not being offered certain support services. I feel because we were so comfortable with the decision, health care professionals assumed we didn’t need or require any support.”*

*“No support really towards continuing just around if we did abort (even asked at 35 weeks pregnant when we thought we had made it very clear it didn't matter to us and we love and very much wanted our baby)”*

*“Someone talked about the fact that I had chosen to continue my pregnancy and therefore I should be fine with having a child with Down syndrome even though I was really struggling with the diagnosis. They didn’t seem to appreciate that continuing the pregnancy doesn’t mean that you are okay, it’s a lot to process.”*

Sometimes respondents noted that they were **signposted to services which were not helpful or relevant** to them:

*“Signposted to ARC who were very negative and upsetting and I never phoned them again.”*

*“I was only given information about down syndrome when we had the NIPT test.... After that it was very much doom and gloom. Gave us a leaflet for Arc which seemed very much pro abortion.”*

*“I don’t think midwives should signpost to ARC until a decision to terminate has been made as it’s upsetting. I was older, well researched and adamant I wouldn’t terminate for DS. I don’t know if a younger, more unsure person would have found things more confusing or be led to terminate.”*

*“When I asked for support from the obstetrician they only gave the details of antenatal results and choices and said there was no other support available. I got in touch with the DSA off my own back…. all they did was tell me about 21&co and ask for my address to say they’d send their information pack, which included very little positive information, it felt very medical, and also included forms asking for money”*

*“I was directed towards ARC but wished that PADS had been my first contact. Would have like the hospital to have made the referral as it felt difficult to contact them myself”.*

In contrast to the above accounts, a number of respondents described the **supportive prenatal care** they experienced. An important aspect of this, which many respondents highlighted, was **feeling that their decisions were respected and supported**:

*“They said that they will support us whatever decision we made and they did. I felt looked after through my pregnancy by all doctors and nurses”*

*“My consultant was fully on board once the decision to proceed was made. I felt no pressure to terminate and felt fully supported during the rest of my pregnancy”*

*“Our hospital was amazing once the diagnosis was confirmed and we stated we wanted to continue with the pregnancy. Termination was never mentioned again and everyone professional we met was fully supportive.”*

*“I was offered invasive testing and there was an available appointment the following Monday… We discussed all of the options and it was made clear to me that it was absolutely my choice and I was totally supported.”*

*“The word termination was never used during any of my appointments unless I was the one to bring it up. The midwives used the phrase 'we will support you, no matter what you decide to do' “*

*“The options were explained about having further tests and I was given reassurance about being able to choose any option and that my pregnancy would be followed up as a potential DS pregnancy even if I didn't have the tests to confirm”*

*“The consultant that I saw and discussed this with was brilliant. He was knowledgable, professional and invited confidence. He 100% respected my explanation that although nothing would prevent me travelling the road I was on, I just wanted to see a few signposts on the way.”*

Many respondents highlighted **the importance of contact with other families of a child with Down syndrome**, through **support organisations,** for their mental wellbeing prenatally:

*“I came across PADS on social media and found this to really help my mental health and educate myself on what I could expect. Hearing from families who had gone through every emotion/ thought/feeling you had and come out the otherside and sharing the lives of their children was eye opening and helped alleviate some fears/ stresses”*

*“Positive About Down Syndrome was a real lifeline…. Pregnancy would have been very lonely otherwise.”*

*“The PADs great expectations group - seeing all the worries and then seeing the mums post their complete love and joy when their babies came made such a huge difference letting me know it would be ok - PADS rule and 21 & co for pairing me up with another lovely mum so we could chat through pregnancy about what we were going through thank you to these two amazing charities”*

*“I feel without the support and information from PADS things would have been very overwhelming. It was amazing to hear other stories and knowing you really are not alone in this journey”*

