

# **Experiences of Women with Long-Term Disabilities, Illnesses or Conditions in their Journey through Maternity Services in Ireland**

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Údarás Náisiúnta Míchumais  
National Disability Authority

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## List of Acronyms

ADMA	Assisted Decision-Making (Capacity) Act 2015
CEUD	Centre for Excellence in Universal Design
CHO	Community Healthcare Organisation
CQC	Care Quality Commission
DOH	Department of Health
HCP	Health Care Professionals
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
ICGP	Irish College of General Practitioners
ISL	Irish Sign Language
NALA	National Adult Literacy Agency
NDA	National Disability Authority
NDIS	National Disability Inclusion Strategy
NMBI	Nursing and Midwifery Board of Ireland
NMES	National Maternity Experience Survey
NUIG	National University of Ireland Galway
NWCI	National Women's Council of Ireland
NWIHP	National Women and Infants Health Programme
OPW	Office of Public Works
PHNs	Public Health Nurses
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

## Executive Summary

### Background

The first National Maternity Experience Survey (NMES) took place in 2020, providing mothers with an opportunity to report on their experiences of care in Ireland's maternity services. This survey was led by the Health Information and Quality Authority (HIQA) and is part of the National Care Experience Programme, an initiative by HIQA, the Health Service Executive (HSE) and the Department of Health (DOH). During the development of NMES, the National Disability Authority (NDA) worked with HIQA to formulate a question to enable survey respondents to report if they had a long-term disability, illness or condition. The NDA particularly welcome the inclusion of this question as it has enabled the present research. There has been a suite of reports published from NMES on women's maternity experiences at national and local level, as well as quality improvement plans based on the survey's findings for all 19 maternity hospitals/units and nine CHO areas.<sup>1</sup>

This report uses NMES data to focus on the maternity care experiences of women with long-term disabilities, illnesses or conditions and is intended to complement the NMES publications. It fulfils the NDA's commitment under the Department of Children, Equality, Disability, Integration and Youth's (DCEDIY's)<sup>2</sup> National Strategy for Women and Girls 2017-2020<sup>3</sup> to "Undertake further research to guide maternity services and supports for women with disabilities during and post pregnancy" (Action 2.20). To date, there have been no NMES reports examining the experiences of women with disabilities.

This report builds on work commissioned by the NDA, in partnership with the National Women's Council of Ireland (NWCII), in 2007. The output from that work was a series of research projects into the strengths and weaknesses of

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<sup>1</sup> See <https://yourexperience.ie/maternity/about-the-survey/> for information on survey and all publications.

<sup>2</sup> Under the previous government, the Department of Justice and Equality were responsible for this Strategy..

<sup>3</sup> Department of Justice and Equality. (2017). National strategy for women and girls 2017-2020. Retrieved from [http://policereform.ie/en/JELR/National\\_Strategy\\_for\\_Women\\_and\\_Girls\\_2017\\_-\\_2020.pdf/Files/National\\_Strategy\\_for\\_Women\\_and\\_Girls\\_2017\\_-\\_2020.pdf](http://policereform.ie/en/JELR/National_Strategy_for_Women_and_Girls_2017_-_2020.pdf/Files/National_Strategy_for_Women_and_Girls_2017_-_2020.pdf)

publicly funded Irish maternity services for women with disabilities.<sup>4 5 6</sup> This work identified a range of challenges for women with disabilities in their access to and experience of healthcare during and after pregnancy and set out recommendations for improvements. In the period since then, particularly in the last five years, there have been a number of significant national milestones in the area of maternity services. These include Ireland's first National Maternity Strategy<sup>7</sup>, the first set of National Standards for Safer Better Maternity Care<sup>8</sup> and HIQA's programme of monitoring these Standards<sup>9</sup>, the development of a model of care for specialist perinatal mental health services<sup>10</sup> and the first National Standards for Antenatal Education<sup>11</sup>.

The aim of this study was to use the NMES 2020 data to describe the experiences of a sample of women with long-term disabilities, illnesses or conditions of maternity services in Ireland and to compare these experiences to a sample of women without disabilities, illnesses or conditions. The overall purpose of this project is to provide policy and practice-relevant research findings on the service and support needs of women with disabilities in maternity services. It is

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<sup>4</sup> Begley et al. (2009a) Women with disabilities: Barriers and facilitators to accessing services during pregnancy, childbirth and early motherhood. Retrieved from <http://nda.ie/File-upload/literaturereview1.pdf>

<sup>5</sup> Begley et al. (2009b) Women with disabilities: Policies governing procedure and practice in service provision in Ireland during pregnancy, childbirth and early motherhood. Retrieved from <http://nda.ie/File-upload/policyreport1.pdf>

<sup>6</sup> Begley et al. (2010). The strengths and weaknesses of publicly-funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth and early motherhood. Retrieved from [http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20\\_full\\_%2018th%20may%202010.pdf](http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20_full_%2018th%20may%202010.pdf)

<sup>7</sup> Department of Health. (2016) National maternity strategy. Creating a better future together. 2016 – 2026. Retrieved from <https://assets.gov.ie/18835/ac61fd2b66164349a1547110d4b0003f.pdf>

<sup>8</sup> HIQA. (2016) National standards for safer better maternity services. Retrieved from <https://www.hiqa.ie/sites/default/files/2017-02/national-standards-maternity-services.pdf>

<sup>9</sup> HIQA. (2020) Overview report of HIQA's monitoring programme against the national standards for safer better maternity services, with a focus on obstetric emergencies. Retrieved from <https://www.hiqa.ie/sites/default/files/2020-02/Maternity-Overview-Report.pdf>

<sup>10</sup> HSE. (2017) Specialist perinatal mental health services. Model of care for Ireland. Retrieved from <https://www.hse.ie/eng/services/list/4/mental-health-services/specialist-perinatal-mental-health/specialist-perinatal-mental-health-services-model-of-care-2017.pdf>

<sup>11</sup> HSE. (2020) National standards for antenatal education in Ireland. Retrieved from <https://www.hse.ie/eng/about/who/healthwellbeing/our-priority-programmes/child-health-and-wellbeing/antenatal-ed.pdf>



important to note that in this report we treat a group of women with a range of disabilities, illnesses or conditions as one group. This approach does not acknowledge the diversity of these women, but it does serve to examine the experiences of a group of women who would be most in need of woman-centred maternity care.

## Methodology

This report was based on secondary data analysis of NMES survey data.<sup>12</sup> The target sample for NMES was mothers aged 16 or over, living in Ireland, who had given birth in October or November 2019. Eligible mothers were contacted by post in February and March 2020 with an invitation to take part and an online link to the survey. Out of 6,357 mothers who were eligible to participate, 50% (n=3,204) completed the survey. Out of this sample, 217 (6.8%) reported that they had a long-term disability, illness or condition.<sup>13</sup> The most common condition was a mental health, psychological or emotional condition reported by over half (57.6%) of these respondents.

The survey included 68 questions pertaining to mothers and their experiences through the full pathway of maternity care, including antenatal care, care during labour and birth, care in hospital after birth, specialised care if their baby was in a neonatal unit, care for feeding their baby, care at home after birth, and their overall experience of maternity care.

Preliminary analyses were conducted to ensure characteristics of those with and without long-term disabilities (for example, their ages) were similar. Any differences were controlled for in the main analyses. Due to such a large proportion of those with a long-term disability having a mental health condition, tests were also conducted to examine whether their experiences were similar to those with other long-term disabilities. Out of 49 tests, there was only one statistically significant<sup>14</sup> difference in experience between those with and without

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<sup>12</sup> See [https://staging.yourexperience.ie/wp-content/uploads/2020/11/NMES\\_Technical\\_Report\\_2020\\_Final.pdf](https://staging.yourexperience.ie/wp-content/uploads/2020/11/NMES_Technical_Report_2020_Final.pdf) for information on the methodology of NMES 2020.

<sup>13</sup> The term 'long-term disability' will be used throughout the report, but is inclusive of other conditions and chronic illnesses reported by respondents. This is for the purpose of brevity but it is acknowledged that not all respondents in this group would identify as having a disability.

<sup>14</sup> In this report, *p* values less than 0.05 are considered statistically significant. A value less than 0.05 means, for example, if our data is suggesting that there is a difference in mean scores given to maternity experiences by women with and without a disability, the probability of these findings occurring due to chance is less than 5%. This gives us a sufficient level of confidence to conclude that these are real, not random, differences.

mental health conditions. This confirmed it was appropriate to treat all those with a long-term disability as one group, for the purposes of this report. The main analyses involved descriptive statistics to describe the maternity care experiences of the women with disabilities who participated in NMES on their individual experiences within the six areas of care<sup>15</sup> and overall. A series of multiple regressions were then conducted to identify whether there were any differences in experiences of maternity care by those with and without long-term disabilities. The two factors which were found to be different between women with and without disabilities, maternal age and type of maternity care, were controlled for in these regressions.

## **Key findings**

Almost nine in ten respondents who reported a long-term disability had one disability, while just over one in ten reported two or more disabilities. Over half (57.6%) of respondents reporting a disability had a mental health, psychological or emotional condition, while over one quarter had another disability or chronic illness (not specified).

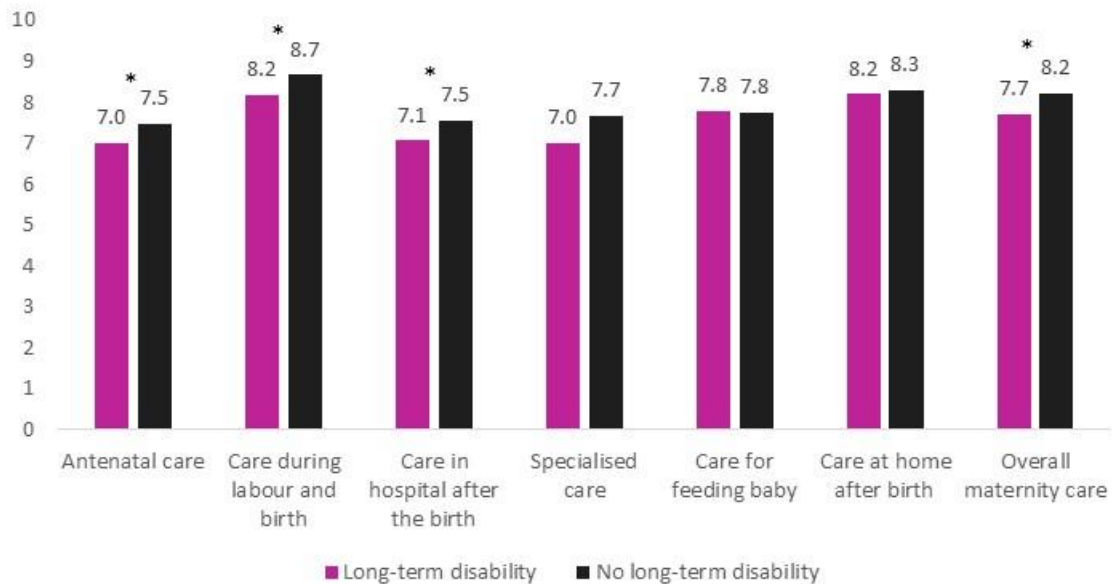
There were many similarities between the maternity care experiences of those with and without disabilities. In addition, nearly all of the most and least positive experiences for both groups of women in each area of care and across the entire maternity pathway were the same. Figure ES.I displays the mean scores for the overall experiences of women with and without a disability for each area of maternity care. The areas asterisked indicate where there were statistically significant differences in the experiences of the two groups. Women with a disability reported significantly<sup>16</sup> less positive experiences overall in their antenatal care, in their care during labour and birth, in their care in hospital after birth, and in their overall maternity care.

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<sup>15</sup> Antenatal care, care during labour and birth, care in hospital after birth, specialised care, care for feeding, and care at home after birth.

<sup>16</sup> The term 'significantly' in this report refers to statistical significance.

**Figure ESI. Overall experiences of women with and without a long-term disability in each area of maternity care**



\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

In the area of antenatal care there was a significant association between having a long-term disability or not and whether women were offered a choice in their care. Those with a long-term disability were more likely not to be able to have a choice of care due to medical conditions (14.3%) compared to women without disabilities (4.7%). Women with disabilities were less likely to do antenatal classes (48.8% were offered them and didn't do them compared to 40.1% of those without disabilities). Women with disabilities reported significantly lower mean scores than women without disabilities on: feeling treated with respect and dignity, having their questions answered in a way that they could understand, having confidence and trust in the health care professionals treating/caring for them, feeling involved in decisions on their care, and receiving enough information about physical changes in their body in pregnancy.

In relation to care during labour and birth, women with a disability reported significantly lower mean scores than women without a disability on: having their partner/companion involved in their care during labour and birth as much as they wanted, having skin-to-skin contact with their baby shortly after birth, and having their questions answered in an understandable way.

With regard to care in hospital after the birth women with a disability reported significantly lower mean scores compared to women without a disability on: being told who to contact if they were worried about their health or their baby's health after discharge, feeling that their questions were answered in a way they

could understand, feeling treated with respect and dignity, being given information on their physical recovery, and feeling involved in decisions about their care after birth.

Newborns of women with a long-term disability were more likely to spend time in a neonatal unit (25.8%) compared to those without a long-term disability (16.9%) There were no significant differences between the experiences of those with and without long-term disabilities with regard to specialised care in the neonatal unit.

Women with a disability were less likely to exclusively breastfeed compared to women without a disability (30.4% vs 42.7%). There were no significant differences between the experiences reported by those with and without long-term disabilities on care for feeding their baby.

With regard to care at home after the birth, women with a disability reported a significantly lower mean score on feeling involved in decisions on their care at home compared to women without a disability.

Where the experiences of women with and without disabilities significantly differed, the experiences of those with disabilities were still generally quite positive-just not as positive as those without disabilities.

## **Conclusion**

The 2020 National Maternity Experience Survey has for the first time enabled a national comparison of the maternity experiences of women with and without disabilities in Ireland. This report has found that women with disabilities generally had quite positive maternity experiences and the areas where they reported particularly strong or weak care were largely the same as those without disabilities. However, they did report less positive care experiences than those without disabilities in a number of areas. These differences did not indicate that women with disabilities had negative care experiences in these areas, rather they suggested perhaps subtle differences in the dynamic of the relationship with their healthcare providers and in the care they received.

These findings are similar to those from the English national maternity survey, in that while women with disabilities had mostly positive experiences, they did have poorer perceptions of their experiences compared to women without disabilities with regard to communication, involvement in decisions, feeling respected, getting enough information on physical recovery and having confidence and trust

in their healthcare providers.<sup>17</sup> The NMES survey did not cover most of the areas raised as weaknesses in care identified in the previous NDA and NWCI work<sup>18</sup>, however issues around communication and information provision were also apparent in this study so some improvements are still needed in those areas.

Differences in care experiences may be due to differing perceptions of care as a result of varying expectations or previous experiences with the health service. And there may also be real differences in the care provided to women due to the knowledge, attitudes and behaviour of healthcare staff, available resources and the culture of a workplace. As healthcare staff were not part of this survey it was not possible to explore this as a possible reason for differences in care experiences.

Only 6.8% of respondents to NMES reported a long-term disability, illness or condition and due to small numbers, it was not possible to report on the experiences of those with specific disabilities, illnesses or conditions. It is also not possible to know how representative the 217 women with a long-term disability who responded to NMES were in relation to all women with a disability who gave birth during the survey's eligible time period.

The NDA welcome plans for a National Maternity Experience Survey in 2022 which will show the progress that has been made in maternity services to bring them closer to the vision of the National Maternity Strategy. A particularly positive aspect of NMES, and the National Care Experience Programme, is that the HSE, maternity services and CHO areas have responded to the feedback from mothers through developing comprehensive national and local quality improvement plans.<sup>19</sup> This report outlines ways in which these plans can adequately address the needs of women with disabilities. The recommendations made in this report are based on the findings in the survey where women with disabilities have reported quite negative experiences or in areas where women with disabilities reported less positive experiences than women without

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<sup>17</sup> Malouf, R., Henderson, J., and Redshaw, M. (2017) Access and quality of maternity care for disabled women during pregnancy, birth and the postnatal period in England: data from a national survey. *BMJ Open*, 7(e016757).

<sup>18</sup> Begley et al. (2010). The strengths and weaknesses of publicly-funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth and early motherhood. Retrieved from [http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20\\_full\\_%2018th%20may%202010.pdf](http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20_full_%2018th%20may%202010.pdf)

<sup>19</sup> HSE. (2020) Listening, responding, and improving. The HSE response to the findings of the national maternity experience survey. Retrieved from <https://www.hse.ie/eng/services/publications/hse-response-to-the-findings-of-the-national-maternity-experience-survey-2020.pdf>

disabilities. These recommendations are limited in that they are not based on the expressed needs of the women who participated in NMES. Furthermore, while the NMES survey has enabled us to examine the different experiences of women with and without disabilities, we are unable to explore the impact on women's health and wellbeing of these different experiences. As a result, the NDA commits to undertaking further work with women with disabilities on their maternity care needs.

Implementation of the following recommendations can help to ensure that maternity services meet the specific needs of women with disabilities, otherwise the proposed quality improvement initiatives may serve to perpetuate or exacerbate existing differences in the care experiences of those with and without disabilities. As with all initiatives targeting women with disabilities, the NDA advises that best practice is to consult with or co-design with these women in the creation of accessible materials and services. What underpins most of these recommendations is improving how healthcare professionals communicate with and relate to women with disabilities or additional care needs, as well as ensuring information is provided to women in an accessible way. Improvements in these areas would help to address many of the issues identified for women with disabilities in this report. These recommendations suggest that stakeholders refer to the following two documents the NDA have been involved in developing, which can provide guidance on ensuring accessible communication and information provision to service users:

- The NDA and HSE's National Guidelines on Accessible Health and Social Care Services which include information on tailoring communication to people with different types of disabilities.<sup>20</sup>
- The NDA's Centre for Excellence in Universal Design's (CEUD's) revised Customer Communications Toolkit for the Public Service.<sup>21</sup> This Toolkit provides guidance for designing and procuring communications using a Universal Design approach to ensure accessibility and covers written, spoken, signed and digital communication. Universal Design is about creating an

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<sup>20</sup> HSE and NDA. (2014) National guidelines on accessible health and social care services. Retrieved from <https://www.hse.ie/eng/services/yourhealthservice/access/natguideaccessibleservices/natguideaccessibleservices.pdf>

<sup>21</sup> NDA and DPER. (2019) Customer communications toolkit for the public service. Retrieved from <http://universaldesign.ie/products-services/customer-communications-toolkit-for-the-public-service-a-universal-design-approach/customer-communications-toolkit-for-the-public-services-a-universal-design-approach.pdf>

environment that can be accessed, understood and used to the greatest extent possible by all people, regardless of their age, size, ability or disability.

### **Statutory duties in providing maternity services to women with disabilities:**

The NDA remind the HSE of their statutory duties under the following legislation:

- The Disability Act 2005: to ensure access to maternity services for people with disabilities.
- The Irish Sign Language Act 2017: to provide access to maternity services through ISL for members of the Deaf or hard-of-hearing community who are ISL signers.
- The EU Web Accessibility Directive: to ensure websites and applications are accessible to persons with disabilities (e.g., [www.mychild.ie](http://www.mychild.ie) and any future mobile phone application for pregnancy).
- The Assisted Decision Making (Capacity) Act 2015: services will be required to adopt new policies and procedures in how they involve women who may lack capacity, to make decisions on their maternity healthcare.

### **To ensure accessible communication for all women throughout the maternity pathway:**

- The NDA advise the National Healthcare Communication Programme to ensure that it incorporates the use of the National Guidelines on Accessible Health and Social Care Services and the Customer Communications Toolkit for the Public Service in its modules.
- The NDA advise the ICGP and the Nursing and Midwifery Board of Ireland to consider specific training in accessible communication and information provision for GPs and for practice nurses/midwives who are main contacts for women in the antenatal and postnatal periods.
- The NDA would encourage the National Clinical Programme for Neonatology that any communications skills training undertaken by staff working in neonatology will include accessible communication with service users with disabilities.

### **To ensure accessible information provision to women throughout the maternity pathway:**

The NDA advise the incorporation of the National Guidelines on Accessible Health and Social Care Services and the Customer Communications Toolkit for the Public Service into the following resources to ensure accessibility for all:

- Antenatal education classes and resources

- The My Pregnancy and My Child resources
- The Specialist Perinatal Mental Health Services' series of mental health information leaflets
- The 'Safer to Ask' leaflet series.

**To ensure care is tailored to the needs of women with disabilities, and that they are treated with respect and dignity, and are involved in decisions in their care to the same extent as those without disabilities:**

- The NDA advise that maternity hospitals/units facilitate healthcare staff to undergo disability competence training.
- The NDA advise that CHO areas facilitate PHNs to undergo disability competence training.

**To ensure women with disabilities have equal opportunities to receive beneficial hospital practices:**

- The NDA advise that maternity hospitals/units give all women an equal opportunity for skin-to-skin contact shortly after birth, regardless of disability status or choice of feeding method.
- The NDA advise the HSE's National Breastfeeding Implementation Group and maternity hospitals/units that a future national audit of National Breastfeeding Standards be focussed on women with disabilities to ensure that all standards are being met in their care and support for breastfeeding.

**To ensure accessibility standards are inclusive of those with sensory disabilities:**

- The NDA encourage HIQA to consider the needs of those with sensory disabilities in Standard 2.7 of the National Standards for Safer Better Maternity Care.
- The NDA advise the National Women and Infants Health Programme that the implementation of Antenatal Education Standard 2.2 be extended to include those with sensory disabilities.

**To ensure accessibility to maternity hospitals/units for all:**

- The NDA encourage the HSE and Hospital Groups to adopt a Universal Design approach in the design or redesign of maternity hospitals/units to ensure accessibility for all.

**To encourage the participation of women with disabilities in the National Maternity Experience Survey 2022:**

- The NDA advises that the National Care Experience Programme ensure their future surveys are made accessible for all and suggest The Customer Communications Toolkit for the Public Service as a useful resource.



## Introduction

In 2007, the National Disability Authority (NDA), in partnership with the National Women's Council of Ireland (NWC), commissioned a series of research projects into the strengths and weaknesses of publicly funded Irish maternity services for women with disabilities.<sup>22 23 24</sup> This work identified a range of challenges for women with disabilities in their access to, and experience of, healthcare during and after pregnancy and set out recommendations for improvements. In the period since then, there have been a number of significant national milestones in the area of maternity services. These include:

- Ireland's first National Maternity Strategy<sup>25</sup> in 2016,
- the first set of National Standards for Safer Better Maternity Care<sup>26</sup> in 2016,
- the Health Information and Quality Authority's (HIQA's) first programme of monitoring these Standards<sup>27</sup> in 2018 and 2019,
- development of a model of care for specialist perinatal mental health services in 2017<sup>28</sup>, and

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<sup>22</sup> Begley et al. (2009a) Women with disabilities: Barriers and facilitators to accessing services during pregnancy, childbirth and early motherhood. Retrieved from <http://nda.ie/File-upload/literaturereview1.pdf>

<sup>23</sup> Begley et al. (2009b) Women with disabilities: Policies governing procedure and practice in service provision in Ireland during pregnancy, childbirth and early motherhood. Retrieved from <http://nda.ie/File-upload/policyreport1.pdf>

<sup>24</sup> Begley et al. (2010). The strengths and weaknesses of publicly-funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth and early motherhood. Retrieved from [http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20\\_full\\_%2018th%20may%202010.pdf](http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20_full_%2018th%20may%202010.pdf)

<sup>25</sup> Department of Health. (2016) National maternity strategy. Creating a better future together. 2016 – 2026. Retrieved from <https://assets.gov.ie/18835/ac61fd2b66164349a1547110d4b0003f.pdf>

<sup>26</sup> HIQA. (2016) National standards for safer better maternity services. Retrieved from <https://www.hiqa.ie/sites/default/files/2017-02/national-standards-maternity-services.pdf>

<sup>27</sup> HIQA. (2020) Overview report of HIQA's monitoring programme against the national standards for safer better maternity services, with a focus on obstetric emergencies. Retrieved from <https://www.hiqa.ie/sites/default/files/2020-02/Maternity-Overview-Report.pdf>

<sup>28</sup> HSE. (2017) Specialist perinatal mental health services. Model of care for Ireland. Retrieved from <https://www.hse.ie/eng/services/list/4/mental-health-services/specialist-perinatal-mental-health/specialist-perinatal-mental-health-services-model-of-care-2017.pdf>

- the first National Standards for Antenatal Education<sup>29</sup> in 2020.

In relation to the lives of persons with disabilities more generally, a key development has been Ireland's ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)<sup>30</sup> in 2018.

The first National Maternity Experience Survey (NMES) also took place in 2020, providing mothers with an opportunity to report on their experiences of care from the antenatal to the postnatal period in Ireland's maternity services. This was part of the National Care Experience Programme, an initiative by HIQA, the Health Service Executive (HSE) and the Department of Health (DOH), which captures feedback on people's health and social care experiences in order to improve the quality of these services in Ireland. There has been a suite of reports published from NMES on women's maternity experiences at national and local level, as well as quality improvement plans based on the survey's findings for all 19 maternity hospitals/units and nine CHO areas.<sup>31</sup> Most of the mothers who responded to NMES had a positive maternity care experience, although 15% of them rated their experience as 'fair to poor'.<sup>32</sup> Areas which needed particular improvement included information around mental health during and after pregnancy and giving mothers an opportunity to debrief following birth.

This report focuses on the maternity care experiences of women with disabilities and is intended to complement the NMES publications. It is based on the NDA's commitment under the Department of Children, Equality, Disability, Integration and Youth's (DCEDIY)<sup>33</sup> National Strategy for Women and Girls 2017-2020<sup>34</sup> to

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<sup>29</sup> HSE. (2020) National standards for antenatal education in Ireland. Retrieved from <https://www.hse.ie/eng/about/who/healthwellbeing/our-priority-programmes/child-health-and-wellbeing/antenatal-ed.pdf>

<sup>30</sup> United Nations. (2006) Convention on the rights of persons with disabilities and optional protocol. Retrieved from <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

<sup>31</sup> See <https://yourexperience.ie/maternity/about-the-survey/> for information on survey and all publications.

<sup>32</sup> NMES. (2020) Findings of the national maternity experience survey 2020. Retrieved from <https://yourexperience.ie/wp-content/uploads/2020/09/National-Maternity-Experience-Survey-results.pdf>

<sup>33</sup> Under the previous government, the Department of Justice and Equality were responsible for this Strategy.

<sup>34</sup> Department of Justice and Equality. (2017). National strategy for women and girls 2017-2020. Retrieved from [http://policereform.ie/en/JELR/National\\_Strategy\\_for\\_Women\\_and\\_Girls\\_2017\\_-\\_2020.pdf/Files/National\\_Strategy\\_for\\_Women\\_and\\_Girls\\_2017\\_-\\_2020.pdf](http://policereform.ie/en/JELR/National_Strategy_for_Women_and_Girls_2017_-_2020.pdf/Files/National_Strategy_for_Women_and_Girls_2017_-_2020.pdf)

“Undertake further research to guide maternity services and supports for women with disabilities during and post pregnancy” (Action 2.20). To date, there have been no NMES reports examining the experiences of women with disabilities. It is particularly important to consider their experiences, as typically there has been limited research conducted into the lived experiences of women with disabilities across pregnancy, birth and motherhood.<sup>35 36</sup> Previous research has also shown they face more challenges in their access to and experience of maternity healthcare than women without disabilities.<sup>37 38</sup> This report will use the data from NMES to describe the maternity experiences of women with long-term disabilities, illnesses or conditions<sup>39</sup> and compare them to the experiences of women without disabilities, illnesses or conditions. The purpose of this work is to provide policy and practice-relevant research findings on the service and support needs of women with disabilities in maternity services.

This report is outlined as follows:

- The next section firstly describes the findings of the previous NDA and NWCI work on the strengths and weaknesses of publicly funded Irish maternity services for women with disabilities. It then provides a summary of findings on the maternity experiences of women with disabilities from several national maternity surveys in the UK. Finally, it outlines recent key national changes to maternity services and the disability landscape in Ireland.
- The Methodology section summarises the method of the National Maternity Experience Survey, describes how the NMES data was accessed and outlines the analytic strategy used in this report.
- The Results section describes the results of the analyses of the NMES data. It firstly reports on characteristics of the respondents and their type of care and

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<sup>35</sup> Walsh-Gallagher, D., Sinclair, M., and McConkey, R. (2012) The ambiguity of disabled women’s experiences of pregnancy, childbirth and motherhood: A phenomenological understanding. *Midwifery*, 28, pp.156-162.

<sup>36</sup> Redshaw, M., Malouf, R., Gao, H., and Gray, R. (2013) Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period. *BMC Pregnancy and Childbirth*, 13, pp.1-14.

<sup>37</sup> Begley et al. (2010). The strengths and weaknesses of publicly-funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth and early motherhood. Retrieved from [http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20\\_full\\_%2018th%20may%202010.pdf](http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20_full_%2018th%20may%202010.pdf)

<sup>38</sup> Malouf, R., Henderson, J., and Redshaw, M. (2017) Access and quality of maternity care for disabled women during pregnancy, birth and the postnatal period in England: data from a national survey. *BMJ Open*, 7(e016757).

<sup>39</sup> Of the total NMES sample of 3,204, 6.8% of the women (n=217) indicated that they had a long-term disability, illness or condition.

birth. It then describes the maternity experiences of women with disabilities and compares them to the experiences of women without disabilities across the maternity pathway: in their choice of care, during the antenatal period, during labour and birth, while in hospital after birth, if their baby had been in a neonatal unit, while feeding their baby and at home after the birth.

- The Discussion section discusses the findings, implications and limitations of this report and makes recommendations to improve the maternity care experiences of women with disabilities in Ireland.

## Summary of Literature and Recent Maternity and Disability Milestones in Ireland

### Maternity care experiences of women with disabilities

#### Previous NDA and NWCI research into maternity experiences of women with disabilities

The work commissioned by the NDA in partnership with the NWCI, into the strengths and weaknesses of publicly funded Irish maternity services for women with disabilities was conducted by researchers from the School of Nursing and Midwifery in Trinity College, Dublin. This work consisted of three reports published in 2009 and 2010.<sup>40 41 42</sup> This was a notable piece of work, especially at that time, given the dearth of research into the lived experiences of women with disabilities across pregnancy, birth and motherhood.<sup>43 44</sup>

The literature review for this study found that childbirth in Ireland and other Western countries had become increasingly medicalised, meaning in turn that women's individual experiences were less of a priority.<sup>45</sup> The authors noted that this may have particularly disadvantaged women with disabilities by having them viewed only through a medical lens. The review demonstrated a history of discrimination against women with disabilities, finding their sexual and reproductive lives to have been negatively impacted by the attitudes and control

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<sup>40</sup> Begley et al. (2009a) Women with disabilities: Barriers and facilitators to accessing services during pregnancy, childbirth and early motherhood. Retrieved from <http://nda.ie/File-upload/literaturereview1.pdf>

<sup>41</sup> Begley et al. (2009b) Women with disabilities: Policies governing procedure and practice in service provision in Ireland during pregnancy, childbirth and early motherhood. Retrieved from <http://nda.ie/File-upload/policyreport1.pdf>

<sup>42</sup> Begley et al. (2010). The strengths and weaknesses of publicly-funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth and early motherhood. Retrieved from [http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20\\_full\\_%2018th%20may%202010.pdf](http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20_full_%2018th%20may%202010.pdf)

<sup>43</sup> Walsh-Gallagher, D., Sinclair, M., and McConkey, R. (2012) The ambiguity of disabled women's experiences of pregnancy, childbirth and motherhood: A phenomenological understanding. *Midwifery*, 28, pp.156-162.

<sup>44</sup> Redshaw, M., Malouf, R., Gao, H., and Gray, R. (2013) Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period. *BMC Pregnancy and Childbirth*, 13, pp.1-14.

<sup>45</sup> Begley et al. (2009a) Women with disabilities: Barriers and facilitators to accessing services during pregnancy, childbirth and early motherhood. Retrieved from <http://nda.ie/File-upload/literaturereview1.pdf>

of society. This study explored the views and experiences of 78 women with disabilities<sup>46</sup> of services they received during pregnancy, childbirth and early motherhood in Ireland, and also gathered insight from 30 health professionals and service providers.<sup>47</sup> The results indicated that women had a range of experiences influenced by a number of factors. These factors included the knowledge, attitudes and behaviours of the health professionals caring for them, how they were communicated with, services available where they lived and the infrastructure and physical environment where services were based. While mostly weaknesses in care were reported, some mothers also reported strengths in the care they received. These included the availability of specialist mental health services in two maternity units, the community mental health team in one area, occasions when staff treated women sensitively and with respect, when staff showed understanding of the woman's disability, when staff communicated with them appropriately, and when care was tailored to women's needs, for example, by sourcing necessary equipment.

On the other hand, key weaknesses in the maternity system reported by women with disabilities included the availability of services, their choice of care, the infrastructure and physical environment, staff knowledge on disability, feeling stigmatised by some health professionals, and in particular, communication and information provision. These are described in more detail below:

**Availability of services:** Respondents felt that available services were fragmented and uncoordinated and due to a lack of continuity of care, women had to keep repeating their history to whoever was treating them. It was reported that there was not enough linkage between maternity, community services and disability service providers to provide appropriate care, and not enough resources in the community after discharge to provide equipment and support for independence. For those with physical and sensory disabilities, a lack of local care as well as inflexible appointment times meant travelling to services was difficult.

Some of the mothers had no access to specialist services – specifically, only 2 of the 19 units provided access to specialist mental health services and there were no specialist services available for those with intellectual disability. Those with

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<sup>46</sup> 78 women included, 20 in the mental health strand, 18 each in the physical disability, hearing impairment, vision impairment groups and 4 in the intellectual disability strand of the study.

<sup>47</sup> Begley et al. (2010). The strengths and weaknesses of publicly-funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth and early motherhood. Retrieved from

[http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20\\_full\\_%2018th%20may%202010.pdf](http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20_full_%2018th%20may%202010.pdf)

intellectual disability were supported by social and support workers, not through the maternity system.

**Choice of care:** Participating women reported that their choice of care in some cases was limited by a lack of resources and sometimes restricted by the opinions of professionals, who overruled mothers' preferences. Experiences reported by participants also indicated that there was a lack of person-centred care within the maternity system.

**Infrastructure and physical environment:** The ageing infrastructures of the three maternity hospitals in Dublin were raised as issues by some participants, as were specific issues in the physical environment which impacted on women's experience and independence, including areas where reception desks were too high for wheelchair users and examination tables or baby cots which were not height adjustable.

**Staff knowledge:** In some cases, it was felt that staff lacked knowledge or understanding about particular disabilities which impacted on how they cared for women. It was reported that some women felt professionals placed unwelcome focus on the woman's disability with regard to its potential impact on the child such as the child inheriting the condition. A number of women across all types of disability felt that their capacity to care for their child was under scrutiny by health professionals and mothers with mental health issues or intellectual disability were frightened that they would lose custody of their child. While health professionals were likely to be following protocol in their assessments and observation of women, what is evident is that these women did not feel reassured or supported during this process. Women with mental health issues also reported a lack of understanding of their distress and received inconsistent advice about medication.

**Staff attitudes:** The attitudes of some health professionals impacted negatively on the experience of mothers. Some of the participants felt they were treated without empathy, and "recalled caregivers that were insensitive, inappropriate, stigmatising and discriminatory".<sup>48</sup>

**Communication:** The study found that communication was considered a major weakness in the service provided to mothers with regard to the provision of information and in interactions between health professionals and mothers. Most

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<sup>48</sup> Begley et al. (2010). The strengths and weaknesses of publicly-funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth and early motherhood, p. xix. Retrieved from [http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20\\_full\\_%2018th%20may%202010.pdf](http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20_full_%2018th%20may%202010.pdf)

of the women with a sensory impairment felt their care was negatively impacted by a lack of sensitivity and awareness about their impairment. Some mothers with hearing difficulties used interpreters, while others experienced resistance to involving interpreters and were told they would have to pay for the service. Those with visual impairments did not have access to information via Braille, and those with hearing impairments were hindered in their ability to communicate about appointments as texting was not typically an option at the time and fax machines were not often used. Those with mental health issues felt there was very little communication around mental health and this had a particularly negative impact on their experience. In some instances, professionals referred to women with a sensory impairment in the third person during communication while mothers with intellectual disability reported that health professionals did not speak to them directly, but to whoever was accompanying them. The area of consent was a particular issue. Some mothers reported not receiving adequate/appropriate information to give consent to certain care during labour while in some cases where women had a visual impairment or intellectual disability consent was sought from a third party rather than the woman herself.

Thirty health professionals were also interviewed for this research in six focus groups to get insight into their experiences and views on the strengths and weaknesses of maternity services for women with disabilities. Professionals acknowledged that services needed to change and identified similar weaknesses as women with disabilities, including a fragmented service, accessibility of the physical environment, and some deficits in their knowledge- particularly around mental health. They also referred to challenges they faced in meeting the specific needs of women with disabilities, including doing so within their available resources. Professionals also described positive ways in which they met the needs of women with disabilities, such as training their staff in sign language, and taking time to build trust with women with intellectual disability, although it was acknowledged that individualised care was not consistent across services.

### **Research on maternity experiences of women with disabilities in UK national maternity surveys**

In the period since the NDA and NWCI research was published, there have been a number of national surveys in the UK on mothers' experiences of maternity care: the Birthrights national Dignity in Childbirth survey in 2013, the Care Quality Commission's (CQC) National Survey of Women's Experience of Maternity Care in England in 2015, and the Scottish Maternity Care Experience Survey in 2015. These surveys asked mothers to self-report a disability or condition that limited their daily living, and this has enabled the experiences of mothers with disabilities to be considered across the maternity care pathway on a national level in the UK.



Findings from the 2013 Birthrights national Dignity in Childbirth survey found that women with disabilities reported less choice and control in their maternity experience than mothers without a disability and this included fewer choices of pain relief during labour.<sup>49</sup> Due to these findings, a further study was commissioned to specifically examine the maternity experiences of pregnant women with disabilities.<sup>50</sup> This study included a survey of 37 mothers from the UK and Ireland, followed by a focus groups with 10 of these mothers. Participants had a physical or sensory impairment, or a long-term condition or conditions which impacted on their daily lives. The research found that in general, respondents were happy with the care they received. Across the different stages of maternity services, satisfaction was high in relation to antenatal care and care during labour and birth, but was not as high in relation to postnatal care. However, there were particular areas they were less satisfied with, especially with regard to support, communication, and feeling listened to, and that these experiences had a negative impact on their ability to make appropriate choices. Over half of the survey respondents felt that maternity healthcare staff did not have appropriate attitudes to disability, and one quarter of respondents felt they were not treated as well due to their disability. A small but notable minority of participants felt that their rights and dignity were poorly respected across the maternity pathway. The authors of this report concluded that training and guidance for healthcare providers was required, particularly with regard to promoting wellbeing, dignity, respect, and the importance of human rights.

Secondary analyses of the 2015 National Survey of Women's Experience of Maternity Care in England compared the experiences of those with disabilities to those without disabilities.<sup>51</sup> This study found that women with disabilities were mostly satisfied with their access to maternity care and received significantly more home visits after discharge than women without disabilities. However, they did have more negative perceptions on their experiences of care in a number of

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<sup>49</sup> As cited by Hall, J., Collins, B., Ireland, J., and Hundley, V. (2018) The human rights and dignity experience of disabled women during pregnancy, childbirth and early parenting. Retrieved from <https://birthrights.org.uk/wp-content/uploads/2018/03/Birthrights-Bournemouth-Liverpool-Human-Rights-and-Dignity-Experiences-of-Disabled-Women-during-Pregnancy-Birth-and-Early-Parenting-1-1.pdf>

<sup>50</sup> Hall, J., Collins, B., Ireland, J., and Hundley, V. (2018) The human rights and dignity experience of disabled women during pregnancy, childbirth and early parenting. Retrieved from <https://birthrights.org.uk/wp-content/uploads/2018/03/Birthrights-Bournemouth-Liverpool-Human-Rights-and-Dignity-Experiences-of-Disabled-Women-during-Pregnancy-Birth-and-Early-Parenting-1-1.pdf>

<sup>51</sup> Malouf, R., Henderson, J., and Redshaw, M. (2017) Access and quality of maternity care for disabled women during pregnancy, birth and the postnatal period in England: data from a national survey. *BMJ Open*, 7(e016757).

areas than those without a disability. Women with disabilities reported significantly poorer experiences in the areas of communication, feeling listened to, feeling supported, feeling encouraged and given help when feeding their baby, being involved in decision making, having confidence and trust in healthcare staff, feeling respected, receiving information in an appropriate format, and getting enough information on physical recovery and emotional changes after birth. This report also identified different perceptions of care experiences according to the woman's disability. Those with a mental health difficulty reported less positive perceptions of care compared to other groups, particularly with regard to communication, getting time for questions, feeling treated with respect, involvement in decisions and having their concerns taken seriously. Women with a learning difficulty reported less positive perceptions of maternity care in relation to communication, being involved in decisions, and being supported and listened to. The authors concluded that disability awareness training for healthcare staff and extra time for care would have a positive impact on the experiences of women with disabilities.

A report on Scotland's 2015 Maternity Care Experience Survey explored whether maternity care in Scotland was equitable based on a range of demographic characteristics, general health status and presence of a health condition which limited daily activities.<sup>52</sup> Of note is that this report found few consistent associations between experiences of care and the presence of a health condition which limited daily activities (with the exception of this group feeling less like their feeding decisions were respected by staff than those without such a condition). However, self-reported poor health was implicated in less positive care experiences in almost all areas of care, including communication, feeling treated with less respect and dignity, in continuity of care, feeling less involved in decisions, having less positive experience of pain management, and less confidence and trust in health professionals. Aside from poor health, the authors reported concluded that maternity care in Scotland was 'generally equitable'.

While these most recent studies are from the UK or have included only a very small non-representative sample from Ireland, they share some findings with the original NDA and NWCI research, particularly around the areas of decision making, communication, and the negative impacts on care when staff lack knowledge and awareness in caring for someone with a disability during pregnancy, birth or motherhood. In the period since the NDA and NWCI research, there have been significant national maternity milestones (outlined

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<sup>52</sup> Cheyne, H., Elders, A., Hill, D., and Milburn, E. (2019) Is maternity care in Scotland equitable? Results of a national maternity care survey. *BMJ Open*, 9(e023282).

below) in Ireland which it is hoped will have had a positive impact on the care for women with disabilities.

While the focus of this report is on quantitative national maternity surveys, it is important to note qualitative research that has taken place on the maternity experiences of women with disabilities in Ireland.<sup>53</sup> Furthermore, work underway in the National University of Ireland Galway (NUIG) on the 'Re(al) Productive Justice: Gender and Disability' project has been exploring the experience of people with disabilities in making reproductive decisions and in accessing reproductive-related services and supports.<sup>54</sup> This work has particular relevance for maternity services and the insight from people with disabilities participating in this project will inform the development of a toolkit for health and social care practitioners.

## **National Maternity Strategy – Creating a Better Future Together 2016-2026**

Ireland's first National Maternity Strategy was launched in 2016 and was developed in response to a number of reports and reviews highlighting significant issues in Irish maternity services.<sup>55</sup> The vision of this strategy is that "Women and babies have access to safe, high quality care in a setting that is most appropriate to their needs; women and families are placed at the centre of all services, and are treated with dignity, respect and compassion; parents are supported before, during and after pregnancy to allow them give their child the best possible start in life."<sup>56</sup> In order to achieve the realisation of this vision, the strategy proposes significant reform of maternity services.

The strategy explicitly mentions women with disabilities with regard to accessible antenatal care and tailored antenatal education, and there is an acknowledgement that some women will have higher care needs which would include a cohort of women with disabilities. The strategy also includes an action on delivering information in an understandable way and assessing whether information has been understood, which also has relevance for some women with disabilities.

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<sup>53</sup> See for example Walsh-Gallagher, Sinclair & McConkey (2012) and Higgins, Tuohy, Murphy & Begley (2016) (this is not an exhaustive list).

<sup>54</sup> See <http://realproductivejustice.com/>

<sup>55</sup> Department of Health. (2016) National maternity strategy. Creating a better future together. 2016 – 2026. Retrieved from <https://assets.gov.ie/18835/ac61fd2b66164349a1547110d4b0003f.pdf>

<sup>56</sup> Department of Health. (2016) National maternity strategy. Creating a better future together. 2016 – 2026, p.4. Retrieved from <https://assets.gov.ie/18835/ac61fd2b66164349a1547110d4b0003f.pdf>

Perinatal mental health is also an important part of this strategy and is covered in the following actions:

- “Access to mental health supports will be improved to ensure appropriate care can be provided in a timely fashion.
- All health care professionals involved in antenatal and postnatal care are trained to identify women at risk of developing or experiencing emotional or mental health difficulties, including an exacerbation of previous mental health issues, in the perinatal period.
- For women at risk of developing or experiencing emotional or mental health difficulties in the perinatal period, a multidisciplinary approach to assessment and support will be adopted.
- Women with a history of a mental health condition are identified early and midwives will work collaboratively with mental health and other services to ensure that the appropriate support is provided.”

A number of elements of this strategy align with recommendations from the NDA and NWCI study, including woman-centred care, integrated, collaborative services, and the communication of information in an understandable way. However, while the creation of this strategy is a positive development for Irish maternity services, a recent HIQA report noted that there has been limited progress in implementing this strategy since 2016.<sup>57</sup> It identified that the National Women and Infants Health Programme (NWIHP), which was established to implement this strategy was limited in what it could progress due to governance and budget issues. The HSE have subsequently improved governance and accountability arrangements for the NWIHP in an effort to resolve this issue.<sup>58</sup> In order to guarantee progress is made on implementing the National Maternity Strategy, HIQA also recommended that the HSE “immediately develop a comprehensive, time-bound and fully costed National Maternity Strategy implementation plan, which spans the remaining time frame of the strategy”.<sup>59</sup>

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<sup>57</sup> HIQA. (2020) Overview report of HIQA’s monitoring programme against the national standards for safer better maternity services, with a focus on obstetric emergencies. Retrieved from <https://www.hiqa.ie/sites/default/files/2020-02/Maternity-Overview-Report.pdf>

<sup>58</sup> HSE. (2020) Listening, responding, and improving. The HSE response to the findings of the national maternity experience survey. Retrieved from <https://www.hse.ie/eng/services/publications/hse-response-to-the-findings-of-the-national-maternity-experience-survey-2020.pdf>

<sup>59</sup> HIQA. (2020) Overview report of HIQA’s monitoring programme against the national standards for safer better maternity services, with a focus on obstetric emergencies, p.16. Retrieved from <https://www.hiqa.ie/sites/default/files/2020-02/Maternity-Overview-Report.pdf>

## National Standards for Safer Better Maternity Care

HIQA published National Standards for Safer Better Maternity Care in 2016 to support the implementation of the National Maternity Strategy.<sup>60</sup> These standards include the following eight dimensions<sup>61</sup>:

- **Safety and quality:** i) Person-centred care and support, ii) Effective care and support, iii) Safe care and support and iv) Better health and wellbeing
- **Capacity and capability:** i) Leadership, governance and management, ii) Workforce, iii) Use of resources, and iv) Use of information.

Women with disabilities are referred to in a number of these standards. Standard 1.3 states that “Women and their babies experience maternity care which respects their diversity and protects their rights” and this includes Standard 1.3.1 which sets out that access to maternity services should not discriminate against various groups, including those with disabilities. Standard 2.7.4 states that “Maternity care is provided in a physical environment that meets the needs of women with a physical disability” and Standard 6.3.20 states that “Healthcare professionals and support staff are provided with disability competence training to equip them with the skills and understanding to provide person-centred care and support to women with disabilities, appropriate to their role.”

Between 2018 and 2019, HIQA monitored all 19 maternity hospitals and units against four of the eight dimensions of the national maternity care standards: effective care and support, safe care and support, leadership, governance and management and workforce. This programme of monitoring placed a focus on risk, for example, the response to obstetric emergencies and identification of women at risk of complications, rather than considering say the promotion of better health and wellbeing. Overall, high levels of compliance with most of the standards examined was found, but areas of non-compliance were also identified as needing to be addressed by the HSE and hospital groups.<sup>62</sup> One problem area was the ‘substandard physical environment and infrastructure of units and hospitals’<sup>63</sup>, which has significant relevance for women with physical and sensory

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<sup>60</sup> HIQA. (2016) National standards for safer better maternity services. Retrieved from <https://www.hiqa.ie/sites/default/files/2017-02/national-standards-maternity-services.pdf>

<sup>61</sup> These align with those of HIQA’s 2012 National Standards for Safer Better Healthcare.

<sup>62</sup> HIQA. (2020) Overview report of HIQA’s monitoring programme against the national standards for safer better maternity services, with a focus on obstetric emergencies. Retrieved from <https://www.hiqa.ie/sites/default/files/2020-02/Maternity-Overview-Report.pdf>

<sup>63</sup> HIQA. (2020) Overview report of HIQA’s monitoring programme against the national standards for safer better maternity services, with a focus on obstetric emergencies, p.6. Retrieved from <https://www.hiqa.ie/sites/default/files/2020-02/Maternity-Overview-Report.pdf>

disabilities and which was also raised as an issue in the NDA and NWCI work. The particular standards relating specifically to women with disabilities were not part of this monitoring programme so it is not possible to describe any progress in these areas.

## **National Antenatal Education Standards**

Nationally, there has been little standardisation or consistency with regards to access to antenatal education, how antenatal education is delivered, and what information is provided to families during classes. The importance of the maternity services offering standardised national antenatal education was referred to in the National Maternity Strategy<sup>64</sup> and National Standards for Safer Better Maternity Care<sup>65</sup>. As a result, the National Antenatal Education Standards were developed and launched in 2020.<sup>66</sup> These standards follow the same eight dimensions of HIQA's national health and maternity standards.

In the standards, antenatal educators need to consider how to meet the specific learning needs and level of understanding of particular groups, including women with disabilities (Standard 1.3), provide “easily accessible” information in a “variety of formats” (Standard 1.4) and provide “Comprehensive, evidence-based information that discusses perinatal mental health issues” (Standard 4.1). Standard 2.2 refers to the physical environment where antenatal education is delivered, and states: “The space in which antenatal education is delivered is adequate and flexible and meets the needs of pregnant women, their partners or family members who may have a physical disability.” The NWIHP, which is responsible for implementing the National Maternity Strategy, will lead on the implementation of these standards.

## **Model of Care for Specialist Perinatal Mental Health Services**

The HSE published a Specialist Perinatal Mental Health Model of Care for Ireland in 2017 which supports the actions on mental health in the National Maternity

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<sup>64</sup> Department of Health. (2016) National maternity strategy. Creating a better future together. 2016 – 2026. Retrieved from

<https://assets.gov.ie/18835/ac61fd2b66164349a1547110d4b0003f.pdf>

<sup>65</sup> HIQA. (2016) National standards for safer better maternity services. Retrieved from

<https://www.hiqa.ie/sites/default/files/2017-02/national-standards-maternity-services.pdf>

<sup>66</sup> HSE. (2020) National standards for antenatal education in Ireland. Retrieved from

<https://www.hse.ie/eng/about/who/healthwellbeing/our-priority-programmes/child-health-and-wellbeing/antenatal-ed.pdf>

Strategy.<sup>67</sup> Implementation of this model of care and recruitment of staff is underway. In this model of care, specialist services are aligned with maternity hospitals/units in a hub and spoke format, with 6 hubs and 13 spoke sites. Hubs are larger sites which have a specialist perinatal mental health service, while mental health midwives will work with liaison mental health teams in the spoke sites. This specialist service focuses on those with moderate to severe mental illness, but also provides a pathway of identification and support for women with milder mental health issues. As part of this service, a mobile application for healthcare staff has been developed to help them provide information on mental health supports to pregnant women and new mothers. This service has also developed a series of leaflets on mental health in pregnancy which include information, advice and signpost to supports. Under this model, planning is also underway for Ireland's first specialist psychiatric mother and baby inpatient unit.

## **United Nations Convention on the Rights of Persons with Disabilities**

Ireland ratified the UNCRPD<sup>68</sup> in 2018. The two articles of most relevance to maternity care are Article 6 - Women with disabilities and Article 25 – Health. Under Article 6, State Parties:

“recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms” and “shall take all appropriate measures to ensure the full development, advancement and empowerment of women”.<sup>69</sup>

Under Article 25, State Parties:

“recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all

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<sup>67</sup> HSE. (2017) Specialist perinatal mental health services. Model of care for Ireland. Retrieved from <https://www.hse.ie/eng/services/list/4/mental-health-services/specialist-perinatal-mental-health/specialist-perinatal-mental-health-services-model-of-care-2017.pdf>

<sup>68</sup> United Nations. (2006) Convention on the rights of persons with disabilities and optional protocol. Retrieved from <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

<sup>69</sup> United Nations. (2006) Convention on the rights of persons with disabilities and optional protocol, p.7. Retrieved from <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>



appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall: a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes”.<sup>70</sup>

By ratifying the UNCRPD, there is a duty on Ireland to ensure that the quality and range of all maternity services provided to women with disabilities is the same of that provided to other women.

Prior to ratification of the UNCRPD in Ireland, a whole of government National Disability Inclusion Strategy (2017-2021)<sup>71</sup> (NDIS) was developed in collaboration with people with disabilities and disability services stakeholders. The themes included in the strategy are education, employment, health and wellbeing, person-centred disability services, housing, transport and accessible places, equality and choice, and joined up services. Many of the NDIS themes intersect when we consider the journey of women with disabilities through the maternity care system: equality and choice, transport and accessible places, joined up services, and health and wellbeing. While the NDIS does include an action on considering the impact of future Government policies on women with disabilities, it does not include any specific actions relating to maternity or women’s reproductive services.