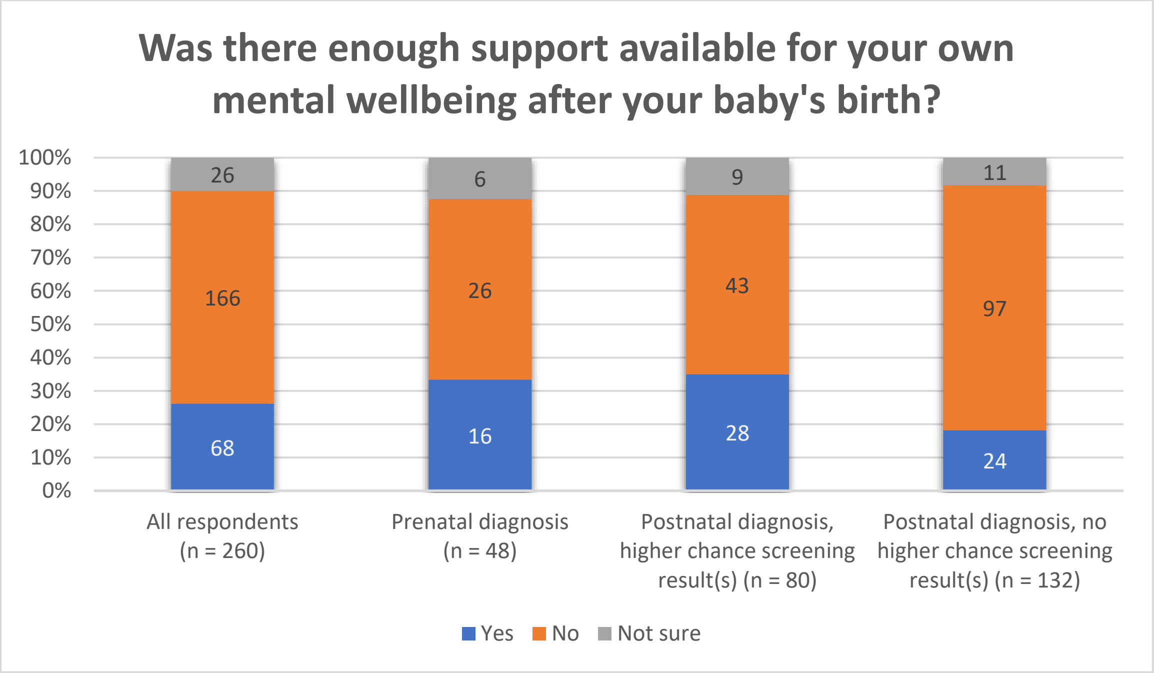
### 3.2.2. *Support after baby’s birth*

***“I felt extremely overwhelmed and shocked by the news. I was very emotional and probably would have helped with some sort of counselling or positive input from families with children with DS.”***

We asked respondents whether they felt there was enough support available for their mental wellbeing after their baby’s birth. Of all 260 respondents who answered this question, 68 (26.2%) reported that there was enough postnatal mental health support, while 166 (63.8%) reported that there was not enough postnatal support, and 26 (10.0%) were not sure. For women who received a postnatal diagnosis and had not received any prenatal results suggesting their baby had a higher chance of having Down syndrome, the proportion who felt there was enough postnatal support for their mental wellbeing was lower, at 18.2% (24 respondents), with 73.5% (97 respondents) reporting that there was not enough support available for their mental wellbeing.

**Figure 3**

*Perceptions of support available after baby’s birth*



In written responses to open-ended questions, many parents mentioned a **lack of emotional support after their baby's postnatal diagnosis**:

*"Nothing was offered for either parent after the postnatal diagnosis in terms of mental health."*

*"The fact that she might have down syndrome was portrayed in a negative way and then after the initial discussion about the possible diagnosis, I feel like it was hardly talked about/not addressed at all until we got the genetic test results. There was no support at all. All we got was a brochure before we were discharged. We cried all the way home."*

*"We received no information or support. We were left to find out information on our own. We only got told to 'look online' which I think is very poor."*

*[It would have helped to have had] "A counsellor on hand to help us process emotions and deal with the immediate diagnosis."*

*"I was told diagnosis and then left to get on with it. No information, no support, no counselling."*

*[It would have helped to have had] "Greater emotional support particularly once we left the hospital and came home to the reality of things."*

*"The possibility of our baby having Down syndrome was raised by the doctor during his newborn physical examination, the morning after he was born…then had to wait until much later in the day for a more senior doctor to come and give a second opinion. During this time I think we would have appreciated the offer of further information and emotional support, following such significant news."*

*"Staff didn't really have any knowledge or information. No signposting to local support groups/websites etc"*

*"Nothing and no one has helped, my baby has routine checks but not one person has checked on me."*

Several respondents highlighted that a **lack of support** at this time made them **feel alone or isolated**:

*"I honestly felt abandoned after having my daughter. After she was discharged from NICU and Hospital, we had very little contact at all from health visitors"*

*"The hospital gave me no support and put me in a side room on my own so actually isolated me completely. They have since apologised but it was awful at the time!"*

*"I raised concerns, within 24 hours of birth, that I felt she had features of Down Syndrome and I felt ignored. Not one member of the medical staff offered support or reassurance. I felt like I was left alone in my own room to reflect on my thoughts."*

*"We were told in a room full of people in the NICU, with no privacy support or information. After being told we were ignored and her diagnosis was not mentioned after this either. Very isolating."*

*"I strongly feel some sort of counselling or even just a chat over a cup of tea would have made a massive difference. The news came as a shock, I couldn't cope, and developed depression, and the stress led to a relationship breakdown. There was no emotional support available, esp when my baby was in nicu and I was alone in the ward not allowed visitors due to covid rules"*

*"I felt very alone and struggled after birth. [Baby's name] was on NICU/ SCBU for 6 days and in hospital for 12 days in total. I felt very isolated with little support for me."*

A number of respondents also highlighted a **lack of sensitivity or consideration for their mental wellbeing** in interactions with healthcare professionals:

*"Community midwife was awful once home…. During one visit I was in tears, she said 'there's no point doing a mood screen, you're obviously upset'. Her student looked horrified-never asked me how I was feeling towards baby/my own mental health"*

*"I was basically told they dont see why i was so shocked and upset as my screen results come back 1 in 48 so i should of prepared or had test"*

*"I felt like our baby was used as a 'learning tool' as many student midwives came in to look at my daughter. One student made very unhelpful comments at a time when I was extremely emotional - "I would be crying too if I were in your situation," "Did you know?""*

*"The doctor we had told us so matter of factly. There was no human aspect to it. Was all a medical point of view. She even told me stood at the head of my hospital bed so I didn't even see her when she briefly mentioned it."*

*"It was communicated horrendously - without an once of empathy. The way the consultant looked and acted when he walked in, I thought he was coming to tell me that my baby had died… We were given NO emotional support and were left feeling shell shocked, overwhelmed and terrified for our future."*

*"The midwife who initially broke the news was very respectful, although a bit negative/concerned. The doctors upon readmission to hospital (HDU) were extremely negative and not supportive. Asking "didn't you have the screening?" "so you didn't know about this?""*

*"The consultant then came a short while later, looked at my baby and with a terribly cold heartless bedside manner, said my baby showed features of ds and they would take bloods before we left which would confirm. She gave me no information whatsoever and then left me. I was on a full ward for everyone to hear. I was upset at the shock and I couldn't even call my husband as I didn't want the rest of the ward to hear me cry. I had to text him and tell him… That was the only day I cried about Down syndrome. I've never had any sadness other than the way the news was delivered."*

Conversely, a number of mothers reported that support after birth was positive, and this was often characterized by **staff showing understanding and kindness**:

*The midwives on the ward though we're brilliant with ensuring we were comfortable and looked after while processing the news*

*“The midwives on the ward though were brilliant with ensuring we were comfortable and looked after while processing the news”*

*“It was presented as a condition. The midwives were extremely supportive”*

*“Overall I had a positive experience after labour. I was treated respectfully and allowances made on the ward for extra visitors…The care from staff I received after was wonderful they put me at ease… Couldn’t praise them enough”*

*“The doctor who told us immediately after our son's birth was very kind and spoke to us honestly and with respect but tried to give us too much information all at once”*

*“I was allocated a new midwife who supports more vulnerable pregnancy’s/ mental health. She was able to see me at home and was able to be present for birth and the month after birth to support me. Whilst she wasn’t an expert in DS, having the more personalised and intensive support meant I was better able to cope and be heard when I had concerns.”*

*“Our neonatal consultant was delivered the news very well, also focussed on the positive newborn test results and came back the next morning to check in and see how we were”*

*“Our neonatal consultant directed me to PADS. Also, a midwife said to me that I was allowed to be sad and that I should allow myself to grieve for the future we had planned, so that we could enjoy the future we now have. This simple anecdote made a huge difference to my mental state.”*

*[What helped me was] “Kindness of the midwives to let us process”*

*“Our neonatal consultant was very compassionate and delivered the news as well as could be.”*

*“The paediatrician was amazing. Arranged for both me and my husband to stay on the ward. A nurse, who had a child with Down syndrome was on the ward and came to visit us!”*

*[What helped me was] “Having our own hospital room so we could talk about what we were going through and tell our parents. The kindness and positivity of the midwives at the hospital.”*

*“Communication was v good and we were aware of what was going to happen when we were in the delivery room so nothing came as a shock - in fact was better as no urgent heart scan needed. The message we had throughout was she is your baby and go and enjoy her - we v much have! After the birth a nurse, my gynaecologist and GP all got in touch to let me know of their sister/children with Down’s syndrome and that it was fine - that was v nice touch.”*

Some mothers also highlighted the positive impact that **connections with other families of a child with Down syndrome** had on their mental wellbeing:

*“All in all I had a very positive experience and a NICU nurse who was the hospitals Down syndrome liaison nurse happens to have a son of 18 with Down syndrome came to visit me and baby on the ward and spoke openly about her son showing me photos of him and telling me about the local support group etc… she also made me feel that I wasn’t alone”*

*“I found most comfort, support and reassurance in the many social media accounts showing what life is really like with Down Syndrome. Also a charity called Positive About Down Syndrome helped massively.”*

*[What helped me was] “Hearing other parents experiences, knowing your not alone. Seeing and hearing from other families. A sense of community amongst other parents of children with DS. We don’t have any local support groups so heavily rely on national charities for this and in particular PADs. They have helped us immensely.. with coming to terms with our sons diagnosis”*

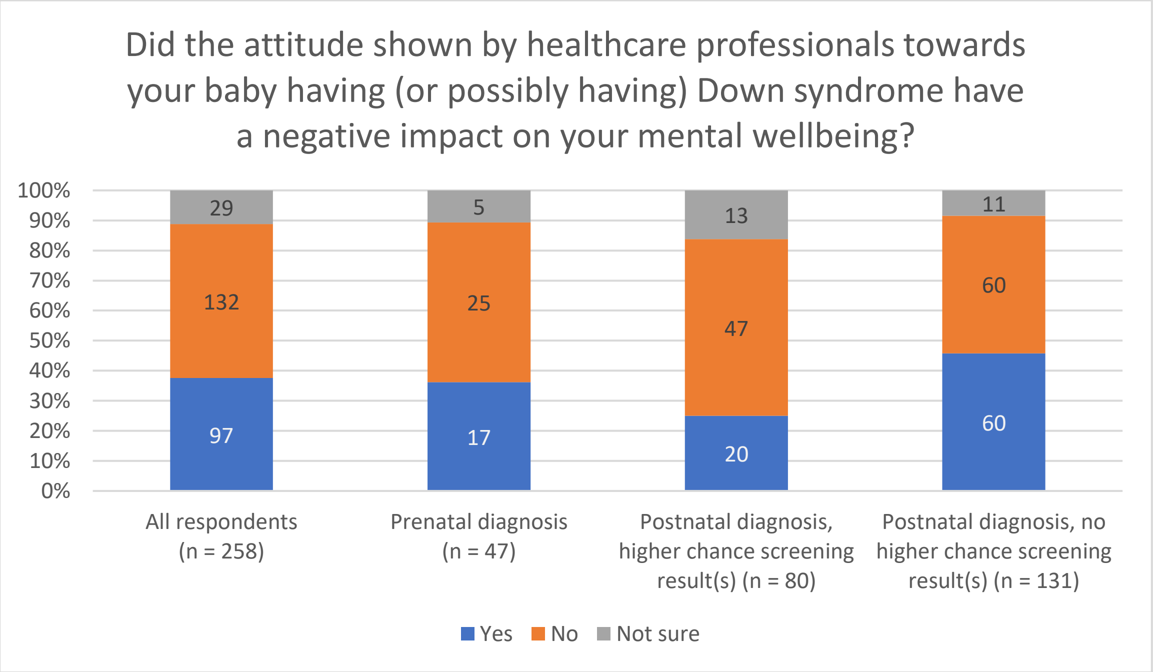
### *3.2.3. Impact of professionals' attitudes*

***"The use of language is so important. If we had been told about our son having Down Syndrome in a positive, well informed way, we might have started our journey differently. When told by a consultant, when in a vulnerable situation, that it's 'bad news', you tend to believe them… until you learn that in fact it's not bad news at all, it's your son and he's amazing."***

We asked participants if they felt that the attitude shown by healthcare professionals towards their baby having or possibly having Down syndrome had negatively impacted their mental wellbeing. Of 258 respondents who answered this question, 97 (37.6%) felt that their mental wellbeing had been negatively affected by healthcare professionals' attitudes towards their baby having Down syndrome, while 132 (51.2%) felt that it had not, and 29 (11.2%) were not sure. For respondents who received a postnatal diagnosis and had not received any higher-chance results from prenatal tests, the proportion who felt their mental wellbeing was negatively impacted in this way was higher, at 45.8% (60 respondents). Among those who had received higher chance screening result(s) followed by a postnatal diagnosis, only 25% (20 respondents) felt that their mental wellbeing had been negatively impacted by the attitude of healthcare professionals. It is important to note that the survey did not balance this question with one about professionals' attitudes having a positive impact on mental well-being.