## **The National Maternity Experience Survey 2020**

The National Maternity Experience Survey was conducted in 2020 and provided mothers with an opportunity to give feedback on their experiences of antenatal to postnatal care in Ireland’s maternity services. This survey was led by the HIQA and is part of the National Care Experience Programme, an initiative by HIQA, the HSE and the DOH. The survey asked mothers about their experiences through the full pathway of maternity care, including antenatal care, care during labour and birth, care in hospital after birth, specialised care if their baby was in a neonatal unit, care for feeding their baby, and care at home after birth.<sup>72</sup> Care

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<sup>70</sup> United Nations. (2006) Convention on the rights of persons with disabilities and optional protocol, p.18. Retrieved from <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

<sup>71</sup> Department of Justice and Equality. (2017) National disability inclusion strategy 2017-2021. Retrieved from <https://assets.gov.ie/18901/26182a87ecf84ddd8d60c215c0ce2520.pdf>

<sup>72</sup> See [https://yourexperience.ie/wp-content/uploads/2020/01/NMES-Questionnaire\\_FINAL-2.pdf](https://yourexperience.ie/wp-content/uploads/2020/01/NMES-Questionnaire_FINAL-2.pdf) for a copy of the survey.



from pregnancy until a mother goes home after giving birth tends to be received from maternity services (although there may be some GP care during pregnancy), while care at home in the community is largely from public health nurses (PHNs) and GPs or GP practice nurses/midwives (although there may be some care from maternity services).

Mothers were asked a range of questions on their care during each stage. They were asked about being given their choice of care, their involvement in decision making, being treated with respect and dignity, their confidence and trust in their caregivers, and having their questions answered in an understandable way. They were also asked about the promotion of theirs and their baby's health and well-being via information on physical health, mental health, nutrition during pregnancy, on smoking, alcohol and drugs, vaccinations and the support, help, advice and encouragement they received from health professionals. Some questions were specific to the area of care – e.g., on pain management during labour and birth and skin-to-skin contact after birth. Overall, most of the mothers who took part in the survey had a positive maternity care experience, although 15% of them did rate their experience as 'fair to poor'.<sup>73</sup> The most positive experiences reported by respondents tended to be around being treated with respect and dignity and having confidence and trust in the healthcare professionals caring for them. On the other hand, areas where respondents rated their experience as less positive were in relation to not receiving enough support or information on their mental health, in not getting the opportunity to ask any questions after the birth of their child, and in the level of their involvement in decisions on their care after birth. Women who had given birth before were more likely to report positive experiences, as were those who chose to have a home birth.

A suite of reports relating to this survey have been published, including national results on the experiences of women, results on women's experiences for individual maternity services and CHO areas, responses to the findings from the HSE and other relevant bodies, and quality improvement plans for all 19 maternity hospitals/units and nine CHOs.<sup>74</sup> The implementation of these quality improvement plans will be evaluated, and in 2022 a second National Maternity Experience Survey will take place to consider the impact of these changes on women's experiences of maternity care.

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<sup>73</sup> NMES. (2020) Findings of the national maternity experience survey 2020. Retrieved from <https://yourexperience.ie/wp-content/uploads/2020/09/National-Maternity-Experience-Survey-results.pdf>

<sup>74</sup> See <https://yourexperience.ie/maternity/about-the-survey/> for information on survey and all publications.

During the development of NMES, the NDA worked with HIQA to formulate a suitable question to enable respondents to report if they had a long-term disability, illness or condition. The NDA particularly welcome the inclusion of this question as it has enabled the present research. As noted, previous NMES reports have not examined the experiences of women with disabilities.

Highlighting the specific experiences of women with disabilities is crucial, bearing in mind the previous NDA and NWCI work which identified weaknesses in the choice of care offered to women with disabilities, the availability of services, in staff knowledge, attitude and communication with women with disabilities, and in how the infrastructure and physical environment of some hospitals/units impeded the access of women with certain disabilities to maternity care.

### **Aims of report**

Using data from the NMES 2020, this report aims to:

- Describe the experiences of a sample of women with long-term disabilities, illnesses or conditions of maternity services in Ireland, and
- Compare the experiences of samples of women with and without long-term disabilities, illnesses or conditions of maternity services in Ireland.

The overall purpose of this project is to provide policy and practice-relevant research findings on the service and support needs of women with disabilities in maternity services.

## Methodology

### National Maternity Experience Survey 2020

This paper is based on secondary data analysis of the National Maternity Experience Survey (NMES) 2020, a survey on the maternity care experiences of new mothers in Ireland.<sup>75</sup> The target sample for this survey was mothers aged 16 or over, living in Ireland, who had given birth in October or November 2019. Mothers were eligible to participate if they gave birth in a large hospital in October, or if they gave birth in a smaller hospital in October or November (to ensure an adequate sample size from hospitals with lower birth rates). Eligible mothers were contacted by post in February and March 2020 with an invitation to take part and an online link to the survey. Those who had not completed the survey were followed up twice in March and April 2020. The survey was available in Irish, Polish, Lithuanian and Romanian and was checked for compliance with National Adult Literacy Agency (NALA) guidelines. Out of 6,357 mothers who were eligible to participate, 50% (n=3,204) completed the survey. Out of this sample, 217 (6.8%)<sup>76</sup> reported that they had a long-term disability, illness or condition.<sup>77</sup> Over half (57.6%) of these reported a long-term mental health, psychological, or emotional condition<sup>78</sup>, with other reported conditions including: chronic illness, sensory impairments, physical disabilities, intellectual disability, difficulty learning, remembering or concentrating and a range of functional difficulties (these will be described in detail in the next chapter).

The survey included 68 questions pertaining to mothers and their experiences through the full pathway of maternity care,<sup>79</sup> including antenatal care, care during labour and birth, care in hospital after birth, specialised care if their baby was in a neonatal unit, care for feeding their baby, and care at home after birth. Most

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<sup>75</sup> See <https://yourexperience.ie/maternity/about-the-survey/> for details on this survey and for results at both national and individual hospital/unit levels.

<sup>76</sup> An examination of data the Growing up in Ireland study, a large nationally representative study of children, identified that approximately 8.3% of mothers of the infant cohort born in 2007/2008 had a long-term chronic physical or mental health problem, illness or disability. This suggests the NMES sample may be under representative of women with disabilities who gave birth during this period.

<sup>77</sup> The term 'long-term disability' will be used throughout the report, but is inclusive of other conditions and chronic illnesses reported by respondents. This is for the purpose of brevity but it is acknowledged that not all respondents in this group will identify as having a disability.

<sup>78</sup> The term 'mental health condition' will be used throughout the report in relation to this group, but is inclusive of psychological or emotional conditions.

<sup>79</sup> See [https://yourexperience.ie/wp-content/uploads/2020/01/NMES-Questionnaire\\_FINAL-2.pdf](https://yourexperience.ie/wp-content/uploads/2020/01/NMES-Questionnaire_FINAL-2.pdf) for a copy of the survey.

questions asked mothers to evaluate their care experience. The response options for these questions varied (e.g., ‘Yes or No’ or ‘Yes definitely, Yes to some extent or No’) and, to enable comparisons across questions, all response options were transformed to scores of 0, 5 or 10. Zero was given to answers which indicated the least positive experience, 10 to the most positive experience, and 5 if they answered positively to some extent. Scores on each experience within a particular stage of care were averaged to give a mean score for mothers’ overall experience in that stage. At the end of the survey, mothers were also asked “Overall, how would you rate your experience of the care you and your baby received during pregnancy, labour and birth and after your baby was born?” on a scale from 0 (very negative) to 10 (very positive).

### **Access to data**

The NDA submitted a data access request form to HIQA in October 2020 and the data was received from them in November 2020.<sup>80</sup> Data were sent in an anonymised, password protected format with no personal identifiers.

### **Analytic strategy**

Data analysis was conducted using IBM SPSS version 25.

### **Preliminary checks**

#### **Comparing the samples of those with and without long-term disabilities**

A series of chi-square tests of independence were conducted to investigate whether those with and without long-term disabilities differed on a number of variables that could potentially be linked with different experiences of care:

- Age
- Ethnicity
- Parity – whether a mother had given birth before (primiparous) or not (nulliparous)
- Type of care received (public, consultant-led private or semi-private, or other care including DOMINO, midwifery-led care in a midwifery-led unit, community midwifery team, or home birth)
- Type of birth (vaginal, assisted vaginal, planned caesarean, unplanned caesarean).

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<sup>80</sup> See <https://yourexperience.ie/about/contact-us/request-data-for-research/> for information on accessing data.

Where there were statistically significant associations between these variables and having a long-term disability or not, these variables were controlled for in the main analyses.

### **Differences in experience according to type of disability**

Due to small numbers of different types of disabilities, illnesses or conditions, it was not possible to examine whether the particular disability, illness or condition respondents had was associated with their experience of care. However, as noted above, the majority (57.6%) of those with a long-term disability had a mental health, psychological or emotional condition. If this group's experiences of care were significantly different to the rest of the sample with long-term disabilities, then it would not be appropriate to treat all those with long-term disabilities as one group for the purposes of this report. In order to assess this, a series of independent t-tests were conducted to compare whether there were any differences in care experiences between those with a mental health condition or other type of long-term disability.

### **Main analyses**

Descriptive statistics were used to describe whether respondents were offered a choice in their type of maternity care, whether they were invited to antenatal classes and if they attended antenatal classes. Chi square tests of independence were then conducted on these variables to identify whether there were any statistically significant associations between the choices offered to women and whether they had a disability or not.

Descriptive statistics were used to describe the maternity care experiences of the women with disabilities who participated in NMES on their individual experiences within the six areas of care<sup>81</sup>, and on their overall experience in each area. A series of multiple regressions were then conducted to identify whether there were any differences in experiences of maternity care by those with and without long-term disabilities, while controlling for any significant differences in the two samples. Experiences of the two groups were compared on individual items within each domain, and on their overall experience in each area.

### **A note on statistical significance**

One of the main outcomes from the tests conducted in the Results section is the level of statistical significance of particular findings. This tells us how likely it is that any relationships or differences that are found between women with and without disabilities have occurred by chance. The level of significance is denoted by a 'p value' and a value less than 0.05 is considered 'statistically significant'. A

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<sup>81</sup> Antenatal care, care during labour and birth, care in hospital after birth, specialised care, care for feeding, and care at home after birth.

value less than 0.05 means, for example, if our data is suggesting that there is a difference in scores given to a particular maternity experience between women with and without a disability, the probability of this finding occurring due to chance is less than 5%. This gives us a sufficient level of confidence to conclude that these are real, not random, differences. The closer the  $p$  value gets to zero, the smaller the probability that differences are due to chance. It is important to note that in the Results, there may be quite small differences in mean scores that are statistically significant, or what seem quite notable differences in percentages that are not statistically significant. Whether or not these differences between women with and without disabilities are statistically significant will depend on the size of the samples in each analysis, how all women in each group have answered the question, and in the case of regressions, the interrelations between our variables of interest and other relevant variables. When describing the results, if a finding is described as 'significant' it means it is statistically significant.

## Results

### Sample characteristics

#### Long-term disabilities, illnesses, or conditions

In total, 3,204 respondents completed NMES 2020. Out of this sample, 217 (6.8%) reported that they had a long-term disability, illness or condition. Out of these respondents, 89.9% reported having one disability (n=195) and 11.1% reported two or more disabilities (n=22). Table 1 outlines the type of long-term disability reported by respondents. Over half of respondents reporting a disability had a mental health, psychological or emotional condition (57.6%), while over one quarter had another disability or chronic illness (not specified) (26.3%). Almost 5% of respondents reporting a disability had deafness or a serious hearing impairment<sup>82</sup>. The same proportion reported having a condition substantially limiting one or more basic physical activities and a further 4.6% reported having difficulty in learning, remembering or concentrating. Around 4% had difficulties going outside home alone or working or attending school. Just under 3% had difficulty taking part in other activities, 2.3% had difficulty in dressing, bathing or getting around inside their home and a small number of respondents were blind/had a serious vision impairment or an intellectual disability.<sup>83</sup>

**Table 1 – Type of disability reported by NMES survey respondents**

Type of disability	n	%
<b>Mental health, psychological or emotional condition</b>	125	57.6
<b>Other disability, including chronic illness</b>	57	26.3
<b>Deafness or a serious hearing impairment</b>	10	4.6
<b>A condition that substantially limits one or more basic physical activities</b>	10	4.6

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<sup>82</sup> This terminology was used in the NMES question, but in the rest of this report the terms deaf or hard of hearing will be used.

<sup>83</sup> It is not possible to compare the types of disabilities this sample of women have reported to all women who gave birth in the same period to consider the representativeness of sample. However, Census 2016 figures indicate that compared to all women with a disability aged 18-40 (with or without children), this sample has a larger proportion of those with a psychological or emotional condition (57.6% vs 33.1%) and lower proportions of all other disability types.

**Table 1 - Continued**

<b>Type of disability</b>	<b>n</b>	<b>%</b>
<b>Difficulty in learning, remembering or concentrating</b>	10	4.6
<b>Blindness or a serious vision impairment</b>	<5 <sup>84</sup>	0.0
<b>An intellectual disability</b>	<5	0.0
<b>Functional difficulty: Difficulty in going outside home alone</b>	9	4.1
<b>Functional difficulty: Difficulty working or attending school</b>	8	3.7
<b>Functional difficulty: Difficulty taking part in other activities</b>	6	2.8
<b>Functional difficulty: Difficulty in dressing, bathing or getting around inside the home</b>	5	2.3

Due to the large proportion of women with disabilities reporting a mental health, psychological or emotional condition, a series of independent t-tests were conducted to compare whether there were any differences in care experiences between those with such a condition or other type of long-term disability.<sup>85</sup> Out of the 42 items and 7 overall scale scores, there was only one significant difference between those with and without mental health conditions.<sup>86</sup> As such, we can conclude for the purposes of this analysis that the maternity care experiences of those with mental health conditions were sufficiently similar enough to those with other long-term disabilities to consider them as one group.

### **Age**

Figure 1 shows the age groups of survey respondents with and without long-term disabilities. Respondents with a long-term disability were significantly younger than those without a disability ( $X^2 (4, N = 3,204) = 51.4, p < .001$ ). For example, 36.9% of those with a long-term disability were under 29 years of age compared to 17.6% of those without a disability. Conversely, 54.8% of those with a long-term disability were between 30 and 39 compared to 73.7% of those without a long-term disability.

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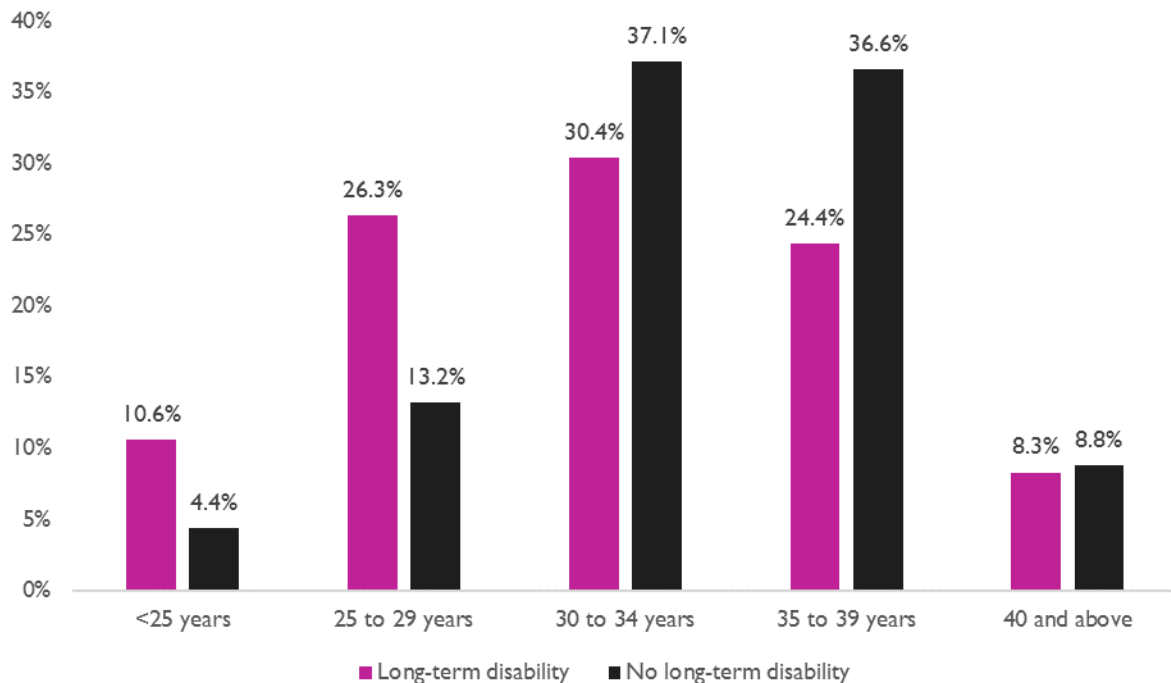
<sup>84</sup> Numbers less than 5 are not published to avoid the possible identification of respondents.

<sup>85</sup> Please see Appendix A for these tests.

<sup>86</sup> On getting adequate support and encouragement in feeding their baby during their hospital stay, those with a mental health, psychological or emotional condition had significantly lower mean score than those with other long-term conditions.



**Figure 1. Age groups of respondents with and without a long-term disability**



### Ethnicity

Table 2 displays the ethnicity of respondents with and without disabilities. Broadly speaking, respondents with and without disabilities were quite similar with regards to ethnicity, with 93.1% of those with a long-term disability being White Irish (81.6%) or from Any Other White Background (11.5%), and 92.0% of those without a long-term disability being White Irish (81.2%) or from Any Other White Background (10.8%). The remaining 6.4% and 6.5% of respondents with and without disabilities, respectively, reported a range of other ethnicities, with both groups including women from African, Indian/Pakistani/Bangladeshi, Mixed, Other, Any Other Asian Background, and Arabic ethnicities. A number of those without long-term disabilities reported their ethnicity as an Irish Traveller, Roma, Chinese or Any Other Black Background. However, none of the respondents with long-term disabilities reported these ethnicities. There were no significant differences between the two groups in terms of ethnicity,  $X^2 (2, N = 3,155) = 0.06, p = .97$ .<sup>87</sup>

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<sup>87</sup> Women with and without disabilities were compared across three groups: White Irish, Any Other White Background and Other Ethnicity.

**Table 2 – Ethnicity of respondents with and without a disability**

<b>Ethnicity</b>	<b>Long-term disability</b>	<b>No long-term disability</b>
<b>White Irish</b>	81.6% (n=177)	81.2% (n=2,425)
<b>Other White Background</b>	11.5% (n=25)	10.8% (n=324)
<b>Other Ethnicities<sup>88</sup></b>	6.5% (n=14)	6.4% (n=190)
<b>Missing</b>	0.5% (n=1)	1.6% (n=48)
<b>Total</b>	<b>100.0%</b> <b>(n=217)</b>	<b>100.0%</b> <b>(n=2,987)</b>

**Parity**

Table 3 shows the parity of respondents with and without a disability. The two groups were very similar, with 36.9% of women with a long-term disability being primiparous compared to 38.8% of women without a long-term disability. There were no significant differences between the two groups in terms of parity,  $X^2 (1, N = 2,938) = 0.28, p = .60$ .

**Table 3 – Parity of respondents with and without a disability**

<b>Parity</b>	<b>Long-term disability</b>	<b>No long-term disability</b>
<b>Primiparous</b>	36.9% (n=80)	38.8% (n=1,160)
<b>Multiparous</b>	54.4% (n=118)	52.9% (n=1,580)
<b>Missing</b>	8.8% (n=19)	8.3% (n=247)
<b>Total</b>	<b>100.0%</b> <b>(n=217)</b>	<b>100.0%</b> <b>(n=2,987)</b>

**Type of birth**

Table 4 shows the type of birth reported by respondents with and without a disability. Just over 60% of women with a long-term disability had a vaginal birth (n=131, 60.4%), 15.7% of which were assisted, compared to 66.0% of women without a disability (n=1,973) (14.3% of which were assisted). Almost 40% of

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<sup>88</sup> Including African, Indian/Pakistani/ Bangladeshi, Mixed, Other, Any Other Asian Background, Chinese, Arabic, Irish Traveller, Roma, and Any Other Black Background.

women with a long-term disability had a caesarean section (n=85), 17.5% of which were emergency caesareans, compared to 33.7% of women without a long-term disability (n=1,007) (15.3% of which were emergency caesareans). There were no significant differences between the two groups in terms of the type of birth they experienced,  $X^2 (3, N = 3,196) = 4.0, p = .26$ .

**Table 4 – Type of birth of respondents with and without a disability**

<b>Type of Birth</b>	<b>Long-term disability</b>	<b>No long-term disability</b>
<b>Vaginal</b>	44.7% (n=97)	51.8% (n=1,547)
<b>Assisted vaginal</b>	15.7% (n=34)	14.3% (n=426)
<b>Planned caesarean</b>	21.7% (n=47)	18.4% (n=551)
<b>Emergency caesarean</b>	17.5% (n=38)	15.3% (n=456)
<b>Missing</b>	0.5% (n=1)	0.2% (n=7)
<b>Total</b>	<b>100.0%</b> <b>(n=217)</b>	<b>100.0%</b> <b>(n=2,987)</b>

### **Type of maternity care**

There was a significant relationship between having a long-term disability or not and the type of maternity care received ( $X^2 (2, N = 3,189) = 37.9, p < .001$ ). Table 5 shows that a higher proportion of those with long-term disabilities availed of public maternity care (82.9%) compared to those without long-term disabilities (62.1%). Lower proportions of those with long-term disabilities availed of consultant-led private or semi-private care (11.5% vs 24.9%) or other care types<sup>89</sup> (4.1% vs 11.6%). Due to these differences, this variable was controlled for in the main analyses.

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<sup>89</sup> Other care types included DOMINO, midwifery-led care in a midwifery-led unit, community midwifery team, or a home birth.

**Table 5 – Type of maternity care received by those with and without a disability**

Type of care	Long-term disability	No long-term disability
<b>Public</b>	82.9% (n=180)	62.1% (n=1,855)
<b>Consultant-led private or semi-private</b>	11.5% (n=25)	24.9% (n=744)
<b>Other care</b>	4.1% (n=9)	11.6% (n=346)
<b>Missing</b>	1.4% (n=3)	0.4% (n=12)
<b>Total</b>	<b>100.0%</b> <b>(n=217)</b>	<b>100.0%</b> <b>(n=2,987)</b>

### **Maternity care and antenatal classes**

#### **Choice of maternity care**

There was a significant association between having a long-term disability or not and whether women were offered a choice in their care, ( $X^2$  (2,  $N = 2,878$ ) = 46.5,  $p < .001$ ). Table 6 shows that those with a long-term disability were more likely not to be able to have a choice of care due to medical conditions (14.3%) compared to women without disabilities (4.7%). A slightly higher proportion of those with disabilities also reported not being offered a choice of care compared to those without disabilities (27.2% vs 24.6%, respectively).

**Table 6 – Choice of care for respondents with and without a disability**

Offered choice of care	Long-term disability	No long-term disability
<b>Yes</b>	43.8% (n=95)	60.8% (n=1,816)
<b>No</b>	27.2% (n=59)	24.6% (n=736)
<b>No choices due to medical conditions</b>	14.3% (n=31)	4.7% (n=141)
<b>Missing</b>	14.7% (n=32)	9.8% (n=297)

Offered choice of care	Long-term disability	No long-term disability
Total	100.0% (n=217)	100.0% (n=2,987)

### Antenatal classes

There was a significant association between having a long-term disability or not and whether women were offered and participated in antenatal classes ( $X^2 (2, N = 3,163) = 10.4, p < .01$ ). Table 7 indicates that a slightly higher proportion of those with a long-term disability reported not being offered antenatal classes (16.6% compare to 15.0% of women without disabilities). However, the main difference in the two groups was that women with disabilities were less likely to do antenatal classes (48.8% were offered them and didn't do them compared to 40.1% of those without disabilities).

**Table 7 – Being offered and participating in antenatal classes by respondents with and without a disability**

Offered/ participated in antenatal classes	Long-term disability	No long-term disability
Yes, and I did them	32.3% (n=70)	43.7% (n=1,305)
Yes, but I did not do them	48.8% (n=106)	40.1% (n=1,198)
No	16.6% (n=36)	15.0% (n=448)
Missing	2.3% (n=5)	1.2% (n=36)
Total	100.0% (n=217)	100.0% (n=2,987)

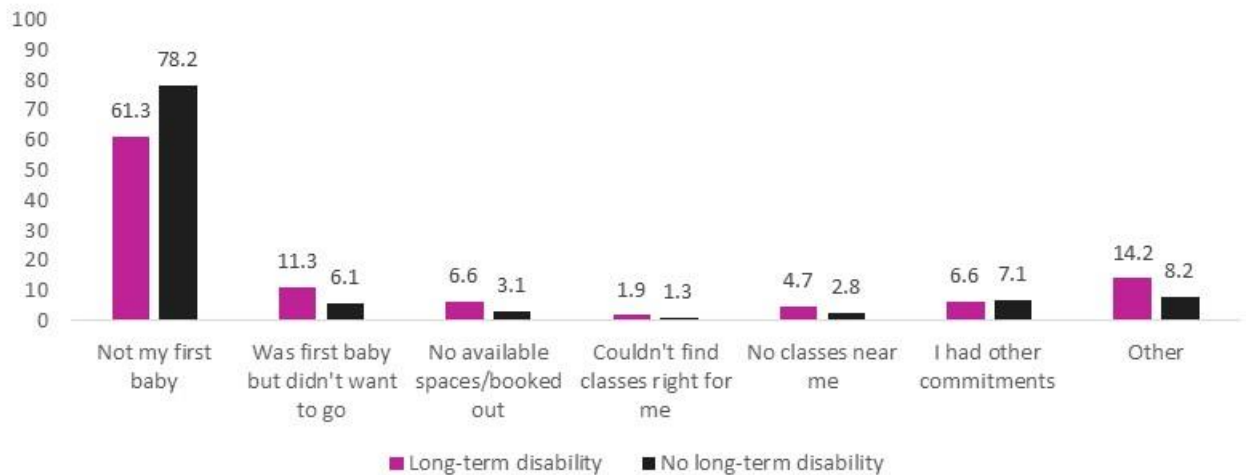
Parents who had been offered classes but who didn't take them were asked about the reasons why they didn't take them (Figure 2)<sup>90</sup>. The main reason for those with and without disabilities was that this wasn't their first baby. Slightly higher proportions of women with disabilities reported that even though it was their first baby they didn't want to go, that there were no available spaces for

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<sup>90</sup> Respondents could choose more than one answer.

them, they couldn't find the right classes, or there were no classes near them. A slightly higher proportion of those without disabilities reported that they had other commitments. Finally, 14.2% of those with disabilities gave another reason compared to 8.2% of those without disabilities, but unfortunately these other reasons were not captured in the NMES survey.

**Figure 2. Reasons why those with and without a disability did not attend antenatal classes**



## Antenatal care experience

Figure 3 shows the mean scores of those with and without long-term disabilities on their experiences of care received during pregnancy across ten items and overall.<sup>91</sup> Average scores in this area of care ranged from 5.0 to 8.4 for those with long-term disabilities and 5.0 to 9.0 for those without long-term disabilities (where 0 is very negative and 10 is very positive). The area of antenatal care rated lowest by those with a long-term disability was on receiving enough information about mental health changes which may occur during pregnancy ( $M=5.0$ ), while their most positive experience was receiving enough information about giving up smoking and other tobacco-related products ( $M=8.4$ ). These items were also the least and most positively rated items by those without long-term disabilities.

Figure 3 also shows any statistically significant differences between the experiences reported by those with and without long-term disabilities (denoted by asterisks)<sup>92</sup>. Those with long-term disabilities rated their antenatal care experience significantly differently than those without long-term disabilities on 5

<sup>91</sup> Please see Appendix B for the full results represented here.

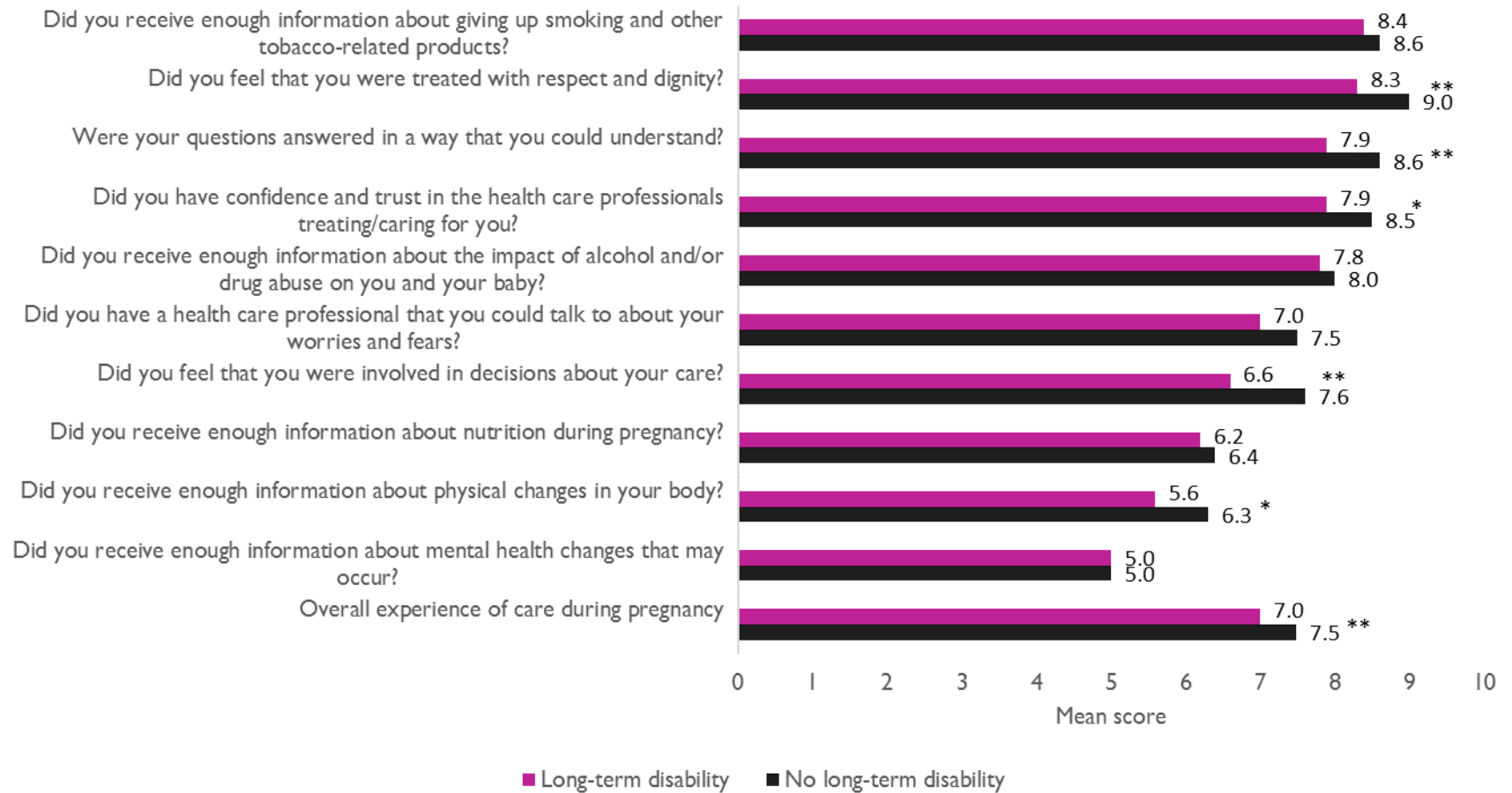
<sup>92</sup> \*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

of the 10 items and on their overall antenatal care experience. Those with long-term disabilities had a mean score of 7.0 out of 10 ( $SD=2.3$ ) for their overall antenatal care experience, and this was significantly lower than the overall score for those without a long-term disability ( $M=7.5$ ,  $SD=2.0$ ). They reported significantly lower mean scores on: feeling treated with respect and dignity, having their questions answered in a way that they could understand, having confidence and trust in the health care professionals treating/caring for them, feeling involved in decisions on their care, and receiving enough information about physical changes in their body in pregnancy. It is important to note that these differences do not necessarily equate to negative care experiences of those with long-term disabilities. This group's mean scores for feeling treated with respect and dignity, having questions answered in an understandable way, and having confidence and trust in their healthcare professionals were 8.3, 7.9 and 7.9, respectively, out of a maximum score of 10. These aspects of care were among the most positively rated experiences of antenatal care by those with long-term disabilities. However, their ratings on feeling involved in decisions about their care ( $M=6.6$ ) and receiving enough information about physical changes in their body ( $M=5.6$ ) suggest less positive experiences for those with long-term disabilities in these areas.

There were no significant differences between those with and without disabilities with regard to receiving information on smoking, the impact of alcohol and drug use on them and their baby, having a healthcare professional to talk to about their worries and fears, information on nutrition and information on mental health changes in pregnancy.



**Figure 3. Antenatal care experiences of respondents with and without a disability**



\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

## Labour and birth care experience

Figure 4 shows the mean ratings of those with and without long-term disabilities on their experiences of care received during labour and birth across 7 items and overall.<sup>93</sup> Average scores in this area of care ranged from 7.3 to 8.9 for those with long-term disabilities and 7.8 to 9.6 for those without long-term disabilities. The area of care during labour and birth rated lowest among those with a long-term disability was with regards to feeling involved in decisions about their care (M=7.3), while their most positive experience was in having their partner/companion involved in their care during labour and birth as much as they wanted (M=8.9). These were also the least and most positive experiences of care during labour and birth reported by those without long-term disabilities.

Figure 4 also shows that those with long-term disabilities rated their labour and birth care experience significantly differently than those without long-term disabilities overall, and on 3 of the 7 individual items. On average, those with long-term disabilities reported a positive labour and birth care experience (M=8.2, SD=2.3), although their rating was significantly lower than those without long-term disabilities (M=8.7, SD=1.8). They reported significantly lower mean scores on: having their partner/companion involved in their care during labour and birth as much as they wanted, having skin-to-skin contact with their baby shortly after birth<sup>94</sup>, and having their questions answered in an understandable way. Despite these significant differences, those with long-term disabilities reported on average positive experiences in these areas, with mean scores on these items ranging from 7.8 to 8.9 out of 10.

There were no significant differences between those with and without disabilities with regard to having confidence and trust in the health care professionals (HCPs) caring for them during labour and birth, having benefits and risks of tests, procedures and treatments explained in an understandable way, their belief that HCPs did everything to help manage their pain, or feeling involved in decisions about their care.

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<sup>93</sup> Please see Appendix B for the full results represented here.

<sup>94</sup> Two regressions were conducted here – one controlling for type of birth (vaginal or caesarean) due to possible link between caesarean section and lower rates of skin-to-skin contact and one controlling for type of birth (not assisted vaginal/planned caesarean vs assisted vaginal/unplanned caesarean) as a proxy for potentially complicated birth which might have impacted on the opportunity for skin-to-skin contact. Please see Appendix C for these results.

**Figure 4. Labour and birth care experiences of respondents with and without a disability**



\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

## Experience of care in hospital after the birth

Figure 5 shows the mean ratings out of 10 of those with and without long-term disabilities on their experiences of care received in hospital after the birth of their baby across 9 items and overall.<sup>95</sup> Average scores in this area of care ranged from 5.2 to 8.4 for those with long-term disabilities and 5.5 to 9.0 for those without long-term disabilities. The area of care in hospital after birth rated lowest among those with a long-term disability was having the opportunity to ask questions about their labour and birth ( $M=5.2$ ), while the most positive experience was being told who to contact if they were worried about their own health or their baby's health after they were discharged ( $M=8.4$ ). These were also the least and most positive experiences of care during labour and birth reported by those without long-term disabilities.

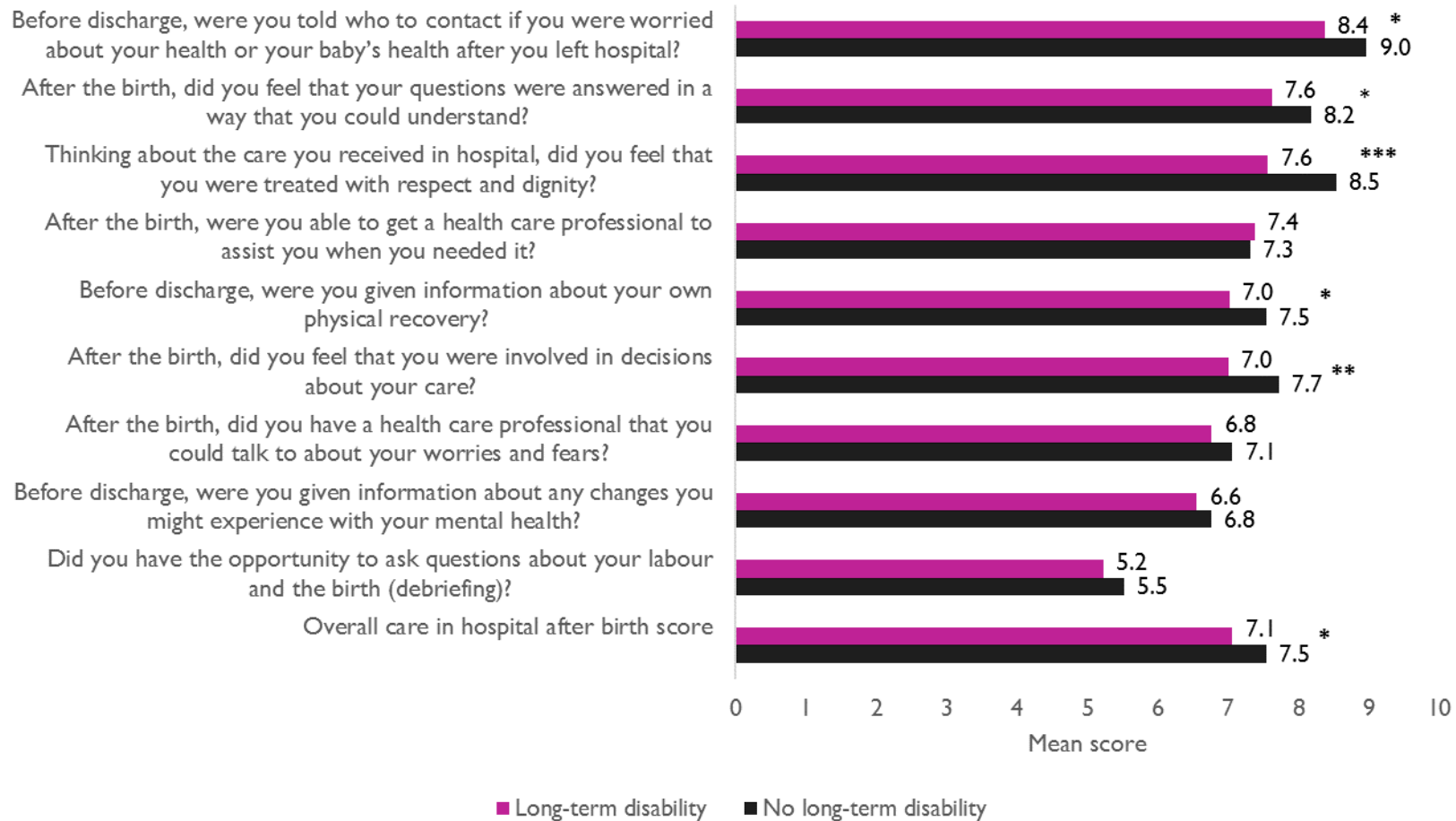
Figure 5 also shows that those with long-term disabilities rated their care in hospital after birth significantly differently than those without long-term disabilities overall, and on 5 of the 9 individual items. Those with long-term disabilities reported quite positive overall experiences of care in hospital after birth ( $M=7.1$ ,  $SD=2.5$ ), although their rating was significantly lower than those without long-term disabilities ( $M=7.5$ ,  $SD=2.2$ ). They reported significantly lower mean scores on: being told who to contact if they were worried about their health or their baby's health after discharge, feeling that their questions were answered in a way they could understand, feeling treated with respect and dignity, being given information on their physical recovery, and feeling involved in decisions about their care after birth. Despite these significant differences, those with long-term disabilities reported on average quite positive experiences in these areas, with mean scores on these items ranging from 7.0 to 8.4 out of 10.

There were no significant differences between those with and without disabilities with regard to getting a HCP to assist them after birth, having a HCP to talk to about worries and fears, receiving information before discharge on any mental health changes they might experience, and having the opportunity to ask questions about their labour and birth ('debriefing'). Women with disabilities gave the question on getting a HCP to assist them after birth a slightly higher mean score than those without disabilities, although this was not statistically significant.

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<sup>95</sup> Please see Appendix B for the full results represented here.

**Figure 5. Experiences of care in hospital after birth of respondents with and without a disability**

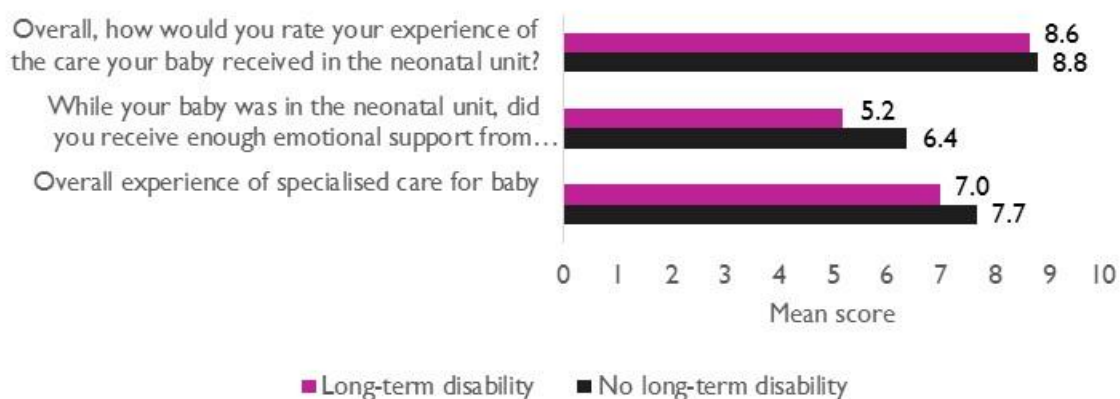


\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

## Specialised care experience

Newborns of women with a long-term disability were more likely to spend time in a neonatal unit (25.8%, n=56) compared to those without a long-term disability (16.9%, n=505) ( $X^2$  (2,  $N$  = 3,155) = 10.5,  $p$  < .01). Figure 6 shows the mean ratings out of 10 of those with and without long-term disabilities whose newborns spent time in the neonatal unit on their experience of specialised care on 2 items and overall.<sup>96</sup> Average scores in this area of care ranged from 5.2 to 8.6 for those with long-term disabilities and 6.4 to 8.8 for those without long-term disabilities. The mean score on overall specialised care experience for those with long-term disabilities was 7.0 out of 10, suggesting quite a positive experience in general. The most positive aspect of this care for parents with and without disabilities was in relation to their experience of the care their baby received ( $M$ =8.6 and  $M$ =8.8, respectively). Parents with and without disabilities had less positive experiences with regard to their experience of emotional support from healthcare professionals ( $M$ =5.2 and  $M$ =6.4, respectively). There were no significant differences between the experiences of those with and without long-term disabilities.

**Figure 6. Specialised care experiences of respondents with and without a disability**



\*  $p$  < .05, \*\*  $p$  < .01, \*\*\*  $p$  < .001

## Care experience in relation to feeding their baby

There was a significant association between type of infant feeding and whether someone had a long-term disability or not ( $X^2$  (3,  $N$  = 3,200) = 21.4,  $p$  < .001). Table 8 shows that women with a disability were less likely to exclusively breastfeed compared to women without a disability (30.4% vs 42.7%) and were more likely to exclusively formula feed (40.6% vs 28.2%). Rates of complementary

<sup>96</sup> Please see Appendix B for the full results represented here.

feeding were quite similar, with 28.1% of women with disabilities feeding their babies breast and formula milk compared to 29.0% of women without disabilities.

**Table 8 – Type of infant feeding by respondents with and without a disability**

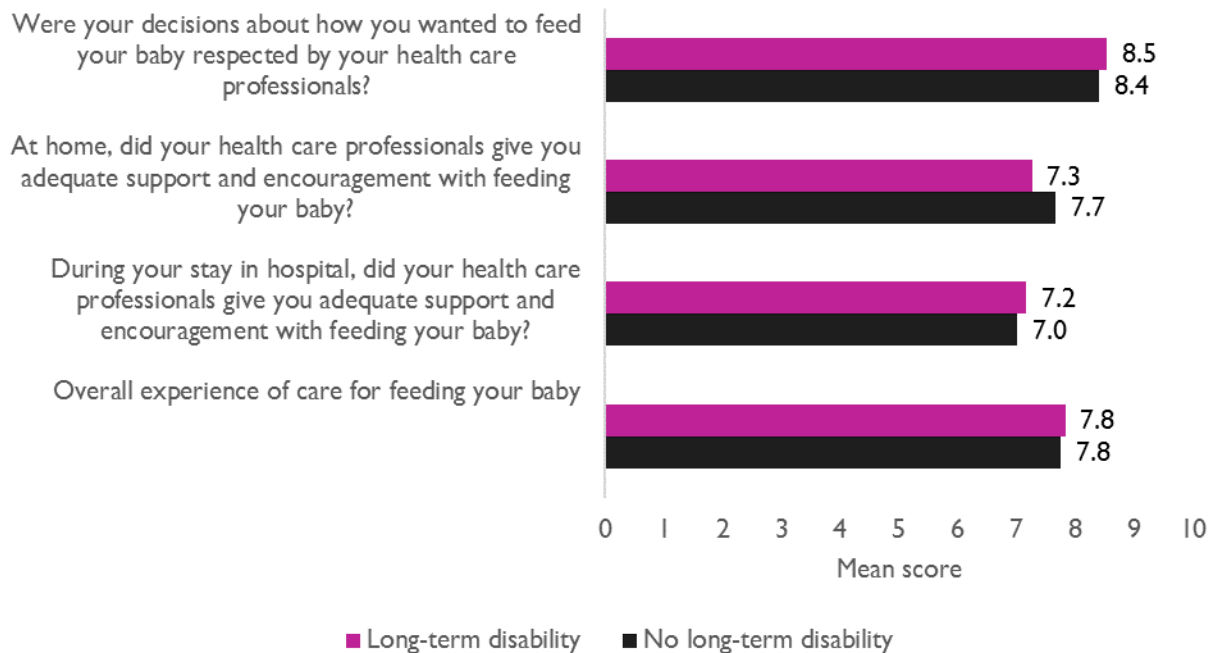
Type of infant feeding	Long-term disability	No long-term disability
Breast milk only	30.4% (n=66)	42.7% (n=1,274)
Breast and formula milk	28.1% (n=61)	29.0% (n=866)
Formula milk only	40.6% (n=88)	28.2% (n=842)
Missing/ Don't know/ Can't remember	0.9% (n=2)	0.2% (n=5)
Total	100.0% (n=217)	100.0% (n=2,987)

Figure 7 shows the mean ratings out of 10 of those with and without long-term disabilities on their experiences of care received in feeding their baby, both in hospital and at home, on 3 items and overall.<sup>97</sup> Average scores in this area of care ranged from 7.0 to 8.5 for those with long-term disabilities and 7.2 to 8.4 for those without long-term disabilities. On average, the experiences reported by those with long-term disabilities were positive ( $M=7.8$ ,  $SD=2.5$ ), and this overall score was the same as those without long-term disabilities ( $M=7.8$ ,  $SD=2.6$ ). The area of care rated lowest by those with long-term disabilities was in relation to getting adequate support and encouragement from healthcare professionals in hospital when feeding their baby ( $M=7.2$ ), while the most positively rated experience was in relation to having their feeding decisions respected by their health care professionals ( $M=8.5$ ). These were also the least and most positive experiences of care for feeding their baby reported by those without long-term disabilities. There were no significant differences between the experiences

<sup>97</sup> Please see Appendix B for the full results represented here.

reported by those with and without long-term disabilities on care for feeding their baby. The mean scores for women with disabilities on having their decisions respected by HCPs, on getting adequate support and encouragement in hospital and overall were slightly higher than for those without disabilities, although these differences were not statistically significant.

**Figure 7. Experiences of care for feeding baby of respondents with and without a disability**



\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

### Experience of care at home after the birth

Figure 8 shows the mean ratings out of 10 of those with and without long-term disabilities on their experiences of care received when they were at home after the birth of their baby on 11 items and overall.<sup>98</sup> Average scores in this area of care ranged from 6.1 to 9.3 for those with long-term disabilities and 5.5 to 9.4 for those without long-term disabilities. On average, the experiences reported by those with long-term disabilities were positive ( $M=8.2$ ,  $SD=1.8$ ), and this overall score was similar to that of those without long-term disabilities ( $M=8.3$ ,  $SD=1.7$ ). The area of care at home rated lowest among those with a long-term disability related to receiving enough information on their physical health from the GP/practice nurse/midwife at the 6 week postnatal check-up. Those with long-term disabilities rated this experience on average 6.1 out of 10, indicating a less

<sup>98</sup> Please see Appendix B for the full results represented here.



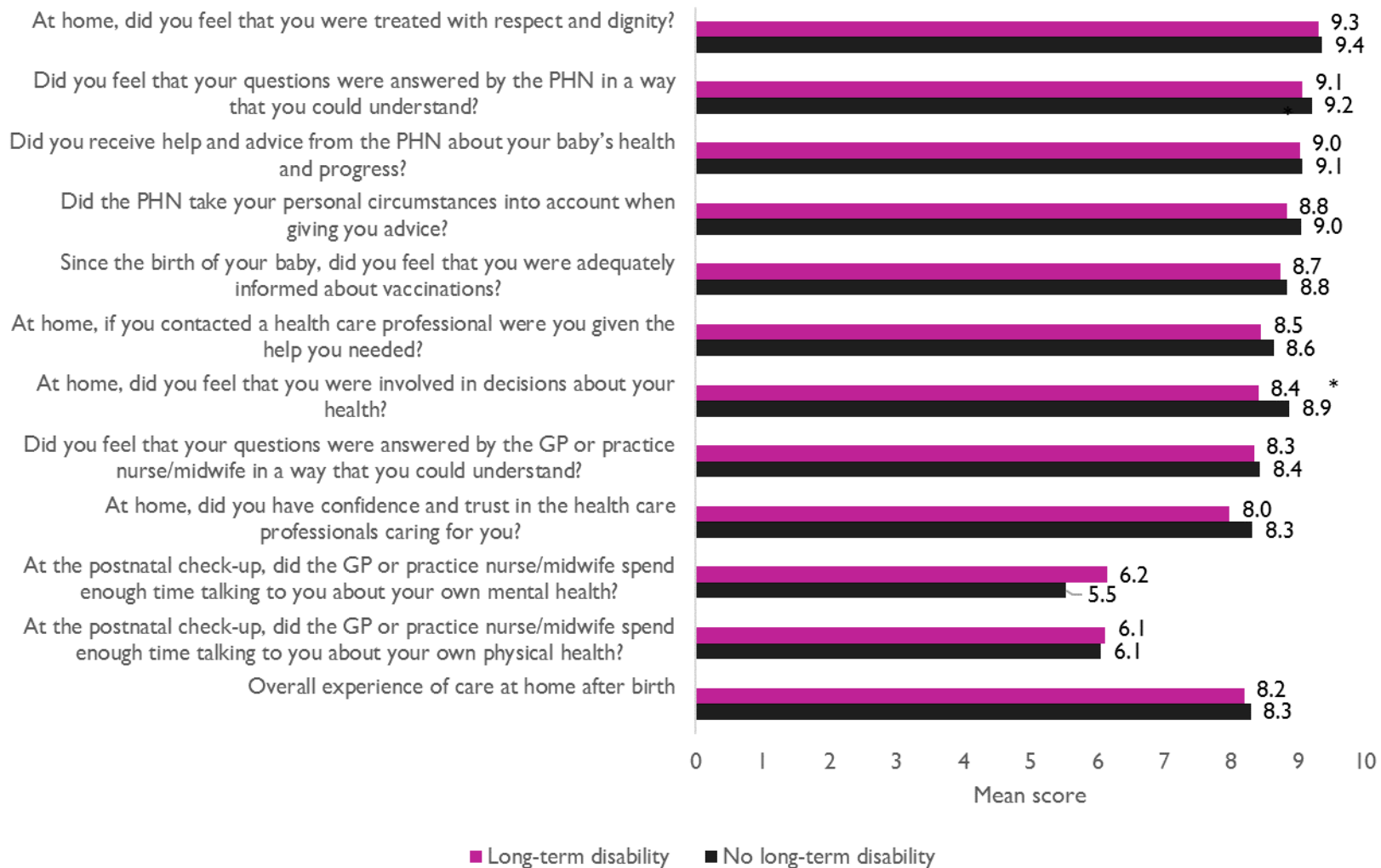
than positive experience. The most positive experience reported by those with long-term disabilities related to feeling treated with respect and dignity at home after the birth, and this was rated 9.3 out of 10, suggesting a very positive experience. Feeling treated with respect and dignity was also the most positive experience reported by those without long-term disabilities ( $M=9.4$ ), but their least positive experience was about getting enough time to talk about their mental health at the 6 week postnatal check-up ( $M=5.5$ ).

Figure 8 also shows that those with long-term disabilities rated their care at home experience significantly differently than those without long-term disabilities in one area. They reported a significantly lower mean score on feeling involved in decisions on their care at home ( $M=8.4$ ,  $SD=2.8$  compared to  $M=8.9$ ,  $SD=2.4$ ). However, their mean score on this item suggests this was generally a positive experience. Of note is that those without a long-term disability rated their experience on spending enough time talking about their mental health at the 6 week postnatal check as poorer than those with a long-term disability ( $M=5.5$ ,  $SD=4.1$  vs  $M=6.2$ ,  $SD=4.1$ ), and this difference in experience almost reached statistical significance ( $p=.054$ ).