**Figure 4**

*Impact of professionals' attitudes*



Mothers described **how negative messages about Down syndrome** were communicated and the impact this had on them:

*“The doctor spent what felt like a very long time describing various features of my child without explaining why he was telling me these thing. He used the words deformities and abnormalities making me wonder if my child had missing limbs, cleft palate etc etc etc. Then finally looking very awkward he said they suspected down syndrome and apologised...reinforcing what a bad thing he thought it was. He then left without providing ANY information on DS... It was awful and I will never forgot it.”*

*“The way the news was given to me should have been a lot better than it was. I had such a smooth pregnancy but it was ruined by everyone being so negative about DS.”*

*“Unfortunately, there are still many people, including healthcare professionals who have this wrong preconceived idea of what Down Syndrome is and if you're completely new to this (like I was in the beginning) what they say can negativity impact your thinking, mindset and wellbeing.”*

*“Our Paediatrician Consultant confirmed that our child had Down Syndrome by saying “I’m sorry, it’s bad news.” This was an upsetting choice of language for us as new parents.”*

*[My experience would have been improved by] “Not referring to them as diysmorphic features, not asking what I think and hire I feel straight away after being given the news or what I know about DS, feels like the it was put on me to know things when it's not something I had thought about it been expecting. Not to apologise when giving them news like it was something awful, more positive attitude.”*

*“When we got the results the dr was very somber and negative when he delivered the news it was as though it was a bereavement. The whole way it was handled was very poor and it was a shock for us. Luckily we have taken [child’s name]’s diagnosis in our stride however if this happened to a different set of parents it would almost definitely have a negative effect on the way they saw their child.”*

*“once my daughter was born, minutes after, I had multiple nurses, midwife’s and doctors to come and see the “Down syndrome baby” to see what they looked like and to see if she looked “Down syndrome” this broke my heart as a mother who didn’t care about a diagnosis and just wanted some time to love and enjoy her baby. Another disrespectful experience”*

Several mothers noted that while many healthcare professionals were respectful and supportive, even **one negative experience can have an enduring impact**:

*"My answers were in relation to 'most' healthcare professionals that I dealt with. There were however one or two that were extremely negative, disrespectful and had a very negative impact on me and my mental health during the pregnancy. Unfortunately those people, although in the minority, did clog my overall experience such that I had a lot of anxiety every time I had medical appointments."*

*[My experience would have been improved by] "More positivity generally - there was only one doctor who reminded us that we were having a baby and that this was still exciting and a reason for congratulations. I do not think it's a coincidence that he also had personal experiences with DS as he said some of his friends had a child with DS and that he was wonderful and a special child. Everyone else treated us like we were in the middle of a great tragedy. It really coloured our initial days with [child's name]"*

*"Baby was in NICU very unwell and I was an absolute emotional wreck - Down Syndrome had not been diagnosed before birth and I was struggling to cope, very anxious etc. I made it very clear that I was struggling and asked the staff on postnatal ward and NICU to manage carefully the way that the result was delivered to me…. 2 hours before we were due to have an in-person meeting to receive the results, a junior doctor came to take my blood for a test. She asked if it was a good time. I said 'yes, because we are meeting the other doctor for the result in 2 hours'. She then grimaced at me, visibly shuddered, and said 'I wouldn't want to see you after that meeting'. I just couldn't believe the insensitivity of it. Not only was she portraying this as terrible news, but she had effectively just straight out told me the result in a flippant, insensitive and offensive manner. I thought about this moment non-stop for many months afterwards. The doctors who handled the meeting themselves did so professionally and in a balanced way. But this junior doctor's behaviour had a long-lasting effect on me. I hope that we can educate medical professionals so that no-one else has to go through something like that, as a vulnerable, struggling mother of a very ill child facing a life changing diagnosis."*