Aside from two elements of care at the postnatal check-up, the care experiences of those with long-term disabilities at home after the birth of their baby were rated positively on average, with ratings ranging from 8.0 to 9.3. The two areas where their care experience was less positive were in relation to spending enough time talking about their mental health ( $M=6.2$ ) and physical health ( $M=6.1$ ) with the GP or practice nurse/midwife at the 6 week postnatal check-up.

There were no significant differences between those with and without disabilities with regard to feeling treated with respect and dignity at home, feeling their questions were answered by the PHN in an understandable way, receiving help and advice from the PHN about their baby, having the PHN take into account their personal circumstances when giving advice, feeling adequately informed about vaccinations, getting help from a HCP if they needed, feeling questions were answered by the GP or practice nurse/midwife in a way they could understand, having trust in professionals caring for them at home, and the GP/practice nurse/midwife spending enough time talking to them about their mental or physical health at the postnatal check.

**Figure 8. Experiences of care at home of respondents with and without a disability**

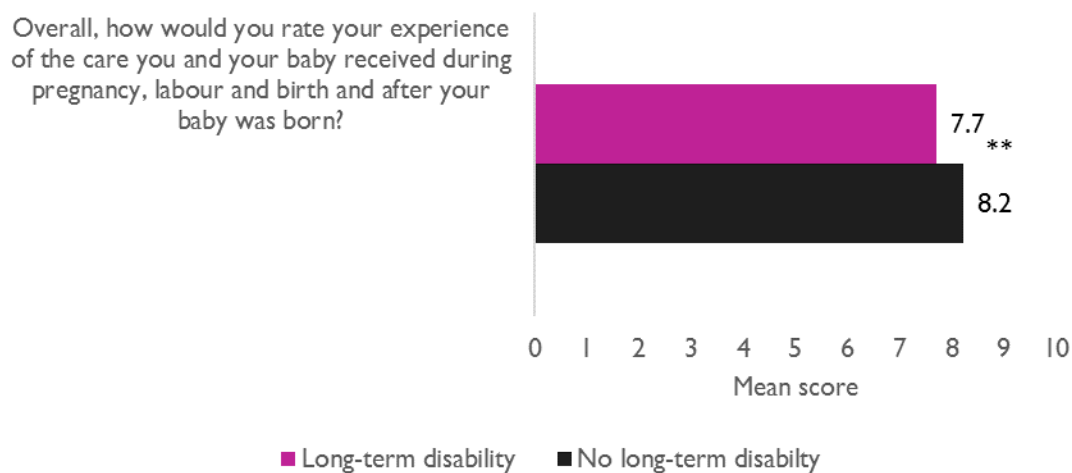


\* $p < .05$ , \*\*  $p < .01$ , \*\*\* $p < .001$

## Overall maternity care experience

Respondents were asked “Overall, how would you rate your experience of the care you and your baby received during pregnancy, labour and birth and after your baby was born?” Figure 9 shows that on average, respondents with long-term disabilities rated their overall experience quite positively, with a mean score of 7.7 out of 10 (SD=2.3).<sup>99</sup> However, this rating was significantly lower than the rating of care experienced by those without long-term disabilities (M=8.2, SD=1.9) indicating a less positive experience for those with long-term disabilities.

**Figure 9. Overall maternity care experience of respondents with and without a disability**



\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

## Most and least positive areas of care experienced

The first graph in Figure 10 shows the overall mean scores for those with long-term disabilities on each specific area of care. With the exception of care for feeding, the mean scores for women with disabilities were lower than those of women without disabilities and were significantly different in the areas of antenatal care, care during labour and birth and care at hospital following birth.

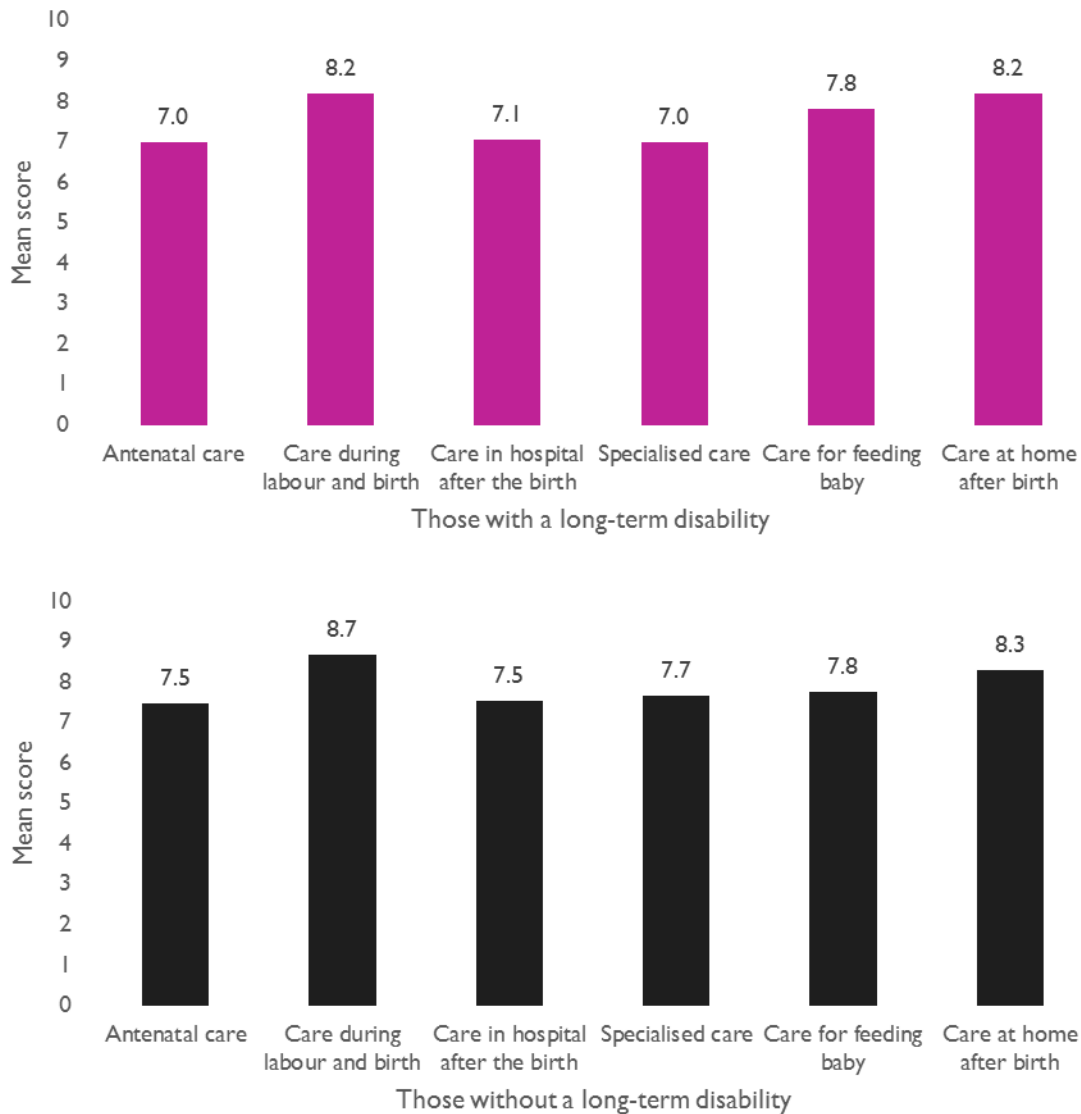
The areas of care for women with disabilities with the lowest scores were antenatal care and specialised care (both 7.0 out of 10), with care in hospital after birth having a similar mean score (7.1 out of 10). The areas with the highest scores were care during labour and birth and care at home after the birth (both 8.2 out of 10). Similarly, the second graph in Figure 10 shows that for those without long-term disabilities, the areas of care with the lowest scores were

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<sup>99</sup> Please see Appendix B for the full results represented here.

antenatal care and care in hospital after birth (both 7.5 out of 10), and the highest score was for care during labour and birth (8.7 out of 10).

**Figure 10. Overall experiences in each area of care of respondents with and without a disability**



Considering all of the specific areas of care respondents were asked about, Table 9 shows the ten most positive experiences reported by those with and without long-term disabilities.

Six of the ten most positive experiences for those with long-term disabilities pertained to experiences at home after the birth of their baby – feeling treated with respect and dignity, having their PHN answer questions in a way they could understand, having the PHN give them help and advice about their baby's

progress, having the PHN take their personal circumstances into account when giving them advice, receiving information on vaccinations and getting help from a health professional if they needed it. Three out of the ten most positive experiences for those with long-term disabilities pertained to experiences during labour and birth –how much their partner/companion could be involved in their care during labour and birth, having confidence and trust in the HCPs caring for them and getting skin-to-skin contact shortly after birth. One of the ten most positive experiences was in relation to having their feeding decisions respected by their healthcare providers. The most positive experiences reported by those without long-term disabilities were very similar, sharing eight of the same ten most positive experiences (areas where they differ are asterisked).

**Table 9 – The most positive maternity experiences by respondents with and without a disability**

<b>Those with long-term disabilities</b>	<b>Those without long-term disabilities</b>
<b>Home:</b> Did you feel that you were treated with respect and dignity? <b>M=9.3</b>	<b>Labour &amp; birth:</b> Was your partner and/or companion involved in your care much as you wanted them to be? <b>M=9.6</b>
<b>Home:</b> Did you feel that your questions were answered by the PHN in a way that you could understand? <b>M=9.1</b>	<b>Home:</b> Did you feel that you were treated with respect and dignity? <b>M=9.4</b>
<b>Home:</b> Did you receive help and advice from the PHN about your baby's health and progress? <b>M=9.0</b>	<b>Labour &amp; birth:</b> Did you have skin to skin contact with your baby shortly after the birth? <b>M=9.3</b>
<b>Labour &amp; birth:</b> Was your partner and/or companion involved in your care as much as you wanted them to be? <b>M=8.9</b>	<b>Home:</b> Did you feel that your questions were answered by the PHN in a way that you could understand? <b>M=9.2</b>
<b>Home:</b> Did the PHN take your personal circumstances into account when giving you advice? <b>M=8.8</b>	<b>Home:</b> Did you receive help and advice from the PHN about your baby's health and progress? <b>M=9.1</b>
<b>Home:</b> Since the birth of your baby, did you feel that you were adequately informed about vaccinations? <b>M=8.7</b>	<b>Home:</b> Did the PHN take your personal circumstances into account when giving you advice? <b>M=9.0</b>
<b>Labour &amp; birth:</b> Did you have confidence and trust in the HCPs	<b>Labour &amp; birth:</b> Did you have confidence and trust in HCPs caring for

Those with long-term disabilities	Those without long-term disabilities
caring for you? <b>M=8.7</b>	you? <b>M=9.0</b>
<b>Labour &amp; birth:</b> Did you have skin to skin contact with your baby shortly after the birth? <b>M=8.6</b>	<b>Antenatal:</b> Did you feel that you were treated with respect and dignity?*
<b>Feeding:</b> Were your decisions about how you wanted to feed your baby respected by your HCPs?*	<b>Care in hospital after baby:</b> Before discharge, were you told who to contact if you were worried about your health or your baby's health after you left hospital? <b>M=9.0</b>
<b>Home:</b> If you contacted a HCP were you given the help you needed?*	<b>Home:</b> Did you feel that you were involved in decisions about your health?*
<b>M=8.5</b>	<b>M=8.9</b>

Table 10 shows the ten least positive experiences reported by those with and without long-term disabilities. Four of these experiences for women with disabilities were in the area of antenatal care: receiving enough information about mental and physical changes that may occur during pregnancy, information on nutrition, and feeling involved in decisions on their care. Three experiences were during care in hospital after birth and included having the opportunity to debrief, receiving information on any changes to their mental health, and having a HCP to talk to about their worries and fears. One of the least positive experiences was during specialised care, on receiving enough emotional support. Two of the least positive experiences pertained to care at home, specifically at the postnatal check on getting enough time to discuss their physical and mental health. The least positive experiences reported by those without long-term disabilities were very similar, sharing nine of the same experiences (areas where they differ are asterisked).

**Table 10 – The least positive maternity experiences by respondents with and without a disability**

Those with long-term disabilities	Those without long-term disabilities
<b>Antenatal:</b> Did you receive enough information about mental health changes that may occur? <b>M=5.0</b>	<b>Antenatal:</b> Did you receive enough information about mental health changes that may occur? <b>M=5.0</b>
<b>Specialised:</b> While your baby was in the neonatal unit, did you receive enough emotional support from	<b>Hospital after birth:</b> Did you have the opportunity to ask questions about your labour and the birth?

Those with long-term disabilities	Those without long-term disabilities
health care professionals? <b>M=5.2</b>	<b>M=5.5</b>
<b>Hospital after birth:</b> Did you have the opportunity to ask questions about your labour and the birth? <b>M=5.2</b>	<b>Home:</b> At the postnatal check-up, did the GP or practice nurse/midwife spend enough time talking to you about your own mental health? <b>M=5.5</b>
<b>Antenatal:</b> Did you receive enough information about physical changes in your body? <b>M=5.6</b>	<b>Home:</b> At the postnatal check-up, did the GP or practice nurse/midwife spend enough time talking to you about your own physical health? <b>M=6.1</b>
<b>Home:</b> At the postnatal check-up, did the GP or practice nurse/midwife spend enough time talking to you about your own physical health? <b>M=6.1</b>	<b>Antenatal:</b> Did you receive enough information about physical changes in your body? <b>M=6.3</b>
<b>Home:</b> At the postnatal check-up, did the GP or practice nurse/midwife spend enough time talking to you about your own mental health? <b>M=6.2</b>	<b>Antenatal:</b> Did you receive enough information about nutrition during pregnancy? <b>M=6.4</b>
<b>Antenatal:</b> Did you receive enough information about nutrition during pregnancy? <b>M=6.2</b>	<b>Specialised:</b> While your baby was in the neonatal unit, did you receive enough emotional support from health care professionals? <b>M=6.4</b>
<b>Hospital after birth:</b> Before you were discharged, were you given information about any changes you might experience with your mental health? <b>M=6.6</b>	<b>Hospital after birth:</b> Before you were discharged, were you given information about any changes you might experience with your mental health? <b>M=6.8</b>
<b>Antenatal:</b> Did you feel that you were involved in decisions about your care?*	<b>Feeding:</b> In hospital, did your health care professionals give you adequate support and encouragement with feeding your baby?*
<b>M=6.6</b>	<b>M=7.0</b>
<b>Hospital after birth:</b> Did you have a HCP that you could talk to about	<b>Hospital after birth:</b> Did you have a HCP that you could talk to about your

<b>Those with long-term disabilities</b>	<b>Those without long-term disabilities</b>
your worries and fears? <b>M=6.8</b>	worries and fears? <b>M=7.1</b>



## Discussion

Overall, there were many similarities between the care experiences of those with and without long-term disabilities, illnesses or conditions. Antenatal care was the least positive experience for both groups, while care at home was their most positive experience. Nearly all of the most and least positive experiences for both groups of women in each area of care and across the entire maternity pathway were the same.

There were also quite a few differences in care experiences reported by those with and without disabilities. Women with disabilities were very slightly less likely to have been offered antenatal classes or given a choice in their care (excluding women who could not be offered a choice of care due to medical conditions). Women with disabilities reported less positive experiences across a number of areas – having confidence and trust in their antenatal caregivers, having their questions answered in an understandable way, being involved in decisions about their care and having their partner involved in their care during labour and birth, getting time for skin-to-skin contact after birth, being treated with respect and dignity, and in receiving information on their physical changes during pregnancy and physical recovery after birth and on who to contact if they were worried about theirs or their baby's health after discharge from hospital.

These findings are similar to those from the English national maternity survey, in that while women with disabilities had mostly positive experiences, they did have poorer perceptions of their experiences compared to women without disabilities with regard to communication, involvement in decisions, feeling respected, getting enough information on physical recovery and having confidence and trust in their healthcare providers.<sup>100</sup> In the Scottish national maternity survey, there was only one reported difference in the experiences of women with and without a disability.<sup>101</sup> This was that women with a disability reported less positive experiences in having their feeding decisions respected by staff. This question was also asked in NMES, but there was no statistically significant difference between those with and without disabilities in this area. Of note though was that this question was one of the few questions where the mean score reported by

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<sup>100</sup> Malouf, R., Henderson, J., and Redshaw, M. (2017) Access and quality of maternity care for disabled women during pregnancy, birth and the postnatal period in England: data from a national survey. *BMJ Open*, 7(e016757).

<sup>101</sup> Cheyne, H., Elders, A., Hill, D., and Milburn, E. (2019) Is maternity care in Scotland equitable? Results of a national maternity care survey. *BMJ Open*, 9(e023282).

women with disabilities was (slightly) higher than women without disabilities. The NMES survey did not cover most of the areas raised as weaknesses in care identified in the previous NDA and NWCI work<sup>102</sup>, however issues around communication and information provision were apparent in this study too.

Where the experiences of women with and without disabilities significantly differed, the experiences of those with disabilities were still generally quite positive-just not as positive as those without disabilities. Differences in care experiences may be due to differing perceptions of care as a result of varying expectations or previous experiences with the health service. And there may also be real differences in the care provided to women due to the knowledge, attitudes and behaviour of healthcare staff, available resources and the culture of a workplace.

A particularly positive aspect of NMES, and the National Care Experience Programme that it is part of, is that the HSE, maternity services and CHO areas have responded to the feedback from mothers through developing comprehensive national and local quality improvement plans.<sup>103</sup> The findings of this report suggest it is critical to ensure that these initiatives will adequately address the needs of women with disabilities or additional care needs. Otherwise, they may serve to perpetuate or exacerbate differences in the care experiences of those with and without disabilities.

This section will discuss the least positive experiences of women with disabilities in their maternity journey, and the areas where they reported different experiences to women without disabilities. It will identify some of the HSE's key initiatives which intend to improve the maternity care experiences of women and will offer some suggestions on how the specific needs of women with disabilities can be met. It will also signpost areas where the HSE has a statutory duty in its service provision to people with disabilities.

## **Communication**

One of the least positive experiences for women with and without disabilities was in relation to debriefing after their baby's birth, with one in four mothers

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<sup>102</sup> Begley et al. (2010). The strengths and weaknesses of publicly-funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth and early motherhood. Retrieved from [http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20\\_full\\_%2018th%20may%202010.pdf](http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20_full_%2018th%20may%202010.pdf)

<sup>103</sup> HSE. (2020) Listening, responding, and improving. The HSE response to the findings of the national maternity experience survey. Retrieved from <https://www.hse.ie/eng/services/publications/hse-response-to-the-findings-of-the-national-maternity-experience-survey-2020.pdf>

reporting that they didn't get an opportunity to ask questions about their labour and birth. Findings from this report also indicate that women with long-term disabilities, illnesses or conditions needed better communication from healthcare professionals in having their questions answered in an understandable way during antenatal care, labour and birth and care in hospital after birth. Of note, is that this did not emerge as an issue when women with disabilities were interacting with PHNs, GPs or practice nurses/midwives once they were at home after their baby's birth. The findings also showed that at a number of points on their maternity journey, women with disabilities did not feel as involved in decisions about their care as women without disabilities. These findings are similar to other research on the maternity experiences of women with disabilities, where areas of communication, including not feeling listened to, not having questions answered in an understandable way or feeling involved in decisions on care have been identified as service weaknesses, or areas where the experiences of women with and without disabilities diverge.<sup>104</sup>

One of the key ways the HSE intends to improve services following NMES is the roll out of a maternity-specific National Healthcare Communication Programme (NHCP).<sup>105 106</sup> This programme aims to improve the skills of healthcare staff in encouraging shared decision-making, showing empathy, information provision and in debriefing following birth. The NDA acknowledges that the NHCP is underpinned by core communication skills which should be applicable for all interactions between HCPs and service users. However, women with particular disabilities will have specific communication needs which may not be adequately addressed by the proposed programme.

The NDA have been involved in developing a number of guidance documents on ensuring accessible communication with service users:

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<sup>104</sup> Malouf, R., Henderson, J., and Redshaw, M. (2017) Access and quality of maternity care for disabled women during pregnancy, birth and the postnatal period in England: data from a national survey. *BMJ Open*, 7(e016757).

<sup>105</sup> HSE. (2020) Listening, responding, and improving. The HSE response to the findings of the national maternity experience survey. Retrieved from <https://www.hse.ie/eng/services/publications/hse-response-to-the-findings-of-the-national-maternity-experience-survey-2020.pdf>

<sup>106</sup> See <https://www.hse.ie/eng/about/our-health-service/healthcare-communication/>

- The NDA and HSE's National Guidelines on Accessible Health and Social Care Services which includes information on tailoring communication to people with different types of disabilities.<sup>107</sup>
- The NDA's Centre for Excellence in Universal Design's (CEUD's) revised Customer Communications Toolkit for the Public Service.<sup>108</sup> This Toolkit provides guidance for designing and procuring communications using a Universal Design approach to ensure accessibility and covers written, spoken, signed and digital communication. Universal Design is about creating an environment that can be accessed, understood and used to the greatest extent possible by all people, regardless of their age, size, ability or disability.

The NDA advise the National Healthcare Communication Programme to ensure that it incorporates the use of the National Guidelines on Accessible Health and Social Care Services and the Customer Communications Toolkit for the Public Service in its modules.

The HSE have also indicated that a 'Safer to Ask' leaflet series<sup>109</sup> will be promoted, which encourages patients to be involved in their care decisions. Considering that women with disabilities feel less involved in decisions on their care, it is important that these leaflets be made accessible for all women using maternity services. This would include for example, women with learning disabilities being able to access an easy read version and ensuring online versions are accessible to those using assistive technology such as screen readers.

The NDA advise the HSE's Quality and Patient Safety Directorate to ensure that the 'Safer to Ask' leaflet series are accessible to women with disabilities.

Although it did not emerge as an issue in this study, it is important to note the commencement of the Irish Sign Language Act 2017 in 2020. Under this Act, public bodies are required to provide access to statutory services through Irish Sign Language (ISL) when requested. Given the challenges reported in the previous NDA and NWCI research by some women with hearing impairments in

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<sup>107</sup> HSE and NDA. (2014) National guidelines on accessible health and social care services.

Retrieved from

<https://www.hse.ie/eng/services/yourhealthservice/access/natguideaccessibleservices/natguideaccessibleservices.pdf>

<sup>108</sup> NDA and DPER. (2019) Customer communications toolkit for the public service. Retrieved from <http://universaldesign.ie/products-services/customer-communications-toolkit-for-the-public-service-a-universal-design-approach/customer-communications-toolkit-for-the-public-services-a-universal-design-approach.pdf>

<sup>109</sup> See <https://www.hse.ie/eng/services/yourhealthservice/hcharter/safertoask.pdf>

accessing interpretation services during maternity care, this is a particularly positive step.

The NDA remind the HSE of their statutory duty under the Irish Sign Language Act 2017 to provide access to maternity services through ISL for members of the Deaf and hard-of-hearing community who are ISL signers.

### **Information provision on health and wellbeing**

Respondents to NMES reported positive experiences with regard to receiving information on risky health behaviours such as smoking, alcohol and drugs, and on their baby's vaccinations. However, the results suggested areas of weakness with regard to getting information on health and wellbeing - specifically, on women's physical health, mental health, and nutrition in the antenatal period and on needing more time to discuss their physical and mental health at the six week postnatal visit with the GP or GP practice nurse/midwife. One of the previous criticisms of maternity services in Ireland was that there was an "inadequate emphasis on general health and wellbeing"<sup>110</sup>. As a result, the National Maternity Strategy places a particular emphasis on health and wellbeing. However, these findings suggest that this may still be an area of weakness in the care provided to women in maternity services in Ireland.

The current report identified gaps between women with and without long-term disabilities, illnesses or conditions in receiving information on the physical changes to their body during pregnancy, on their physical recovery after birth and on who to contact once they were discharged from hospital if they were concerned about their health or their baby's health. These gaps may allude to difficulties in communication between HCPs and women with disabilities. However, they may also suggest a lack of knowledge or understanding on the part of staff members on particular disabilities or conditions, as was identified as an issue in the previous NDA and NWCI study in Ireland.<sup>111</sup> A key underpinning of the National Maternity Strategy is women-centred care and these findings suggest that that further improvements are needed to ensure that maternity services are adequately tailored to women's individual needs.

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<sup>110</sup> Department of Health. (2016) National maternity strategy. Creating a better future together. 2016 – 2026, p.4. Retrieved from <https://assets.gov.ie/18835/ac61fd2b66164349a1547110d4b0003f.pdf>

<sup>111</sup> Begley et al. (2010). The strengths and weaknesses of publicly-funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth and early motherhood. Retrieved from [http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20\\_full\\_%2018th%20may%202010.pdf](http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20_full_%2018th%20may%202010.pdf)

In the HSE's response to NMES, they outlined ways in which healthcare staff were being supported in their caring roles, one of which is efforts to improve staffing levels, which would give staff more time to engage with the women in their care. This would facilitate the realisation of the National Maternity Strategy's vision of woman-centred care. They have also highlighted recently developed information resources which are available to all pregnant families and parents of young children which may help to address reported gaps in information on health and wellbeing. These include books (My Pregnancy<sup>112</sup>, My Child: 0-2 years<sup>113</sup> and My Child: 2-5 years<sup>114</sup>) and a website ([www.mychild.ie](http://www.mychild.ie)), which provide expert advice and guidance on pregnancy and early childhood. Parents should receive the My Pregnancy book from maternity services and the My Child books from their PHN in the community. The HSE also notes that a mobile phone application for pregnancy is being considered.

The NDA advise that the National Women and Infants Health Programme and the National Healthy Childhood Programme develop easy to read versions of the My Pregnancy and My Child books and ensure online versions of these books are in a format suitable for those using assistive technologies. The NDA also advise that these programmes use the Customer Communications Toolkit for the Public Service when planning future revisions of these resources.

Under the EU Web Accessibility Directive (EU) 2016/2102<sup>115</sup>, public bodies are required to ensure their websites and applications are accessible to persons with disabilities.

The NDA remind the HSE that their websites, including [mychild.ie](http://mychild.ie), and mobile applications should meet the standards set out in the EU Web Accessibility Directive.

The HSE have also outlined that the implementation of the recently developed National Antenatal Education Standards<sup>116</sup> will help to meet the informational needs of women during pregnancy. These standards refer to tailoring education to meet the learning needs of different groups, including women with disabilities.

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<sup>112</sup> See <https://www2.hse.ie/file-library/child-health/my-pregnancy-book.pdf>

<sup>113</sup> See <https://www2.hse.ie/file-library/child-health/my-child-0-to-2-years-book.pdf>

<sup>114</sup> See <https://www2.hse.ie/file-library/child-health/my-child-2-to-5-years-book.pdf>

<sup>115</sup> EU Web Accessibility Directive (EU) 2016/2102. Retrieved from <https://eur-lex.europa.eu/legal-content/en/TXT/?uri=CELEX%3A32016L2102>

<sup>116</sup> HSE. (2020) National standards for antenatal education in Ireland. Retrieved from <https://www.hse.ie/eng/about/who/healthwellbeing/our-priority-programmes/child-health-and-wellbeing/antenatal-ed.pdf>

The NDA advise the National Women and Infants Health Programme to consider the National Guidelines on Accessible Health and Social Care Services and the Customer Communications Toolkit for the Public Service in the design of antenatal education classes and resources, and remind them of the HSE's duties under the EU Web Accessibility Directive and the Irish Sign Language Act 2017.

In general, women with and without disabilities had positive experiences in their care at home following their baby's birth, with the exception of getting enough time to discuss their physical and mental health with their GP or practice nurse/midwife at the six week postnatal check-up. In response to this finding, the Irish College of General Practitioners (ICGP) acknowledged that "Integral to quality care is the need to give time to the women attending their GP...particularly in the early days of postnatal care".<sup>117</sup> A poll of 1,000 attendees at a seminar which was raising awareness of the NMES findings indicated that half of those participating in the poll "indicated a need for more time per consultation".<sup>118</sup> However, there was no indication as to whether women will be offered more time at antenatal and postnatal appointments as a result. The ICGP did indicate that findings from the survey will be used to inform updates to GP training, and that in early 2021 GPs will have access to an education pack which emphasises reflective practice and improving communication skills. Additionally education and training will be available to practice nurses/midwives where relevant. To ensure that the gap that emerged between the care received by women with and without disabilities at parts of the maternity pathway does not occur during GP visits:

The NDA advise the ICGP and the Nursing and Midwifery Board of Ireland to consider specific training in accessible communication and information provision for GPs and for practice nurses/midwives who are a main contact for women in the antenatal and postnatal periods. The National Guidelines on Accessible Health and Social Care Services would be a useful reference point for any future education or training.

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<sup>117</sup> HSE. (2020) Listening, responding, and improving. The HSE response to the findings of the national maternity experience survey, p.11. Retrieved from <https://www.hse.ie/eng/services/publications/hse-response-to-the-findings-of-the-national-maternity-experience-survey-2020.pdf>

<sup>118</sup> HSE. (2020) Listening, responding, and improving. The HSE response to the findings of the national maternity experience survey, p.12. Retrieved from <https://www.hse.ie/eng/services/publications/hse-response-to-the-findings-of-the-national-maternity-experience-survey-2020.pdf>

## **Choice, control, respect and dignity**

Women with long-term disabilities were slightly less likely to have been offered antenatal classes or offered a choice in their care (excluding women who could not be offered choice of care due to medical conditions). These were small differences, and do not necessarily suggest that women with disabilities were having their choices restricted. However, there was a clear pattern where women with disabilities did not feel as involved in decisions on their care as women without disabilities during antenatal care, care in hospital after birth and care at home after birth. This was the only area where women with disabilities differed to women without disabilities during their care at home. Given that women with disabilities reported less positive experiences with regard to having their questions answered in an understandable way at a number of points in their care, this may have meant they did not have enough information to make informed choices. As previously noted, the NHCP<sup>119</sup> and 'Safer to Ask' leaflet series<sup>120</sup> are two of the ways in which the HSE will seek to improve how staff and service users work together on decisions about care.

However, as well as feeling less involved in decisions on their care, women with disabilities also reported less positive experiences in having their partners involved in their care during labour and birth. This may suggest a need to improve the disability competence of health professionals. This is reinforced by the fact that women with disabilities also reported less positive experiences with regard to being treated with respect and dignity during antenatal care and care in hospital after birth. Of note here is that the most positive experience of women with disabilities in their entire maternity journey was being treated with respect and dignity at home. This suggests more of a need to improve disability competence in maternity settings than in the community. Antenatal settings would be a priority given that antenatal care had the most gaps in experience between women with and without disabilities, and in particular, women with disabilities reported less confidence and trust in their antenatal caregivers. It is important to note here again, that although there were differences in experiences between women with and without disabilities, the findings do not indicate that women with disabilities had negative experiences. However, what these differences suggest are perhaps subtle differences in treatment. In line with Standard 6.3.20 of the National Standards for Safer Better Maternity care, disability competence training is suggested to equip staff "with the skills and

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<sup>119</sup> See <https://www.hse.ie/eng/about/our-health-service/healthcare-communication/>

<sup>120</sup> See <https://www.hse.ie/eng/services/yourhealthservice/hcharter/safertoask.pdf>



understanding to provide person-centred care and support to women with disabilities, appropriate to their role.”<sup>121</sup>

The NDA advise that maternity hospitals/units facilitate healthcare staff to undergo disability competence training. The NDA also advise that CHO areas facilitate PHNs to undergo disability competence training. It will be important that such training is tracked and evaluated and that it is designed with the input of women with disabilities particularly those with experience of maternity services.

Given that women with disabilities were given less choice in their type of maternity care and felt less involved in the decisions made on their care at times, it is worth noting the Assisted Decision-Making (Capacity) Act 2015 (ADMA). The ADMA will have an impact on how maternity services engage with women with particular disabilities in making decisions on their care once it is fully commenced in 2022. In this instance, the Act will apply to women over the age of 18 who may lack capacity to make decisions on their maternity care, or who require assistance to make decisions on their maternity care. Previously, in such cases, other people such as family members, carers or healthcare staff will likely have made decisions for these women and this tended to be on the basis of what was in their (or their baby's) best interest. Under the Act, maternity healthcare staff will need to presume that women have the capacity to make decisions relevant to their care, unless proven otherwise, and they will have to give effect to the will and preferences of the woman as far as practicable. Healthcare staff should also seek to identify whether the woman has created an Advance Healthcare Directive, which is advance expression made by a person with capacity in accordance with the requirements of the 2015 Act of the person's will and preferences concerning healthcare treatment decisions that may arise if he or she subsequently lacks capacity. However, the 2015 Act imposes restrictions on the enforceability of an advance refusal of treatment contained in an Advance Healthcare Directive where a Directive-Maker lacks capacity and is pregnant. These restrictions apply only where the health and social care professional concerned considers that the refusal of treatment 'would have a deleterious effect on the unborn'. More information is contained in the Code of Practice on Advance Healthcare Directives for Health and Social Care Professionals, which will be made public in due course. A new decision-making support framework will be established under the legislation, which will see various 'decision-making supporters' work with people to maximise their capacity to make decisions. The level of involvement of these supporters will depend on the person's level of capacity to make the decision in question. In some cases, the High Court will

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<sup>121</sup> HIQA. (2016) National standards for safer better maternity services. Retrieved from <https://www.hiqa.ie/sites/default/files/2017-02/national-standards-maternity-services.pdf>

appoint a Decision-Making Representative to make decisions on behalf of the individual, where that individual lacks decision-making capacity. The Decision Support Service is a new body established by the legislation, and will regulate and monitor decision-making support arrangements. This means that in these situations healthcare staff in maternity services will have to engage with both the woman under their care and the decision-making supporter.

The NDA remind maternity services that under the Assisted Decision Making (Capacity) Act 2015 they will be required to adopt new policies and procedures in how they involve women who may lack capacity to make decisions on their maternity healthcare.

### **Information and discussion on mental health during and after pregnancy**

The least positive experience reported by women with and without disabilities in their entire maternity journey was not getting information on mental health changes during pregnancy. Some of their other least positive experiences included not getting information on any changes to their mental health after they've given birth, or getting enough time to discuss their mental health at the six week postnatal check with the GP or GP practice nurse/midwife. This is a critical gap given that it is estimated that up to one fifth of women develop a mental health problem during pregnancy or in the year after birth<sup>122</sup>, with depression and anxiety being most common.<sup>123</sup> Pre-existing mental health conditions may also be exacerbated during or after pregnancy.<sup>124,125</sup>

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<sup>122</sup> Royal College of Obstetricians and Gynaecologists. (2017) Maternal mental health-women's voices. Retrieved from

<https://www.rcog.org.uk/globalassets/documents/patients/information/maternalmental-healthwomens-voices.pdf>

<sup>123</sup> National Institute for Health Care and Excellent (NICE). (2014) Antenatal and postnatal mental health: clinical management and service guidance. Retrieved from <https://www.nice.org.uk/guidance/cg192/resources/antenatal-and-postnatal-mental-health-clinical-management-and-service-guidance-pdf-35109869806789>

<sup>124</sup> Viguera, A. C., Tondo, L., Koukopoulos, A. E., Reginaldi, D., Lepri, B., and Baldessarini, R. J. (2011) Episodes of mood disorders in 2,252 pregnancies and postpartum periods. *American Journal of Psychiatry*, 168(11), pp.1179-1185.

<sup>125</sup> National Institute for Health Care and Excellent (NICE). (2014) Antenatal and postnatal mental health: clinical management and service guidance. Retrieved from <https://www.nice.org.uk/guidance/cg192/resources/antenatal-and-postnatal-mental-health-clinical-management-and-service-guidance-pdf-35109869806789>

In the previous NDA and NWCI report, a key issue raised was that only 2 of the 19 maternity hospitals/units provided access to specialist mental health services.<sup>126</sup> Since then, this issue has been addressed with the roll out of a National Specialist Perinatal Mental Health Service to treat those with mental illness or who acquire mental illness during or after pregnancy. This service has also developed a series of information leaflets on mental health in pregnancy which were published in 2020 after the NMES survey took place.<sup>127</sup>

The NDA advise that the National Programme for Specialist Perinatal Mental Health Services ensure that their 2020 series of mental health information leaflets are accessible to women with disabilities.

### **Interpersonal support**

Two of the least positive experiences reported by women with and without disabilities were around having a HCP to talk to about their worries and fears in hospital after the birth and getting enough emotional support from HCPs if their baby was in a neonatal unit. In addition, the newborns of women with disabilities in NMES were more likely to spend time in the neonatal unit. As previously noted, women with disabilities had less positive experiences than women without disabilities during antenatal care, including for example, less positive experiences in having their questions answered in understandable ways, being treated with respect and dignity, and being involved in decisions on their care. Given this, it is perhaps not surprising that they also reported less confidence and trust in their antenatal healthcare provider.

In their response to NMES, the HSE did acknowledge the challenge for healthcare staff: “Working in health care carries an increased risk of burnout in comparison to other professions, when burnout occurs staff can often deliver care in a depersonalised way.”<sup>128</sup> As well as addressing issues with staffing levels, the HSE have indicated a range of initiatives seeking to encourage cultural shifts in the

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<sup>126</sup> Begley et al. (2010). The strengths and weaknesses of publicly-funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth and early motherhood. Retrieved from

[http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20\\_full\\_%2018th%20may%202010.pdf](http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20_full_%2018th%20may%202010.pdf)

<sup>127</sup> See <https://www.hse.ie/eng/services/list/4/mental-health-services/specialist-perinatal-mental-health/>

<sup>128</sup> HSE. (2020) Listening, responding, and improving. The HSE response to the findings of the national maternity experience survey, p.61. Retrieved from <https://www.hse.ie/eng/services/publications/hse-response-to-the-findings-of-the-national-maternity-experience-survey-2020.pdf>

health service, in order to improve work environments and the way care is delivered.<sup>129</sup>

In the response to NMES, the National Clinical Programme for Neonatology have encouraged staff working in neonatology to take HSE communication skills training and have indicated that one of the key values which will underpin an update to the neonatal model of care will be an approachable service.<sup>130</sup>

The NDA would encourage the National Clinical Programme for Neonatology that any communications skills training undertaken by staff working in neonatology will include accessible communication with service users with disabilities. The skills training should be underpinned by the National Guidelines on Accessible Health and Social Care Services.

### **Skin-to-skin contact**

This report found a difference in experience between women with and without disabilities with regard to skin-to-skin contact after birth, even when taking into consideration a potentially complicated birth or a caesarean section which might have explained differing rates of skin-to-skin contact. Almost three in ten (28%) women with disabilities did not have skin-to-skin contact compared to 17% of women without disabilities. For 16% of women with disabilities this was due to medical reasons, compared to 11% of women without disabilities (and 0.3% of these women did not want skin-to-skin contact). This means that there was no clear reason why 12% of women with disabilities and 6% of women without disabilities would not have had skin-to-skin contact after birth.

Considering the promotion of skin-to-skin contact is strongly linked to the promotion of breastfeeding<sup>131</sup>, and that women with disabilities in this study were more likely to exclusively formula feed their babies, further exploration of the data was conducted to consider whether type of feeding had an impact on these findings. The results indicated that once type of feeding was controlled for, the difference in experience between women with and without disabilities on skin-to-skin contact was no longer statistically significant. Considering the NMES sample

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<sup>129</sup> Including, Values in Action, Caring Behaviours Assurance System, National Programme to Enable Cultures of Person-Centredness, Open Disclosure, Schwartz Rounds.

<sup>130</sup> HSE. (2020) Listening, responding, and improving. The HSE response to the findings of the national maternity experience survey. Retrieved from <https://www.hse.ie/eng/services/publications/hse-response-to-the-findings-of-the-national-maternity-experience-survey-2020.pdf>

<sup>131</sup> See <https://www.unicef.org.uk/babyfriendly/baby-friendly-resources/implementing-standards-resources/skin-to-skin-contact/>

as a whole, analyses found that those who formula fed exclusively were significantly less likely to have engaged in skin-to-skin contact soon after birth.<sup>132</sup>

Regardless of intention to formula feed or breastfeed, under the 2019 HSE National Infant Feeding Policy for Maternity & Neonatal Services, “2.7.17: All mothers and their babies should have unhurried SSC [skin-to-skin contact] immediately following the birth and it should be continued uninterrupted for at least 60 minutes.”<sup>133</sup> Skin-to-skin contact is important for all mothers and babies as it develops the infant’s microbiome<sup>134</sup> and promotes mother-infant attachment.<sup>135</sup> It is unclear why women who formula fed their babies were less likely to have had skin-to-skin contact. It may have been a lack of skin-to-skin contact which made breastfeeding more challenging, or it may be that women who planned to breastfeed were more likely to advocate for it given it can facilitate breastfeeding. It might also suggest that maternity services are less likely to provide skin-to-skin time for mothers who intend to formula feed. If this is the case, this practice could unfairly disadvantage women with disabilities, as there may be some who cannot breastfeed due to medical reasons or medication contraindications.

The NDA advises that maternity hospitals/units give an opportunity for skin-to-skin contact for all women equally regardless of disability status or choice of feeding method.

Although there is limited literature on the experiences of breastfeeding by women with disabilities<sup>136</sup>, the findings here align with other evidence that suggests women with disabilities are less likely to breastfeed than women without

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<sup>132</sup> See Appendix C for these analyses.

<sup>133</sup> HSE. (2019) National infant feeding policy for maternity & neonatal services, p. 7. Retrieved from <https://www.hse.ie/file-library/infant-feeding-policy-for-maternity-neonatal-services-2019.pdf>

<sup>134</sup> Mutic, A. D., Jordan, S., Edwards, S. M., Ferranti, E. P., Thul, T. A. and Yang, I., (2017) The postpartum maternal and newborn microbiomes. *American Journal of Maternal Child Nursing*, 42(6), pp.326-331.

<sup>135</sup> Cleveland, L., Hill, C.M., Pulse, W.S., DiCioccio, H.C., Field, T. and White-Traut, R. (2017) Systematic review of skin-to-skin care for full-term, healthy newborns. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, 46(6), pp.857-869.

<sup>136</sup> Andrews, E. E., Powell, R. M. and Ayers, K. B. (2021) Experiences of breastfeeding among disabled women. *Women's Health Issues*, 31(1), pp.82-89.

disabilities.<sup>137</sup> <sup>138</sup> Possible reasons for this may be because of the disability itself or medication contraindications – for example in women who are taking certain antidepressants. However, in this study, women with mental health conditions were just as likely as women with other types of disability to breastfeed. The breastfeeding journey may be also more challenging for women with certain disabilities. Women with physical disabilities may need assistance with breastfeeding positions, and women with sensory and learning difficulties will need advice tailored specifically to their communication needs.

The NDA advise the HSE's National Breastfeeding Implementation Group and maternity hospitals/units that a future national audit of National Breastfeeding Standards be focussed on women with disabilities to ensure that all standards are being met in their care and support for breastfeeding.

### **Accessibility of environment**

In the previous NDA and NWCI research, issues with infrastructure and the physical environment were identified as weaknesses in maternity care for women with disabilities.<sup>139</sup> As NMES was a general population survey it did not explore this issue. However, as noted earlier, the “substandard physical environment and infrastructure of units and hospitals”<sup>140</sup> was identified as a problem area in HIQA's recent inspections of all maternity hospitals. This has particular relevance for women with disabilities. In addition, the Joint Oireachtas Committee on Disability Matters recently heard that women with disabilities still experience

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<sup>137</sup> Mitra, M., Clements, K.M., Zhang, J., Iezzoni, L.I., Smeltzer, S.C. and Long-Bellil, L.M. (2015) Maternal characteristics, pregnancy complications and adverse birth outcomes among women with disabilities. *Medical Care*, 53(12), pp.1027-1032.

<sup>138</sup> Morton, C., Le, J.T., Shahbandar, L., Hammond, C., Murphy, E.A. and Kirschner, K.L. (2013) Pregnancy outcomes of women with physical disabilities: a matched cohort study. *American Academy of Physical Medicine and Rehabilitation*, 5(2), pp.90-98.

<sup>139</sup> Begley et al. (2010). The strengths and weaknesses of publicly-funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth and early motherhood. Retrieved from [http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20\\_full\\_%2018th%20may%202010.pdf](http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20_full_%2018th%20may%202010.pdf)

<sup>140</sup> HIQA. (2020) Overview report of HIQA's monitoring programme against the national standards for safer better maternity services, with a focus on obstetric emergencies, p.6. Retrieved from <https://www.hiqa.ie/sites/default/files/2020-02/Maternity-Overview-Report.pdf>

issues in accessing basic health services.<sup>141</sup> It is clear that these issues have not been entirely addressed in the time since the NDA and NWCI work.

Public bodies have a statutory duty to ensure access to services for people with disabilities under the Disability Act 2005 and to ensure that their public buildings are, as far as practicable, accessible to persons with disabilities. This includes a requirement under Section 25(3) of the Act to bring public buildings, into compliance with Part M of the building regulations by January 2022. The NDA's CEUD has produced "Building for Everyone: A Universal Design Approach"<sup>142</sup>, comprehensive best practice guidance on how to design, build and manage buildings and spaces so that they can be readily accessed and used by everyone regardless of a person's age, size, ability or disability.

The NDA remind the HSE of their statutory duty under the Disability Act 2005 to ensure access to services for people with disabilities. There are recommendations to facilitate public bodies to meet their obligations to make public building accessible in An Operational Review of the Effectiveness of Section 25 of the Act<sup>143</sup>, carried out by the NDA and the Office of Public Works (OPW). The NDA encourage the HSE and Hospital Groups to adopt a Universal Design approach in the design or redesign of maternity hospitals/units to ensure accessibility for all.

As noted earlier, the National Standards for Safer Better Maternity Care<sup>144</sup> and the new National Antenatal Education Standards<sup>145</sup> specify that physical environments for maternity care and antenatal education should meet the needs of women with a physical disability. While this is welcomed, the needs of those with sensory disabilities such as those with a visual or hearing impairment, or those who may be on the autistic spectrum also need to be considered.

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<sup>141</sup> Joint Committee on Disability Matters debate, 9 March 2021. Retrieved from [https://www.oireachtas.ie/en/debates/debate/joint\\_committee\\_on\\_disability\\_matters/2021-03-09/2/](https://www.oireachtas.ie/en/debates/debate/joint_committee_on_disability_matters/2021-03-09/2/)

<sup>142</sup> NDA. (2012) Building for everyone: A universal design approach. Retrieved from <http://universaldesign.ie/Built-Environment/Building-for-Everyone>

<sup>143</sup> NDA and OPW. (2019) An operational review of the effectiveness of section 25 of the disability act. Retrieved from <http://nda.ie/publications/environment-housing/environment-publications/operational-review-of-the-effectiveness-of-section-25-of-the-disability-act-20051.pdf>

<sup>144</sup> HIQA. (2016) National standards for safer better maternity services. Retrieved from <https://www.hiqa.ie/sites/default/files/2017-02/national-standards-maternity-services.pdf>

<sup>145</sup> HSE. (2020) National standards for antenatal education in Ireland. Retrieved from <https://www.hse.ie/eng/about/who/healthwellbeing/our-priority-programmes/child-health-and-wellbeing/antenatal-ed.pdf>

The NDA encourage HIQA to consider the needs of those with sensory disabilities in Standard 2.7 of the National Standards for Safer Better Maternity Care.

The NDA advise the National Women and Infants Health Programme that the implementation of Antenatal Education Standard 2.2 be extended to include those with sensory disabilities.

### **Limitations of this report**

Due to the use of data from NMES, a general population survey, this report is missing details on areas of maternity care particularly relevant to women with disabilities, such as the physical infrastructure and accessibility of services, accommodations made for their disability, or information on attitudes or disability-specific knowledge of healthcare professionals caring for them. This report is also missing the perspectives of healthcare staff who work with pregnant women and new mothers in maternity services and in the community.

Only 6.8% of respondents to NMES reported a long-term disability, illness or condition and due to small numbers, it was not possible to report on the experiences of those with specific disabilities or conditions. As a result, in this report women with a range of disabilities, illnesses or conditions were considered as one group. This approach does not acknowledge the diversity of women with disabilities, but it does serve to examine the experiences of a group of women who would be most in need of woman-centred care.

It is not possible to know how representative the 217 women with a long-term disability who responded to NMES were in relation to all women with a disability who gave birth during the survey's eligible time period. However research from the Growing up in Ireland national longitudinal study of children identified that 8.3% of mothers of the infant cohort born in 2007/2008 had a long-term chronic physical or mental health problem, illness or disability. This suggests that perhaps women with disabilities were underrepresented in the NMES survey. While the invitation to participate in NMES and the survey questions were compliant with NALA guidelines, there was no explicit statement in the invitation on accommodations that could be made for women whose disability might make it challenging to complete the survey online or on paper

The NDA advises that the National Care Experience Programme ensure their future surveys are made accessible for all and suggest The Customer Communications Toolkit for the Public Service as a useful resource.

The recommendations made in this report are based on the findings in the survey where women with disabilities have reported quite negative experiences, or in



areas where women with disabilities reported less positive experiences than women without disabilities. While it is expected that implementation of these recommendations should improve the care experiences of women, they are limited in that they are not based on the expressed needs of these women. Furthermore, while the NMES survey has enabled us to examine the different experiences of women with and without disabilities, we are unable to explore the impact of these different experiences on women's health and wellbeing. With this in mind, the NDA commits to undertaking further work with women with disabilities on their maternity care needs.

## **Conclusion and Recommendations**

The 2020 National Maternity Experience Survey has, for the first time, enabled a national comparison of the maternity experiences of women with and without long-term disabilities, illnesses or conditions in Ireland. This report has found that women with long-term disabilities generally had quite positive maternity experiences and the areas where they reported particularly strong or weak care were largely the same as those without disabilities. However, they did report less positive care experiences than those without disabilities in a number of areas. These differences did not indicate that women with disabilities had negative care experiences in these areas, rather they suggested perhaps subtle differences in the dynamic of the relationship with their healthcare providers and in the care they received. The HSE has already responded to the feedback from mothers in NMES through developing comprehensive national and local quality improvement plans. This report has outlined ways in which these initiatives can adequately address the needs of women with disabilities. Implementation of these recommendations will help to ensure that maternity services can meet the specific needs of women with disabilities, otherwise these initiatives may serve to perpetuate or exacerbate existing differences in the care experiences of those with and without disabilities.

The NDA welcome plans for a National Maternity Experience Survey in 2022 which will show the progress that has been made in maternity services to bring them closer to the vision of the National Maternity Strategy of a service where: "Women and babies have access to safe, high quality care in a setting that is most appropriate to their needs; women and families are placed at the centre of all services, and are treated with dignity, respect and compassion; parents are

supported before, during and after pregnancy to allow them give their child the best possible start in life.”<sup>146</sup>

Below is a summary of the recommendations for ways in which the HSE, maternity services, CHO areas, the ICGP, and the Nursing and Midwifery Board of Ireland (NMBI) can meet the specific needs of women with disabilities, and truly make steps towards a woman-centred maternity service. What underpins most of these recommendations is improving how healthcare professionals communicate with and relate to women with disabilities or additional care needs, as well as ensuring information is provided to women in an accessible way. Improvements in these areas would help to address many of the issues identified for women with disabilities in this report.

### **Statutory duties in providing maternity services to people with disabilities:**

The NDA remind the HSE of their statutory duties under the following legislation:

- The Disability Act 2005: to ensure access to maternity services for people with disabilities.
- The Irish Sign Language Act 2017: to provide access to maternity services through ISL for members of the Deaf or hard-of-hearing community who request this.
- The EU Web Accessibility Directive: to ensure websites and applications are accessible to persons with disabilities (e.g., [www.mychild.ie](http://www.mychild.ie) and any future mobile phone application for pregnancy).
- The Assisted Decision Making (Capacity) Act 2015: services will be required to adopt new policies and procedures in how they involve women who may lack capacity to make decisions on their maternity healthcare.

### **To ensure accessible communication for all women throughout the maternity pathway:**

- The NDA advise the National Healthcare Communication Programme to ensure that it incorporates the use of the National Guidelines on Accessible Health and Social Care Services and the Customer Communications Toolkit for the Public Service in its modules.

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<sup>146</sup> Department of Health. (2016) National maternity strategy. Creating a better future together. 2016 – 2026, p.4. Retrieved from <https://assets.gov.ie/18835/ac61fd2b66164349a1547110d4b0003f.pdf>

- The NDA advise the ICGP and the Nursing and Midwifery Board of Ireland to consider specific training in accessible communication and information provision for GPs and for practice nurses/midwives who are main contacts for women in the antenatal and postnatal periods.
- The NDA would encourage the National Clinical Programme for Neonatology that any communications skills training undertaken by staff working in neonatology will include accessible communication with service users with disabilities.

**To ensure accessible information provision to women throughout the maternity pathway:**

The NDA advise the incorporation of the National Guidelines on Accessible Health and Social Care Services and the Customer Communications Toolkit for the Public Service into the following resources to ensure accessibility for all:

- Antenatal education classes and resources
- The My Pregnancy and My Child resources
- The Specialist Perinatal Mental Health Services' series of mental health information leaflets
- The 'Safer to Ask' leaflet series

**To ensure care is tailored to the needs of women with disabilities, and that they are treated with respect and dignity, and are involved in decisions in their care to the same extent as those without disabilities:**

- The NDA advise that maternity hospitals/units facilitate healthcare staff to undergo disability competence training.
- The NDA advise that CHO areas facilitate PHNs to undergo disability competence training.

**To ensure women with disabilities have equal opportunities to receive beneficial hospital practices:**

- The NDA advise that maternity hospitals/units give all women an equal opportunity for skin-to-skin contact shortly after birth, regardless of disability status or choice of feeding method.
- The NDA advise the HSE's National Breastfeeding Implementation Group and maternity hospitals/units that a future national audit of National Breastfeeding Standards be focussed on women with disabilities to ensure that all standards are being met in their care and support for breastfeeding.