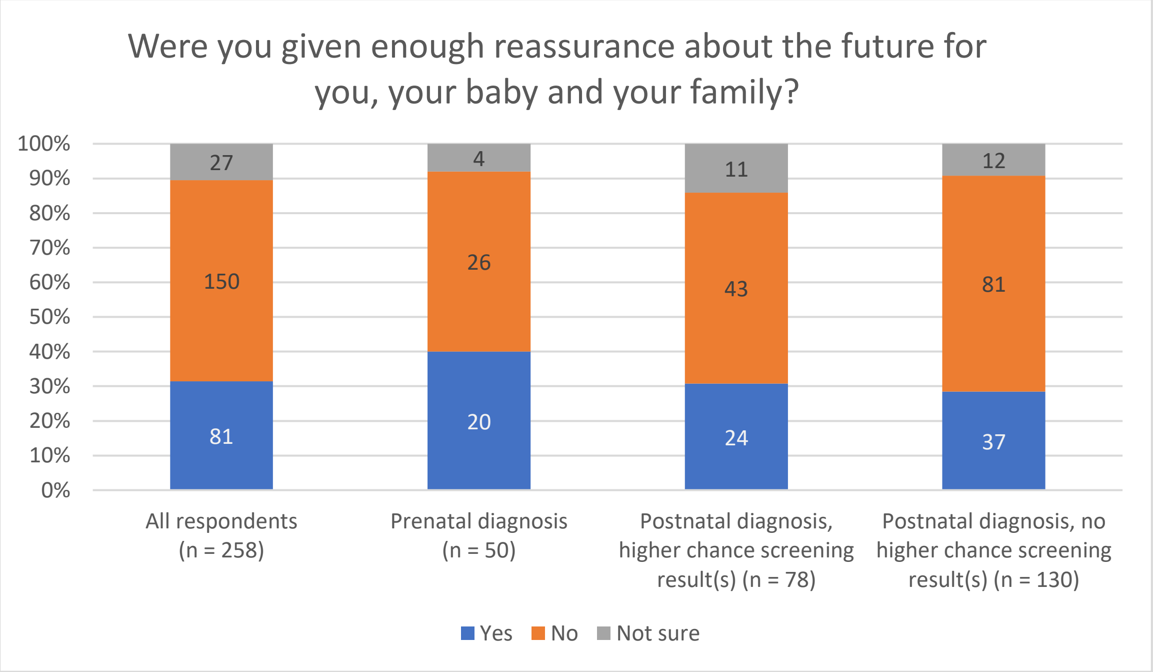
### 3.2.4. Reassurance about the future

***“Overall, staff need educating - news needs to be given in a balanced manner. My daughter is a happy, so far capable 2.5 year old. The prognosis we were given and the life we believed we were going to have does not match the reality. Having a child with DS can be challenging but it does not have to be portrayed by people without experience, as a terrible future that requires obliterating before it begins.”***

We asked participants if they were given enough reassurance about the future for themselves, their baby and their family (Figure 5). Of 258 respondents who answered this question, 81 (31.4%) felt they were given enough reassurance about the future, while 58.1% (150 participants) did not, and a further 27 (10.5%) were unsure. Among participants who received a prenatal diagnosis, the proportion who felt they were given enough reassurance about the future was higher, at 40.0% (20 respondents).

**Figure 5**

*Reassurance about the future*



A number of written responses detailed experiences of receiving **incomplete or largely negative information**, with healthcare professionals unable to provide an understanding of life with Down syndrome:

*"… no positive information given. When asked if he'd be able to speak, walk etc we were told unable to tell so early. I feel we should have been told. Yes most people with DS do do those things and more but it's impossible to know how amazing he'll be when he's only 3 days old!"*

*"immediate signposting to the incredible charities and communities like PADS would have been a game changer. Instead we were sent home with a single leaflet that looked like it was from the 1980's on caring for a baby with DS. We were totally unprepared for the journey ahead and felt entirely alone once home."*

*"The initial fetal medicine consultants were full of 'I'm sorry', sad faces, sombre etc, they overly medicalised everything and had very limited comprehension of what it would be like raising a child with ds. They also wrote our little one would need life long institutional care in our notes. We should have made a complaint but felt so overwhelmed we couldn't face it."*

*"The general attitude, everything i was told was the worse case outcome and I understand they have to prepare you for what could happens but from the diagnosis is was "I'm sorry you're baby has Down syndrome, they will suffer" not your baby has Down syndrome but with help they can live completely normal fulfilling lives."*

*"I was told my daughter may not walk talk and will struggle and need a lot off support in her life she was newborn and it was devastating took a long time to realise things will be ok"*

*"We also did not receive any literature until the diagnosis was confirmed (days later), so we were left with only what the doctor had told us (mostly the negatives surrounded health) and Google (which was the worst thing ever). The more positive information (e.g. from PADS) would have been better to have seen at an earlier stage…. Even though we had amazing midwives who were incredibly caring and supportive, there was still a lack of information about what this diagnosis actually meant and what our future might be."*

*Was told by Dr in NNU, your baby has DS, when I asked what does that mean for the child (meaning her future) Dr just told me, DS means 3 copies of 21st Chromosome, which didn't really answer my question. When I tearfully told Dr next day that I'd been up all night Googling DS and getting scared, Dr just replied, "Google is not your friend, so only trust NHS websites" , but wasn't offered any information on DS nor that there were support groups available."*