**To ensure accessibility standards are inclusive of those with sensory disabilities:**

- The NDA encourage HIQA to consider the needs of those with sensory disabilities in Standard 2.7 of the National Standards for Safer Better Maternity Care.
- The NDA advise the National Women and Infants Health Programme that the implementation of Antenatal Education Standard 2.2 be extended to include those with sensory disabilities.

**To ensure accessibility to maternity hospitals/units for all:**

- The NDA encourage the HSE and Hospital Groups to adopt a Universal Design approach in the design or redesign of maternity hospitals/units to ensure accessibility for all.

**To encourage the participation of women with disabilities in National Maternity Experience Survey 2022:**

- The NDA advises that the National Care Experience Programme ensure their future surveys are made accessible for all and suggest The Customer Communications Toolkit for the Public Service as a useful resource.

## References

- Andrews, E. E., Powell, R. M. and Ayers, K. B. (2021) Experiences of breastfeeding among disabled women. *Women's Health Issues*, 31(1), pp.82-89.
- Begley et al. (2009a) Women with disabilities: Barriers and facilitators to accessing services during pregnancy, childbirth and early motherhood. Retrieved from <http://nda.ie/File-upload/literaturereview1.pdf>
- Begley et al. (2009b) Women with disabilities: Policies governing procedure and practice in service provision in Ireland during pregnancy, childbirth and early motherhood. Retrieved from <http://nda.ie/File-upload/policyreport1.pdf>
- Begley et al. (2010) The strengths and weaknesses of publicly-funded Irish health services provided to women with disabilities in relation to pregnancy, childbirth and early motherhood. Retrieved from [http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20\\_full\\_%2018th%20may%202010.pdf](http://nda.ie/ndasitefiles/NDA%20report%20final%20draft%20_full_%2018th%20may%202010.pdf)
- Cheyne, H., Elders, A., Hill, D., and Milburn, E. (2019) Is maternity care in Scotland equitable? Results of a national maternity care survey. *BMJ Open*, 9(e023282).
- Cleveland, L., Hill, C.M., Pulse, W.S., DiCioccio, H.C., Field, T. and White-Traut, R. (2017) Systematic review of skin-to-skin care for full-term, healthy newborns. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, 46(6), pp.857-869.
- Department of Health. (2016) National maternity strategy. Creating a better future together. 2016 – 2026. Retrieved from <https://assets.gov.ie/18835/ac61fd2b66164349a1547110d4b0003f.pdf>
- Department of Justice and Equality. (2017) National disability inclusion strategy 2017-2021. Retrieved from <https://assets.gov.ie/18901/26182a87ecf84ddd8d60c215c0ce2520.pdf>
- EU Web Accessibility Directive (EU) 2016/2102. Retrieved from <https://eur-lex.europa.eu/legal-content/en/TXT/?uri=CELEX%3A32016L2102>
- Hall, J., Collins, B., Ireland, J., and Hundley, V. (2018) The human rights and dignity experience of disabled women during pregnancy, childbirth and early parenting. Retrieved from <https://birthrights.org.uk/wp-content/uploads/2018/03/Birthrights-Bournemouth-Liverpool-Human-Rights-and-Dignity-Experiences-of-Disabled-Women-during-Pregnancy-Birth-and-Early-Parenting-1-1.pdf>

HIQA. (2016) National standards for safer better maternity services. Retrieved from <https://www.hiqa.ie/sites/default/files/2017-02/national-standards-maternity-services.pdf>

HIQA. (2020) Overview report of HIQA's monitoring programme against the national standards for safer better maternity services, with a focus on obstetric emergencies. Retrieved from <https://www.hiqa.ie/sites/default/files/2020-02/Maternity-Overview-Report.pdf>

HSE. (2017) Specialist perinatal mental health services. Model of care for Ireland. Retrieved from <https://www.hse.ie/eng/services/list/4/mental-health-services/specialist-perinatal-mental-health/specialist-perinatal-mental-health-services-model-of-care-2017.pdf>

HSE. (2019) National infant feeding policy for maternity & neonatal services, p. 7. Retrieved from <https://www.hse.ie/file-library/infant-feeding-policy-for-maternity-neonatal-services-2019.pdf>

HSE. (2020) Listening, responding, and improving. The HSE response to the findings of the national maternity experience survey. Retrieved from <https://www.hse.ie/eng/services/publications/hse-response-to-the-findings-of-the-national-maternity-experience-survey-2020.pdf>

HSE and NDA. (2014) National guidelines on accessible health and social care services. Retrieved from <https://www.hse.ie/eng/services/yourhealthservice/access/natguideaccessibleservices/natguideaccessibleservices.pdf>

Malouf, R., Henderson, J., and Redshaw, M. (2017) Access and quality of maternity care for disabled women during pregnancy, birth and the postnatal period in England: data from a national survey. *BMJ Open*, 7(e016757).

Mitra, M., Clements, K.M., Zhang, J., Iezzoni, L.I., Smeltzer, S.C. and Long-Bellil, L.M. (2015) Maternal characteristics, pregnancy complications and adverse birth outcomes among women with disabilities. *Medical Care*, 53(12), pp.1027-1032.

Morton, C., Le, J.T., Shahbandar, L., Hammond, C., Murphy, E.A. and Kirschner, K.L. (2013) Pregnancy outcomes of women with physical disabilities: a matched cohort study. *American Academy of Physical Medicine and Rehabilitation*, 5(2), pp.90-98.

Mutic, A. D., Jordan, S., Edwards, S. M., Ferranti, E. P., Thul, T. A. and Yang, I., (2017) The postpartum maternal and newborn microbiomes. *American Journal of Maternal Child Nursing*, 42(6), pp.326-331.

National Institute for Health Care and Excellent (NICE). (2014) Antenatal and postnatal mental health: clinical management and service guidance. Retrieved from <https://www.nice.org.uk/guidance/cg192/resources/antenatal-and-postnatal-mental-health-clinical-management-and-service-guidance-pdf-35109869806789>

NDA. (2012) Building for everyone: A universal design approach. Retrieved from <http://universaldesign.ie/Built-Environment/Building-for-Everyone>

NDA and DPER. (2019) Customer communications toolkit for the public service. Retrieved from <http://universaldesign.ie/products-services/customer-communications-toolkit-for-the-public-service-a-universal-design-approach/customer-communications-toolkit-for-the-public-services-a-universal-design-approach.pdf>

NDA and OPW. (2019) An operational review of the effectiveness of section 25 of the disability act. Retrieved from <http://nda.ie/publications/environment-housing/environment-publications/operational-review-of-the-effectiveness-of-section-25-of-the-disability-act-20051.pdf>

NMES. (2020) Findings of the national maternity experience survey 2020. Retrieved from <https://yourexperience.ie/wp-content/uploads/2020/09/National-Maternity-Experience-Survey-results.pdf>

Redshaw, M., Malouf, R., Gao, H., and Gray, R. (2013) Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period. BMC Pregnancy and Childbirth, 13, pp.1-14.

Royal College of Obstetricians and Gynaecologists. (2017) Maternal mental health-women's voices. Retrieved from <https://www.rcog.org.uk/globalassets/documents/patients/information/maternalmental-healthwomens-voices.pdf>

United Nations. (2006) Convention on the rights of persons with disabilities and optional protocol. Retrieved from <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

Viguera, A. C., Tondo, L., Koukopoulos, A, E., Reginaldi, D., Lepri, B, and Baldessarini, R. J. (2011) Episodes of mood disorders in 2,252 pregnancies and postpartum periods. American Journal of Psychiatry, 168(11), pp.1179-1185.

Walsh-Gallagher, D., Sinclair, M., and McConkey, R. (2012) The ambiguity of disabled women's experiences of pregnancy, childbirth and motherhood: A phenomenological understanding. Midwifery, 28, pp.156-162.

## Appendices

### Appendix A - Comparing care experiences of those with mental health conditions and other types of long-term disabilities

Due to the large proportion of women with disabilities reporting a mental health, psychological or emotional condition, a series of independent t-tests were conducted to compare whether there were any differences in care experiences between those with such a condition or other type of long-term disability. Please note that scores on each item and scale ranged from 0 (very negative) to 10 (very positive). As some of the sample who have more than one disability have a mental health condition and another condition, these tests were only conducted on those with one disability (n=195, 89.9% of those with a disability).

**Table A1.1 – Descriptives of antenatal care experiences of those with mental health conditions with other long-term disabilities**

	Has mental health condition N	Has mental health condition Mean	Has mental health condition SD	Has other long-term disability N	Has other long-term disability Mean	Has other long-term disability SD
<b>Did you receive enough information about physical changes in your body?</b>	97	5.4	3.9	83	5.8	3.8



**Table A1.1 – Continued**

	<b>Has mental health condition N</b>	<b>Has mental health condition Mean</b>	<b>Has mental health condition SD</b>	<b>Has other long-term disability N</b>	<b>Has other long-term disability Mean</b>	<b>Has other long-term disability SD</b>
<b>Did you receive enough information about mental health changes that may occur?</b>	107	5.3	4.3	82	4.7	4.0
<b>Did you receive enough information about nutrition during pregnancy?</b>	104	6.3	3.5	83	6.0	3.6
<b>Did you receive enough information about giving up smoking and other tobacco related products (e-cigarettes, vaping devices etc)?</b>	65	8.3	3.3	59	8.6	2.8
<b>Did you receive enough information about the impact of alcohol and/or drug abuse on you and your baby?</b>	73	7.7	3.4	68	7.8	3.7
<b>Did you feel that you were involved in decisions about your care?</b>	107	6.8	3.5	87	6.8	3.5
<b>Did you feel that you were treated with respect and dignity?</b>	108	8.2	2.7	87	8.6	2.7

**Table A1.1 – Continued**

	<b>Has mental health condition N</b>	<b>Has mental health condition Mean</b>	<b>Has mental health condition SD</b>	<b>Has other long-term disability N</b>	<b>Has other long-term disability Mean</b>	<b>Has other long-term disability SD</b>
<b>Did you have confidence and trust in the health care professionals treating/caring for you?</b>	108	7.6	3.1	87	8.2	2.9
<b>Were your questions answered in a way that you could understand?</b>	107	7.8	3.0	87	8.1	3.0
<b>Did you have a health care professional that you could talk to about your worries and fears?</b>	106	6.9	3.8	84	7.3	3.7
<b>Overall experience of care during pregnancy</b>	108	6.9	2.4	87	7.1	2.2

**Table A1.2 – Independent samples t-tests comparing antenatal care experiences of those with mental health conditions with other long-term disabilities**

	<b>t</b>	<b>df</b>	<b>p</b>
<b>Did you receive enough information about physical changes in your body?</b>	0.75	178	0.45
<b>Did you receive enough information about mental health changes that may occur?</b>	-1.04	187	0.30
<b>Did you receive enough information about nutrition during pregnancy?</b>	-0.43	185	0.67
<b>Did you receive enough information about giving up smoking and other tobacco related products (e-cigarettes, vaping devices etc)?</b>	0.45	122	0.65
<b>Did you receive enough information about the impact of alcohol and/or drug abuse on you and your baby?</b>	0.09	139	0.93
<b>Did you feel that you were involved in decisions about your care?</b>	0.13	192	0.90
<b>Did you feel that you were treated with respect and dignity?</b>	1.06	193	0.29
<b>Did you have confidence and trust in the health care professionals treating/caring for you?</b>	1.45	193	0.15
<b>Were your questions answered in a way that you could understand?</b>	0.67	192	0.51
<b>Did you have a health care professional that you could talk to about your worries and fears?</b>	0.79	188	0.43
<b>Overall experience of care during pregnancy?</b>	0.61	193	0.55

**Table A2.1 – Descriptives of labour and birth care experiences of those with mental health conditions with other long-term disabilities**

	<b>Has mental health condition N</b>	<b>Has mental health condition Mean</b>	<b>Has mental health condition SD</b>	<b>Has other long-term disability N</b>	<b>Has other long-term disability Mean</b>	<b>Has other long-term disability SD</b>
<b>Did you feel that you were involved in decisions about your care?</b>	108	7.1	3.8	86	7.3	3.7
<b>Were your questions answered in a way that you could understand?</b>	105	7.6	3.3	86	8.1	3.1
<b>Before you had any tests, procedures and treatments, were the benefits and risks explained to you in a way you could understand?</b>	107	8.2	3.2	86	8.4	2.9
<b>Do you think your health care professionals did everything they could to help manage your pain during labour and birth?</b>	102	7.6	3.5	83	8.1	3.4

**Table A2.1 – Continued**

	<b>Has mental health condition N</b>	<b>Has mental health condition Mean</b>	<b>Has mental health condition SD</b>	<b>Has other long-term disability N</b>	<b>Has other long-term disability Mean</b>	<b>Has other long-term disability SD</b>
<b>Did you have skin to skin contact (baby naked on your chest or tummy) with your baby shortly after the birth?</b>	89	8.2	3.9	77	9.0	3.1
<b>Was your partner and/or companion involved in your care during labour and birth as much as you wanted them to be?</b>	106	8.7	3.4	85	9.1	2.9
<b>Did you have confidence and trust in the health care professionals caring for you during your labour and birth?</b>	108	8.4	2.8	87	8.9	2.4
<b>Overall experience of care during labour and birth</b>	108	7.9	2.5	87	8.4	2.1

**Table A2.2 – Independent samples t-tests comparing labour and birth care experiences of those with mental health conditions with other long-term disabilities**

	<b>t</b>	<b>df</b>	<b>p</b>
<b>Did you feel that you were involved in decisions about your care?</b>	0.36	192	0.72
<b>Were your questions answered in a way that you could understand?</b>	0.99	189	0.33
<b>Before you had any tests, procedures and treatments, were the benefits and risks explained to you in a way you could understand?</b>	0.44	191	0.66
<b>Do you think your health care professionals did everything they could to help manage your pain during labour and birth?</b>	1.05	183	0.30
<b>Did you have skin to skin contact (baby naked on your chest or tummy) with your baby shortly after the birth?</b>	1.41 <sup>147</sup>	163	0.16
<b>Was your partner and/or companion involved in your care during labour and birth as much as you wanted them to be?</b>	0.81	189	0.42
<b>Did you have confidence and trust in the health care professionals caring for you during your labour and birth?</b>	1.15 <sup>148</sup>	192	0.25
<b>Overall experience of care during labour and birth</b>	1.37	193	0.17

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<sup>147</sup> Alternative t-statistic due to violation of Levene's test for equality of variance

<sup>148</sup> Alternative t-statistic due to violation of Levene's test for equality of variance

**Table A3.1 – Descriptives of care in hospital after birth experiences of those with mental health conditions with other long-term disabilities**

	<b>Has mental health condition N</b>	<b>Has mental health condition Mean</b>	<b>Has mental health condition SD</b>	<b>Has other long-term disability N</b>	<b>Has other long-term disability Mean</b>	<b>Has other long-term disability SD</b>
<b>After your baby was born, did you have the opportunity to ask questions about your labour and the birth (often called ‘debriefing’)?</b>	100	5.4	4.2	76	5.5	4.2
<b>If you needed assistance while you were in hospital after the birth, were you able to get a health care professional to assist you when you needed it?</b>	102	7.4	3.1	79	7.2	3.2
<b>Thinking about the care you received after the birth of your baby while you were in hospital, did you feel that you were involved in decisions about your care?</b>	107	6.9	3.7	83	7.2	3.7

**Table A3.1 – Continued**

	<b>Has mental health condition N</b>	<b>Has mental health condition Mean</b>	<b>Has mental health condition SD</b>	<b>Has other long-term disability N</b>	<b>Has other long-term disability Mean</b>	<b>Has other long-term disability SD</b>
<b>Thinking about the care you received after the birth of your baby while you were in hospital, did you feel that your questions were answered in a way that you could understand?</b>	108	7.6	3.3	86	7.7	3.4
<b>Thinking about the care you received after the birth of your baby while you were in hospital, did you have a health care professional that you could talk to about your worries and fears?</b>	105	6.8	3.5	82	7.0	3.5
<b>Before you were discharged from hospital, were you given information about your own physical recovery?</b>	107	7.0	3.5	84	7.0	3.6



**Table A3.1 – Continued**

	<b>Has mental health condition N</b>	<b>Has mental health condition Mean</b>	<b>Has mental health condition SD</b>	<b>Has other long-term disability N</b>	<b>Has other long-term disability Mean</b>	<b>Has other long-term disability SD</b>
<b>Before you were discharged from hospital, were you given information about any changes you might experience with your mental health?</b>	106	6.8	3.7	82	6.1	4.0
<b>Before you were discharged from hospital, were you told who to contact if you were worried about your health or your baby's health after you left hospital?</b>	100	8.4	3.7	84	8.5	3.6
<b>Thinking about the care you received in hospital, did you feel that you were treated with respect and dignity?</b>	107	7.5	3.3	85	7.8	3.3
<b>Overall care in hospital at birth score</b>	108	7.1	2.4	86	7.1	2.6

**Table A3.2 – Independent samples t-tests comparing care in hospital after birth experiences of those with mental health conditions with other long-term disabilities**

	<b>t</b>	<b>df</b>	<b>p</b>
<b>After your baby was born, did you have the opportunity to ask questions about your labour and the birth (often called ‘debriefing’)?</b>	0.17	174	0.86
<b>If you needed assistance while you were in hospital after the birth, were you able to get a health care professional to assist you when you needed it?</b>	-0.29	179	0.77
<b>Thinking about the care you received after the birth of your baby while you were in hospital, did you feel that you were involved in decisions about your care?</b>	0.55	188	0.58
<b>Thinking about the care you received after the birth of your baby while you were in hospital, did you feel that your questions were answered in a way that you could understand?</b>	0.26	192	0.79
<b>Thinking about the care you received after the birth of your baby while you were in hospital, did you have a health care professional that you could talk to about your worries and fears?</b>	0.48	185	0.63
<b>Before you were discharged from hospital, were you given information about your own physical recovery?</b>	-0.09	189	0.93
<b>Before you were discharged from hospital, were you given information about any changes you might experience with your mental health?</b>	-1.24	186	0.22
<b>Before you were discharged from hospital, were you told who to contact if you were worried about your health or your baby’s health after you left hospital?</b>	0.10	182	0.92
<b>Thinking about the care you received in hospital, did you feel that you were treated with respect and dignity?</b>	0.50	190	0.62
<b>Overall care in hospital at birth score</b>	0.19	192	0.85

**Table A4.1 – Descriptives of specialised care experiences of those with mental health conditions with other long-term disabilities**

	<b>Has mental health condition N</b>	<b>Has mental health condition Mean</b>	<b>Has mental health condition SD</b>	<b>Has other long-term disability N</b>	<b>Has other long-term disability Mean</b>	<b>Has other long-term disability SD</b>
<b>While your baby was in the neonatal unit, did you receive enough emotional support from health care professionals?</b>	29	4.8	4.3	18	6.1	4.4
<b>Overall, how would you rate your experience of the care your baby received in the neonatal unit?</b>	29	8.5	2.4	20	9.2	1.4
<b>Overall experience of specialised care for baby</b>	29	6.7	3.0	20	7.8	2.6

**Table A4.2 – Independent samples t-tests comparing specialised care experiences of those with mental health conditions with other long-term disabilities**

	<b>t</b>	<b>df</b>	<b>p</b>
<b>While your baby was in the neonatal unit, did you receive enough emotional support from health care professionals?</b>	0.98	45	0.33
<b>Overall, how would you rate your experience of the care your baby received in the neonatal unit?</b>	1.14	47	0.26
<b>Overall experience of specialised care for baby</b>	1.42	47	0.16

**Table A5.1 – Descriptives of care for feeding baby experiences of those with mental health conditions with other long-term disabilities**

	<b>Has mental health condition N</b>	<b>Has mental health condition Mean</b>	<b>Has mental health condition SD</b>	<b>Has other long-term disability N</b>	<b>Has other long-term disability Mean</b>	<b>Has other long-term disability SD</b>
<b>Were your decisions about how you wanted to feed your baby respected by your health care professionals?</b>	107	8.4	3.0	87	8.5	2.7
<b>During your stay in hospital, did your health care professionals give you adequate support and encouragement with feeding your baby?</b>	97	6.8	3.8	72	7.9	3.2
<b>At home after the birth of your baby, did your health care professionals give you adequate support and encouragement with feeding your baby?</b>	93	6.9	3.8	71	7.6	3.5
<b>Overall experience of care for feeding your baby</b>	107	7.5	2.6	87	8.1	2.4

**Table A5.2 – Independent samples t-tests comparing care for feeding experiences of those with mental health conditions with other long-term disabilities**

	<b>t</b>	<b>df</b>	<b>p</b>
<b>Were your decisions about how you wanted to feed your baby respected by your health care professionals?</b>	0.23	192	0.82
<b>During your stay in hospital, did your health care professionals give you adequate support and encouragement with feeding your baby?</b>	2.16	163	0.03
<b>At home after the birth of your baby, did your health care professionals give you adequate support and encouragement with feeding your baby?</b>	1.16	162	0.25
<b>Overall experience of care for feeding your baby</b>	1.64 <sup>149</sup>	192	0.10

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<sup>149</sup> Alternative t-statistic due to violation of Levene's test for equality of variance.

**Table A6.1 – Descriptives of care at home after birth of baby experiences of those with mental health conditions with other long-term disabilities**

	<b>Has mental health condition N</b>	<b>Has mental health condition Mean</b>	<b>Has mental health condition SD</b>	<b>Has other long-term disability N</b>	<b>Has other long-term disability Mean</b>	<b>Has other long-term disability SD</b>
<b>When you were at home after the birth of your baby, if you contacted a health care professional were you given the help you needed?</b>	93	8.5	2.8	72	8.5	3.2
<b>Did the public health nurse take your personal circumstances into account when giving you advice?</b>	103	8.8	2.7	84	8.8	2.3
<b>Did you feel that your questions were answered by the public health nurse in a way that you could understand?</b>	105	9.1	2.1	84	9.2	2.0
<b>Did you receive help and advice from the public health nurse about your baby's health and progress?</b>	104	9.2	1.8	86	8.8	2.3

**Table A6.1 – Continued**

	<b>Has mental health condition N</b>	<b>Has mental health condition Mean</b>	<b>Has mental health condition SD</b>	<b>Has other long- term disability N</b>	<b>Has other long- term disability Mean</b>	<b>Has other long- term disability SD</b>
<b>At the postnatal check-up, around 6 weeks after the birth, did the GP or practice nurse/midwife spend enough time talking to you about your own physical health?</b>	104	6.1	4.3	85	6.2	4.1
<b>At the postnatal check-up, did the GP or practice nurse/midwife spend enough time talking to you about your own mental health?</b>	105	6.0	4.2	84	6.0	4.1
<b>Did you feel that your questions were answered by the GP or practice nurse/midwife in a way that you could understand?</b>	106	8.1	3.3	85	8.6	2.6
<b>Since the birth of your baby, did you feel that you were adequately informed about vaccinations?</b>	108	8.6	2.9	87	8.9	2.6



**Table A6.1 – Continued**

	<b>Has mental health condition N</b>	<b>Has mental health condition Mean</b>	<b>Has mental health condition SD</b>	<b>Has other long-term disability N</b>	<b>Has other long-term disability Mean</b>	<b>Has other long-term disability SD</b>
<b>When you were at home after the birth of your baby, if you contacted a health care professional were you given the help you needed?</b>	93	8.5	2.8	72	8.5	3.2
<b>Did the public health nurse take your personal circumstances into account when giving you advice?</b>	103	8.8	2.7	84	8.8	2.3
<b>Did you feel that your questions were answered by the public health nurse in a way that you could understand?</b>	105	9.1	2.1	84	9.2	2.0
<b>Did you receive help and advice from the public health nurse about your baby's health and progress?</b>	104	9.2	1.8	86	8.8	2.3

**Table A6.1 – Continued**

	<b>Has mental health condition N</b>	<b>Has mental health condition Mean</b>	<b>Has mental health condition SD</b>	<b>Has other long-term disability N</b>	<b>Has other long-term disability Mean</b>	<b>Has other long-term disability SD</b>
<b>Thinking about the care you received at home after the birth of your baby, did you have confidence and trust in the health care professionals caring for you?</b>	107	7.8	2.8	85	8.2	2.7
<b>Thinking about the care you received at home after the birth of your baby, did you feel that you were involved in decisions about your health?</b>	105	8.6	2.6	82	8.2	3.0
<b>Thinking about the care you received at home after the birth of your baby, did you feel that you were treated with respect and dignity?</b>	106	9.4	1.6	87	9.3	2.0
<b>Overall experience of care at home after birth</b>	108	8.2	1.9	87	8.2	1.7

**Table A6.2 – Independent samples t-tests comparing care at home after birth experiences of those with mental health conditions with other long-term disabilities**

	<b>t</b>	<b>df</b>	<b>p</b>
<b>At the postnatal check-up, around 6 weeks after the birth, did the GP or practice nurse/midwife spend enough time talking to you about your own physical health?</b>	0.10	163	0.92
<b>At the postnatal check-up, did the GP or practice nurse/midwife spend enough time talking to you about your own mental health?</b>	0.06	185	0.95
<b>Did you feel that your questions were answered by the GP or practice nurse/midwife in a way that you could understand?</b>	0.08	187	0.94
<b>Since the birth of your baby, did you feel that you were adequately informed about vaccinations?</b>	-1.31 <sup>150</sup>	162	0.19
<b>When you were at home after the birth of your baby, if you contacted a health care professional were you given the help you needed?</b>	0.19	187	0.85
<b>Did the public health nurse take your personal circumstances into account when giving you advice?</b>	-0.08	187	0.94
<b>Did you feel that your questions were answered by the public health nurse in a way that you could understand?</b>	1.11 <sup>151</sup>	189	0.27
<b>Did you receive help and advice from the public health nurse about your baby's health and progress?</b>	0.86	193	0.39

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<sup>150</sup> Alternative t-statistic due to violation of Levene's test for equality of variance.

<sup>151</sup> Alternative t-statistic due to violation of Levene's test for equality of variance.

**Table A6.2 – Continued**

	<b>t</b>	<b>df</b>	<b>p</b>
<b>Thinking about the care you received at home after the birth of your baby, did you have confidence and trust in the health care professionals caring for you?</b>	0.93	190	0.35
<b>Thinking about the care you received at home after the birth of your baby, did you feel that you were involved in decisions about your health?</b>	-0.94	185	0.35
<b>Thinking about the care you received at home after the birth of your baby, did you feel that you were treated with respect and dignity?</b>	-0.29	191	0.77
<b>Overall experience of care at home after birth</b>	0.27	193	0.79

**Table A7.1 – Descriptives of overall maternity care experiences of those with mental health conditions with other long-term disabilities**

	<b>Has mental health condition N</b>	<b>Has mental health condition Mean</b>	<b>Has mental health condition SD</b>	<b>Has other long-term disability N</b>	<b>Has other long-term disability Mean</b>	<b>Has other long-term disability SD</b>
<b>Overall, how would you rate the experience of the care you and your baby received during pregnancy, labour and birth and after your baby was born?</b>	108	7.6	2.4	86	8.1	2.0

**Table A7.2 – Independent samples t-tests comparing overall maternity care experiences of those with mental health conditions with other long-term disabilities**

	<b>t</b>	<b>df</b>	<b>p</b>
<b>Overall, how would you rate the experience of the care you and your baby received during pregnancy, labour and birth and after your baby was born?</b>	1.67	192	0.10

## Appendix B - Comparing care experiences of those with and without long-term disabilities

A series of multiple regressions were conducted to identify whether there were any differences in experiences of maternity care by those with and without long-term disabilities, while controlling for maternal age and type of maternity care. In the following section a table of descriptive statistics is first presented for each area of care, followed by a table showing the relevant results extracted from the regressions.