*"I felt scared and lost and had no idea what it meant for my baby. Whilst in hospital my husband and I had to reach out for Google to see what would happen next. We stayed in NICU to establish feeding and wait for the results which took a week to receive. Information by the hospital was drip fed and I had to ask lots of questions."*

*[My experience would have been improved by] "Accurate information on DS; Staff having experience of infants with DS: we had a lot of 'she will never X because she has DS' this stopped us trying breastfeeding for example"*

*"I unfortunately had a very negative experience from health care professionals. I was made to believe that my daughter would be a "burden" I was scaremongered into believing all sorts of horrible things about my baby."*

*"In our two months in NICU, the DS was mentioned again and again in regard to my son's deficiencies and health struggles. Yet nobody offered to speak to me about DS, about the services that we could and should access, about the early intervention that is so vital for little ones with DS. There was much talk of the deficiencies relating to DS but nothing about how we might improve his outcomes or deal with some of the difficulties."*

*"The doctor came and told us at his cot side… We asked if there was any information he could give us about down syndrome and what that meant and he responded with instructions to look on the down syndrome association website….. I struggled with breastfeeding advice and assistance and was told not to get my hopes up as he might never feed off me and not too expect too much from him."*

*"There was nothing about the lived experiences of people with and families of people with Down's syndrome."*

*[My experience would have been improved by] "support from online groups, parents that have been through the same thing . Supportive staff in NICU,staff that didn't under estimate my baby's ability as they told me not to expect him to be able to breast feed. I'm so glad I ignored them but it really affected my mental health and they made me feel like I wasn't doing the best for my baby"*

Parents highlighted the importance of **reassurance they received through connections with other families** of children with Down syndrome, particularly **through charities** such as Positive About Down Syndrome (PADS):

*[What helped me was] "Positive about down syndrome and all the support it offers. Hands down the best resource-so supportive and made life seem like it might be ok. Blog posts and Instagram stories showing what life with DS is like - not the scaremongering/out dated information if you just google"*

*"I found PADs by doing my own research and I am glad I did because they reassured me and made everything seem easier and positive. I didn't get any information at time of diagnosis except being told all the negatives."*

*[What helped me was] "Hearing positive stories from other families who had an unexpected DS diagnosis. At the time I found it hard to see the light and imagine our future."*

*[What helped me was] "PADS; Meeting other families in the same situation - realising we weren't alone and life wasn't over!"*

*"A friend messaged me to say she knew somebody with a boy with DS and arranged for them to send me a Facebook message. It was so nice to hear from somebody who had been where I was and that it wasn't all bad"*

*[What helped me was] "Falling across pads on Facebook. Seeing others journeys and seeing others who are further in their journey gives hope for your own and whilst it doesn't hide the struggles as people talk openly it gives hope for the future and the ability to overcome those struggles."*

*"In the beginning I was in a really bad place. I felt that my life was over, we would never go on holiday again, I would be tied to the child forever and our daughter would be unfairly burdened. When I joined PADS new parents group on Facebook it was so reassuring because so many People ahead of me on the journey said they used to think like this but they and their family are okay, more than okay. They gave me hope that I would come out of the other side. I believed it would be OK and trusted in that before I felt it."*

*"My conversation with other parents of children with DS was probably the most helpful and uplifting. It was so refreshing to discover they were just 'normal' families and that the parents could relate up our anxieties and fears but that they could also reassure us."*

*"Having pads to read up on and the welcome book I recieved really opened my eyes that life will not be restricted just because you have a child with down syndrome"*

*"[local charity] were really supportive and it was nice to see that not everything needed to be 'negative'. They shared with us ways we could support our child and help them with their development."*

*"My sons diagnosis was postnatal, he… was on the NICU very quickly after birth. His nurse that day was a lady who has a grown up daughter with Down syndrome, speaking to her so early on in our journey was massively beneficial to both myself and my partner. I think that all families blessed to be part of the lucky few should meet another parent face to face early on in their journey. The understanding and reassurance aswell as genuine advise she gave us is something I'll never forget and will always be grateful for, it is also something that you could only get from another parent who has been where you are and knows where you are going"*

*"Pads has been fabulous - just awareness of how normal life can be with a child with DS"*

Some parents shared their experiences of **healthcare professionals providing reassurance, or facilitating connections** to other families:

*"We cannot fault the care we were given when we were told our son may have Down syndrome a few hours after his birth. Every health professional that came to see us in hospital and at home always congratulated us on the birth of our son before they said anything else. No negative language was ever used and I clearly remember the paediatrician in the hospital reassuring me that first and foremost our son was [child's name] and absolutely beautiful. We know we were very lucky to have had such a positive experience."*