**Table B1.1 - Descriptive statistics on antenatal care experienced by those with and without long-term disabilities**

	<b>Has disability N</b>	<b>Has disability M</b>	<b>Has disability SD</b>	<b>No disability N</b>	<b>No disability M</b>	<b>No disability SD</b>
<b>Did you receive enough information about giving up smoking and other tobacco related products (e-cigarettes, vaping devices etc)?</b>	142	8.4	3.1	1794	8.6	2.8
<b>Did you feel that you were treated with respect and dignity?</b>	217	8.3	2.8	2981	9.0	2.2
<b>Did you have confidence and trust in the health care professionals treating/caring for you?</b>	217	7.9	3.0	2982	8.5	2.6
<b>Were your questions answered in a way that you could understand?</b>	215	7.9	3.0	2962	8.6	2.5

**Table B1.1 - Continued**

	<b>Has disability N</b>	<b>Has disability M</b>	<b>Has disability SD</b>	<b>No disability N</b>	<b>No disability M</b>	<b>No disability SD</b>
<b>Did you receive enough information about the impact of alcohol and/or drug abuse on you and your baby?</b>	160	7.8	3.5	2182	8.0	3.3
<b>Did you have a health care professional that you could talk to about your worries and fears?</b>	211	7.0	3.8	2867	7.5	3.4
<b>Did you feel that you were involved in decisions about your care?</b>	216	6.6	3.6	2953	7.6	3.2
<b>Did you receive enough information about nutrition during pregnancy?</b>	209	6.2	3.5	2905	6.4	3.6
<b>Did you receive enough information about physical changes in your body?</b>	202	5.6	3.8	2812	6.3	3.6
<b>Did you receive enough information about mental health changes that may occur?</b>	211	5.0	4.2	2850	5.0	4.0
<b>Overall score for antenatal care</b>	217	7.0	2.3	2987	7.5	2.0

**Table B1.2 - Statistics from individual regressions on antenatal care experiences**

	<b>1. Info. physical changes Beta</b>	<b>1. Info. physical changes t</b>	<b>2. Info. mental health changes Beta</b>	<b>2. Info. mental health changes t</b>	<b>3. Info. nutrition Beta</b>	<b>3. Info. nutrition t</b>
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	-0.04	-2.06*	0.00	-0.16	-0.02	-1.18
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	0.01	0.46	-0.08	-3.97***	-0.09	-4.83***
<b>Type of care: Other care (compared to public)</b>	0.07	3.55***	0.04	2.30*	0.01	0.37
<b>Age: 30 to 39 (compared to under 29)</b>	0.03	1.37	-0.03	-1.39	-0.04	-1.85
<b>Age: 40 and over (compared to under 29)</b>	0.06	2.71**	0.01	0.55	0.00	0.14

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$



**Table B1.2 – Continued**

	<b>4. Info. smoking/ tobacco Beta</b>	<b>4. Info. smoking/ tobacco t</b>	<b>5. Info. alcohol/ drug abuse Beta</b>	<b>5. Info. alcohol/ drug abuse t</b>	<b>6. Involve- ment in decisions Beta</b>	<b>6. Involve- ment in decisions t</b>
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	-0.02	-0.64	-0.02	-0.96	-0.05	-2.93**
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	0.01	0.22	-0.07	-3.17**	0.19	10.27***
<b>Type of care: Other care (compared to public)</b>	0.02	1.01	-0.02	-0.77	0.09	5.07***
<b>Age: 30 to 39 (compared to under 29)</b>	0.00	-0.15	-0.02	-0.85	0.07	3.34**
<b>Age: 40 and over (compared to under 29)</b>	0.02	0.61	-0.01	-0.28	0.06	2.78**

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

**Table B1.2 – Continued**

	<b>7. Respect and dignity Beta</b>	<b>7. Respect and dignity t</b>	<b>8. Confidence and trust Beta</b>	<b>8. Confidence and trust t</b>	<b>9. Answering questions Beta</b>	<b>9. Answering questions t</b>
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	-0.06	-3.48**	-0.04	-2.32*	-0.05	-2.87**
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	0.10	5.65***	0.16	8.77***	0.15	8.23***
<b>Type of care: Other care (compared to public)</b>	0.05	2.54*	0.08	4.51***	0.10	5.40***
<b>Age: 30 to 39 (compared to under 29)</b>	0.08	3.61***	0.02	1.01	0.06	2.63**
<b>Age: 40 and over (compared to under 29)</b>	0.06	2.72**	0.05	2.40*	0.07	3.19**

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

**Table B1.2 – Continued**

	<b>10. Worries and fears Beta</b>	<b>10. Worries and fears t</b>	<b>11. Overall antenatal experience Beta</b>	<b>11. Overall antenatal experience t</b>
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	-0.01	-0.63	-0.05	-2.53*
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	0.14	7.58***	0.08	4.45***
<b>Type of care: Other care (compared to public)</b>	0.08	4.37***	0.08	4.64***
<b>Age: 30 to 39 (compared to under 29)</b>	0.09	4.24***	0.03	1.48
<b>Age: 40 and over (compared to under 29)</b>	0.07	3.34**	0.06	2.84**

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

**Table B2.1 - Descriptive statistics on care during labour and birth experienced by those with and without long-term disabilities**

	<b>Has disability N</b>	<b>Has disability M</b>	<b>Has disability SD</b>	<b>No disability N</b>	<b>No disability M</b>	<b>No disability SD</b>
<b>Did you feel that you were involved in decisions about your care?</b>	216	7.2	3.7	2973	7.8	3.3
<b>Were your questions answered in a way that you could understand?</b>	213	7.8	3.2	2929	8.5	2.7
<b>Before you had any tests, procedures and treatments, were the benefits and risks explained to you in a way you could understand?</b>	215	8.3	3.0	2924	8.5	2.9
<b>Do you think your health care professionals did everything they could to help manage your pain during labour and birth?</b>	206	7.8	3.5	2773	8.1	3.2

**Table B2.1 - Continued**

	<b>Has disability N</b>	<b>Has disability M</b>	<b>Has disability SD</b>	<b>No disability N</b>	<b>No disability M</b>	<b>No disability SD</b>
<b>Did you have skin to skin contact (baby naked on your chest or tummy) with your baby shortly after the birth?</b>	182	8.6	3.5	2651	9.3	2.5
<b>Was your partner and/or companion involved in your care during labour and birth as much as you wanted them to be?</b>	212	8.9	3.1	2906	9.6	2.0
<b>Did you have confidence and trust in the health care professionals caring for you during your labour and birth?</b>	217	8.7	2.6	2975	9.0	2.3
<b>Overall experience of care during labour and birth</b>	217	8.2	2.3	2985	8.7	1.8

**Table B2.2 - Statistics from individual regressions on labour and birth care experiences**

	<b>1. Involvement in decisions Beta</b>	<b>1. Involvement in decisions t</b>	<b>2. Answering questions Beta</b>	<b>2. Answering questions t</b>	<b>3. Tests, procedures &amp; treatments Beta</b>	<b>3. Tests, procedures &amp; treatments t</b>
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	-0.03	-1.39	-0.05	-2.74**	-0.01	-0.42
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	0.07	3.72***	0.06	3.31**	0.01	0.76
<b>Type of care: Other care (compared to public)</b>	0.03	1.39	0.03	1.41	-0.02	-1.02
<b>Age: 30 to 39 (compared to under 29)</b>	0.07	3.32**	0.08	3.81***	0.07	3.16**
<b>Age: 40 and over (compared to under 29)</b>	0.08	3.95***	0.10	4.52***	0.07	3.11**

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

**Table B2.2 - Continued**

	<b>4. Pain management Beta</b>	<b>4. Pain management t</b>	<b>5. Skin to skin contact**** Beta</b>	<b>5. Skin to skin contact t</b>	<b>6. Partner/ companion involvement Beta</b>	<b>6. Partner/ companion involvement t</b>
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	-0.01	-0.60	-0.05	-2.86**	-0.07	-3.78***
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	0.04	2.16*	0.02	1.19	0.00	-0.21
<b>Type of care: Other care (compared to public)</b>	0.01	0.77	0.03	1.79	0.02	0.91
<b>Age: 30 to 39 (compared to under 29)</b>	0.09	4.10***	0.09	4.22***	0.07	3.40**
<b>Age: 40 and over (compared to under 29)</b>	0.09	4.14***	0.07	3.32**	0.03	1.48

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

\*\*\*\*See Appendix C for all analyses on skin-to-skin experience

**Table B2.2 – Continued**

	<b>7. Confidence &amp; trust Beta</b>	<b>7. Confidence &amp; trust t</b>	<b>8. Overall care during labour &amp; birth Beta</b>	<b>8. Overall care during labour &amp; birth t</b>
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	-0.03	-1.60	-0.05	-2.66**
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	0.02	0.81	0.05	2.82**
<b>Type of care: Other care (compared to public)</b>	-0.01	-0.35	0.02	1.16
<b>Age: 30 to 39 (compared to under 29)</b>	0.08	3.68***	0.12	5.79***
<b>Age: 40 and over (compared to under 29)</b>	0.08	3.77***	0.11	5.45***

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$



**Table B3.1 - Descriptive statistics on care in hospital after birth experienced by those with and without long-term disabilities**

	<b>Has disability N</b>	<b>Has disability M</b>	<b>Has disability SD</b>	<b>No disability N</b>	<b>No disability M</b>	<b>No disability SD</b>
<b>After your baby was born, did you have the opportunity to ask questions about your labour and the birth (often called ‘debriefing’)?</b>	195	5.2	4.2	2617	5.5	4.1
<b>If you needed assistance while you were in hospital after the birth, were you able to get a health care professional to assist you when you needed it?</b>	200	7.4	3.1	2749	7.3	3.2
<b>Thinking about the care you received after the birth of your baby while you were in hospital, did you feel that you were involved in decisions about your care?</b>	211	7.0	3.7	2936	7.7	3.3
<b>Thinking about the care you received after the birth of your baby while you were in hospital, did you feel that your questions were answered in a way that you could understand?</b>	215	7.6	3.3	2917	8.2	2.9

**Table B3.1 - Continued**

	<b>Has disability N</b>	<b>Has disability M</b>	<b>Has disability SD</b>	<b>No disability N</b>	<b>No disability M</b>	<b>No disability SD</b>
<b>Thinking about the care you received after the birth of your baby while you were in hospital, did you have a health care professional that you could talk to about your worries and fears?</b>	209	6.8	3.6	2806	7.1	3.5
<b>Before you were discharged from hospital, were you given information about your own physical recovery?</b>	213	7.0	3.5	2919	7.5	3.2
<b>Before you were discharged from hospital, were you given information about any changes you might experience with your mental health?</b>	209	6.6	3.8	2859	6.8	3.7
<b>Before you were discharged from hospital, were you told who to contact if you were worried about your health or your baby's health after you left hospital?</b>	204	8.4	3.7	2771	9.0	3.0
<b>Thinking about the care you received in hospital, did you feel that you were treated with respect and dignity?</b>	214	7.6	3.3	2960	8.5	2.7
<b>Overall care in hospital are birth score</b>	216	7.1	2.5	2965	7.5	2.2

**Table B3.2 - Statistics from individual regressions on care in hospital after birth experiences**

	<b>1. Debriefing Beta</b>	<b>1. Debriefing t</b>	<b>2. Assistance in hospital Beta</b>	<b>2. Assistance in hospital t</b>	<b>3. Involvement in decision Beta</b>	<b>3. Involvement in decision t</b>
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	0.00	-0.23	0.00	0.24	-0.05	-2.74**
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	0.09	4.59***	-0.03	-1.38	0.03	1.60
<b>Type of care: Other care (compared to public)</b>	-0.01	-0.57	-0.04	-2.08*	-0.02	-0.85
<b>Age: 30 to 39 (compared to under 29)</b>	0.06	2.81**	0.04	1.75	0.02	0.95
<b>Age: 40 and over (compared to under 29)</b>	0.09	3.84***	0.08	3.50***	0.07	3.32**

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

**Table B3.2 – Continued**

	<b>4. Answering questions Beta</b>	<b>4. Answering questions t</b>	<b>5. Worries and fears Beta</b>	<b>5. Worries and fears t</b>	<b>6. Info. physical recovery Beta</b>	<b>6. Info. physical recovery t</b>
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	-0.04	-2.02*	-0.02	-0.83	-0.04	-2.41*
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	0.03	1.64	0.04	1.93	-0.02	-0.81
<b>Type of care: Other care (compared to public)</b>	0.00	-0.12	-0.03	-1.67	-0.04	-2.13*
<b>Age: 30 to 39 (compared to under 29)</b>	0.08	3.80***	0.04	1.91	0.01	0.44
<b>Age: 40 and over (compared to under 29)</b>	0.10	4.51***	0.06	2.61**	0.03	1.50

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

**Table B3.2 – Continued**

	<b>7. Info. mental health changes Beta</b>	<b>7. Info. mental health changes t</b>	<b>8. Told who to contact Beta</b>	<b>8. Told who to contact t</b>	<b>9. Respect &amp; dignity Beta</b>	<b>9. Respect &amp; dignity t</b>
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	-0.02	-1.07	-0.04	-2.17*	-0.08	-4.38***
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	-0.05	-2.75**	0.00	-0.15	0.02	1.08
<b>Type of care: Other care (compared to public)</b>	-0.03	-1.71	0.03	1.68	0.00	-0.06
<b>Age: 30 to 39 (compared to under 29)</b>	0.01	0.21	0.06	2.64**	0.07	3.24**
<b>Age: 40 and over (compared to under 29)</b>	0.03	1.17	0.08	3.55***	0.08	3.60***

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

**Table B3.2 – Continued**

	<b>10. Overall care in hospital after birth Beta</b>	<b>10. Overall care in hospital after birth t</b>
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	-0.05	-2.60*
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	0.02	0.81
<b>Type of care: Other care (compared to public)</b>	-0.02	-1.35
<b>Age: 30 to 39 (compared to under 29)</b>	0.06	3.02**
<b>Age: 40 and over (compared to under 29)</b>	0.10	4.58***

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

**Table B4.1 - Descriptive statistics on specialised care experienced by those with and without long-term disabilities**

	<b>Has disability N</b>	<b>Has disability M</b>	<b>Has disability SD</b>	<b>No disability N</b>	<b>No disability M</b>	<b>No disability SD</b>
<b>While your baby was in the neonatal unit, did you receive enough emotional support from health care professionals?</b>	53	5.2	4.4	482	6.4	4.0
<b>Overall, how would you rate your experience of the care your baby received in the neonatal unit?</b>	55	8.6	2.3	505	8.8	2.0
<b>Overall experience of specialised care for baby</b>	55	7.0	2.9	507	7.7	2.7

**Table B4.2 - Statistics from individual regressions on specialised care experiences**

	<b>1. Emotional support Beta</b>	<b>1. Emotional support t</b>	<b>2. Care for baby Beta</b>	<b>2. Care for baby t</b>	<b>3. Overall specialised care Beta</b>	<b>3. Overall specialised care t</b>
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	-0.08	-1.76	-0.03	-0.78	-0.07	-1.62
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	0.03	0.68	-0.03	-0.67	0.01	0.22
<b>Type of care: Other care (compared to public)</b>	-0.02	-0.54	-0.05	-1.24	-0.03	-0.76
<b>Age: 30 to 39 (compared to under 29)</b>	0.09	1.69	-0.03	-0.57	0.05	0.92
<b>Age: 40 and over (compared to under 29)</b>	0.01	0.24	-0.08	-1.55	-0.02	-0.46

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$



**Table B5.1 - Descriptive statistics on care for feeding baby experienced by those with and without long-term disabilities**

	<b>Has disability N</b>	<b>Has disability M</b>	<b>Has disability SD</b>	<b>No disability N</b>	<b>No disability M</b>	<b>No disability SD</b>
<b>Were your decisions about how you wanted to feed your baby respected by your health care professionals?</b>	216	8.5	2.7	2979	8.4	3.0
<b>During your stay in hospital, did your health care professionals give you adequate support and encouragement with feeding your baby?</b>	187	7.2	3.6	2760	7.0	3.7
<b>At home after the birth of your baby, did your health care professionals give you adequate support and encouragement with feeding your baby?</b>	183	7.3	3.7	2581	7.7	3.5
<b>Overall experience of care for feeding your baby</b>	216	7.8	2.5	2985	7.8	2.6

**Table B5.2 - Statistics from individual regressions on care for feeding baby experiences**

	<b>1. Decisions respected Beta</b>	<b>1. Decisions respected t</b>	<b>2. Support &amp; encourage- ment at hospital Beta</b>	<b>2. Support &amp; encourage- ment at hospital t</b>	<b>3. Support &amp; encourage- ment at home Beta</b>	<b>3. Support &amp; encourage- ment at home t</b>
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	0.02	1.33	0.01	0.43	-0.03	-1.55
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	-0.02	-1.14	-0.06	-2.89**	-0.07	-3.54***
<b>Type of care: Other care (compared to public)</b>	0.04	1.99*	-0.01	-0.73	-0.02	-0.79
<b>Age: 30 to 39 (compared to under 29)</b>	0.11	5.29***	0.03	1.44	0.05	2.24*
<b>Age: 40 and over (compared to under 29)</b>	0.09	4.32***	0.05	2.39*	0.04	1.78

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

**Table B5.2 – Continued**

	<b>4. Overall care for feeding experience Beta</b>	<b>4. Overall care for feeding experience t</b>
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	0.01	0.65
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	-0.07	-3.56***
<b>Type of care: Other care (compared to public)</b>	0.01	0.30
<b>Age: 30 to 39 (compared to under 29)</b>	0.09	4.08***
<b>Age: 40 and over (compared to under 29)</b>	0.09	4.19***

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

**Table B6.1 - Descriptive statistics on care at home after birth experienced by those with and without long-term disabilities**

	<b>Has disability N</b>	<b>Has disability M</b>	<b>Has disability SD</b>	<b>No disability N</b>	<b>No disability M</b>	<b>No disability SD</b>
<b>When you were at home after the birth of your baby, if you contacted a health care professional were you given the help you needed?</b>	181	8.5	3.0	2389	8.6	2.7
<b>Did the public health nurse take your personal circumstances into account when giving you advice?</b>	209	8.8	2.5	2901	9.0	2.3
<b>Did you feel that your questions were answered by the public health nurse in a way that you could understand?</b>	210	9.1	2.2	2922	9.2	2.0
<b>Did you receive help and advice from the public health nurse about your baby's health and progress?</b>	212	9.0	2.1	2921	9.1	2.1

**Table B6.1 - Continued**

	<b>Has disability N</b>	<b>Has disability M</b>	<b>Has disability SD</b>	<b>No disability N</b>	<b>No disability M</b>	<b>No disability SD</b>
<b>Thinking about the care you received at the postnatal check-up, around 6 weeks after the birth, did the GP or practice nurse/midwife spend enough time talking to you about your own physical health?</b>	209	6.1	4.2	2917	6.1	4.1
<b>Thinking about the care you received at the postnatal check-up, did the GP or practice nurse/midwife spend enough time talking to you about your own mental health?</b>	209	6.1	4.1	2899	5.5	4.1
<b>Did you feel that your questions were answered by the GP or practice nurse/midwife in a way that you could understand?</b>	211	8.3	3.0	2876	8.4	2.8
<b>Since the birth of your baby, did you feel that you were adequately informed about vaccinations?</b>	217	8.7	2.7	2953	8.8	2.4

**Table B6.1 - Continued**

	<b>Has disability N</b>	<b>Has disability M</b>	<b>Has disability SD</b>	<b>No disability N</b>	<b>No disability M</b>	<b>No disability SD</b>
<b>Thinking about the care you received at home after the birth of your baby, did you have confidence and trust in the health care professionals caring for you?</b>	213	8.0	2.8	2964	8.3	2.7
<b>Thinking about the care you received at home after the birth of your baby, did you feel that you were involved in decisions about your health?</b>	208	8.4	2.8	2918	8.9	2.4
<b>Thinking about the care you received at home after the birth of your baby, did you feel that you were treated with respect and dignity?</b>	214	9.3	1.9	2965	9.4	1.9
<b>Overall experience of care at home after birth</b>	217	8.2	1.8	2987	8.3	1.7

**Table B6.2 - Statistics from individual regressions on care at home after birth experiences**

	<b>1. Help when needed Beta</b>	<b>1. Help when needed t</b>	<b>2. Personal circumstances considered Beta</b>	<b>2. Personal circumstances considered t</b>	<b>3. PHN answering questions understandable way Beta</b>	<b>3. PHN answering questions understandable way t</b>
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	-0.02	-0.91	-0.03	-1.51	-0.02	-1.06
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	-0.03	-1.27	-0.08	-3.98***	-0.07	-3.57***
<b>Type of care: Other care (compared to public)</b>	0.01	0.62	-0.02	-1.16	-0.01	-0.34
<b>Age: 30 to 39 (compared to under 29)</b>	0.01	0.20	0.02	1.04	0.03	1.35
<b>Age: 40 and over (compared to under 29)</b>	0.02	0.92	0.06	2.75**	0.05	2.44*

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

**Table B6.2 – Continued**

	<b>4. Help &amp; advice about baby Beta</b>	<b>4. Help &amp; advice about baby t</b>	<b>5. Postnatal check-physical health Beta</b>	<b>5. Postnatal check-physical health t</b>	<b>6. Postnatal check-mental health Beta</b>	<b>6. Postnatal check-mental health t</b>
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	-0.01	-0.64	0.01	0.38	0.04	1.93
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	-0.09	-4.89***	0.03	1.65	-0.02	-1.18
<b>Type of care: Other care (compared to public)</b>	0.02	1.25	-0.01	-0.46	0.00	-0.20
<b>Age: 30 to 39 (compared to under 29)</b>	-0.01	-0.60	0.01	0.33	0.00	-0.16
<b>Age: 40 and over (compared to under 29)</b>	0.02	0.74	0.05	2.51*	0.04	1.67

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$



**Table B6.2 – Continued**

	<b>7. GP answering questions understand- able way Beta</b>	<b>7. GP answering questions understand- able way t</b>	<b>8. Informed about vaccinations Beta</b>	<b>8. Informed about vaccinations t</b>	<b>9. Confidence &amp; trust Beta</b>	<b>9. Confidence &amp; trust t</b>
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	0.00	-0.06	-0.01	-0.27	-0.03	-1.63
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	0.01	0.39	0.02	1.03	-0.04	-2.27*
<b>Type of care: Other care (compared to public)</b>	0.01	0.42	0.00	-0.21	0.00	0.23
<b>Age: 30 to 39 (compared to under 29)</b>	0.05	2.38*	0.05	2.13*	0.05	2.35*
<b>Age: 40 and over (compared to under 29)</b>	0.08	3.57***	0.04	1.85	0.08	3.68***

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

**Table B6.2 – Continued**

	<b>10. Involvement in decisions Beta</b>	<b>10. Involvement in decisions t</b>	<b>11. Respect &amp; dignity Beta</b>	<b>11. Respect &amp; dignity t</b>	<b>12. Overall care at home experience Beta</b>	<b>12. Overall care at home experience t</b>
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	-0.04	-2.05*	0.00	0.04	-0.01	-0.68
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	0.00	0.07	-0.03	-1.38	-0.04	-1.89
<b>Type of care: Other care (compared to public)</b>	0.00	0.20	-0.01	-0.38	0.00	-0.13
<b>Age: 30 to 39 (compared to under 29)</b>	0.08	3.86***	0.10	4.69***	0.05	2.36*
<b>Age: 40 and over (compared to under 29)</b>	0.07	3.10**	0.07	3.18**	0.08	3.87***

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

**Table B7.1- Statistics from regression on overall maternity care experiences**

The overall mean score for overall maternity experience for women without disabilities was 8.2 (SD=1.9) (N=2,957), while it was 7.7 (SD=2.3) for women with disabilities (N=216).

	<b>Overall maternity care experience Beta</b>	<b>Overall maternity care experience t</b>
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	-0.06	-3.07**
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	0.06	3.17**
<b>Type of care: Other care (compared to public)</b>	0.03	1.35
<b>Age: 30 to 39 (compared to under 29)</b>	0.06	2.92**
<b>Age: 40 and over (compared to under 29)</b>	0.06	2.73**

## Appendix C - Further analyses on skin-to-skin contact experience

As the type of birth women had may have had an impact on whether they got time for skin-to-skin contact, further regressions were conducted on experience of skin-to-skin contact, controlling for firstly, caesarean birth, and secondly, potentially complicated birth. In the tables below: \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$ .

**Table C1.1 – Further regressions on skin-to-skin contact controlling for caesarean birth**

	Beta	t
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	-0.05	-2.54*
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	0.03	1.66
<b>Type of care: Other care (compared to public)</b>	0.00	0.09
<b>Age: 30 to 39 (compared to under 29)</b>	0.10	4.85***
<b>Age: 40 and over (compared to under 29)</b>	0.10	4.83***
<b>Birth: Caesarean (compared to vaginal)</b>	-0.27	-14.95***

**Table C1.2 – Further regressions on skin-to-skin contact controlling for potentially complicated birth**

	Beta	t
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	-0.05	-2.80**
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	0.02	1.03
<b>Type of care: Other care (compared to public)</b>	0.03	1.53
<b>Age: 30 to 39 (compared to under 29)</b>	0.08	3.85***
<b>Age: 40 and over (compared to under 29)</b>	0.06	2.93***
<b>Birth: Assisted vaginal or unplanned caesarean (compared to vaginal (unassisted) or planned caesarean)</b>	-0.18	-9.62***

In order to further understand why women with a disability were less likely to get time for skin-to-skin contact shortly after birth, a further analysis was conducted to control for type of infant feeding women engaged in.

**Table C1.3 – Further regressions on skin-to-skin contact controlling for type of feeding**

	<b>Beta</b>	<b>t</b>
<b>Disability: Does not have long-term disability (compared to has a long-term disability)</b>	-0.05	-2.67
<b>Type of care: Consultant-led private/semi-private care (compared to public)</b>	0.01	0.67
<b>Type of care: Other care (compared to public)</b>	0.03	1.43
<b>Age: 30 to 39 (compared to under 29)</b>	0.09	3.81***
<b>Age: 40 and over (compared to under 29)</b>	0.07	3.15**
<b>Feeding: Exclusively formula feeding (compared to exclusive breastfeeding or complementary breast and formula feeding)</b>	-0.09	-4.48***