*"Consultant was very clear that there was no doubt he definitely had DS. She didn't present the news negatively and told us life wouldn't be so different. The midwife told me to pick up my baby and cuddle him when I got upset as he was the same baby he was 5 minutes ago before I got the news which helped."*

*"My obstetrician told me of one of her cousins children who had DS and how lovely she is etc. The obst really tried to encourage me to join groups, they were very positive"*

*"I was told that my child was like any other baby that needed love, attention, feeding etc. This made me feel better about my next stage with my child."*

*"the health visitor put me in touch with a mum who had a toddler with Down syndrome which helped with our expectations"*

# 4. Conclusions

## 4.1. Conclusions

The aim of this research was to investigate and describe the experiences that mothers have had of mental health support during their pregnancy and after the birth of their child with Down syndrome.

The key finding of this research is that **the majority of mothers felt there was not enough support available for their mental wellbeing,** both prenatally and postnatally. 34.5% of mothers felt there was enough support for their mental wellbeing during pregnancy, while 26.2% felt there was enough support for them after their baby with Down syndrome was born.

Over one third of respondents (37.6%) felt that the attitude of healthcare professionals towards their baby having Down syndrome had had a negative impact on their mental wellbeing. Fewer than one third of respondents (31.4%) reported that they were given enough reassurance about the future for themselves, their baby and their family.

In written responses, mothers who had received a higher chance screening result or prenatal diagnosis recounted that they had needed someone to talk to and to answer their questions, but this was not available. Some mothers also highlighted a sense that support was not offered because they had declined further testing or chosen to continue their pregnancy, with professionals mistakenly assuming that they were not having difficulty adjusting to the news. On the other hand, an important aspect of prenatal support for many who had positive experiences was feeling that their decisions were supported by healthcare professionals.

Concerning the period after their baby’s birth, respondents who received a postnatal diagnosis highlighted that they needed support to help them process the significant news, but this was not available. Several mothers highlighted that a lack of support at this time made them feel alone or isolated. There were a number of interactions recounted when healthcare professionals displayed insensitivity or inconsideration for respondents’ emotional wellbeing, which had a substantial impact on them as new mothers. Support after birth that was described positively, on the other hand, was often characterized by healthcare professionals displaying kindness and compassion for parents as they processed the unexpected news.

Concerning mental health support both during and after pregnancy, respondents repeatedly highlighted the importance of being able to connect with other families of a child with Down syndrome. This alleviated feelings of isolation and provided access to positive narratives and hope for the future. These connections were largely facilitated by charities and frequently as a result of mothers’ own research to find organisations online, often much later in their journey than they would have liked. Indeed, a consistent feature of respondents’ written accounts was the impetus being on them to research and find their own support, since healthcare practitioners were unable to provide or signpost to this.

Each year, the Care Quality Commission conducts a national Maternity Survey of women receiving NHS maternity care in England, which includes a question about mental health support during pregnancy. In 2022, 85% of women who completed this survey reported receiving enough support for their mental health during their pregnancy (Care Quality Commission, 2023). The comparative figure from the current survey, excluding respondents who answered ‘*Not sure,’* was 38.1%.

## 4.2. Limitations

This study has a number of limitations which are important to consider when interpreting the findings.

The survey was only available online and took approximately 20 minutes to complete. The sample is therefore comprised of participants who were able to access the internet and find the time to complete the questions. We know that time pressures can be significant for parents of a young child with Down syndrome and we may not have captured the views of those with the highest demands on their time.

Participants were recruited by charities supporting parents of children with disabilities, primarily by the charity Positive About Down Syndrome. Therefore all mothers in our sample are already in contact with organisations who can offer them support. The findings may not reflect the experiences of mothers who do not have connections with supportive charities.

Similarly, relative to the general population, the sample contains a high proportion of respondents who are white and university-educated. We cannot assume that the current findings can be applied to those from other sociodemographic backgrounds.

It is important to note that this survey reflects only the experiences of mothers who have had a baby with Down syndrome. As noted, a large proportion of expectant mothers who receive a prenatal diagnosis of Down syndrome go on to have a pregnancy termination. The maternity healthcare experiences of these women is a crucial consideration and may differ in significant ways from those represented in the present research.

Finally, as a number of respondents have noted, their experiences were often diverse, with exemplary care provided by many healthcare professionals, despite other interactions perhaps being less supportive. The survey format is limited in its ability to capture this diversity.

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