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# Exploring disability prevalence among childbearing women attending a tertiary maternity service in Melbourne, Australia using an audit and cross-sectional survey $\frac{2}{3}$

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# ABSTRACT

*Background:* Although there is an estimated rate of 10% of women of childbearing age in Australia who have a disability, there is a lack of accurate prevalence data, with the true rate unknown. The timing and questions used to collect women's disability status in pregnancy vary, and there is limited knowledge on how women accessing maternity services in Australia would like to be asked about their disability status. *Objective:* To explore the prevalence of women with a disability receiving maternity care using a direct and indirect disability identification question. Secondary aims were to explore how women would like to be asked about their disability status and to examine the difference between self-reported and clinician-documented disability status within medical records.

*Research design/Setting:* The study was conducted at a tertiary maternity hospital in Melbourne, Australia, and included two components. Component one used a cross-sectional survey with two different cohorts of women administered face-to-face on the postnatal ward (Cohort 1 – February 2019, Cohort 2 – December 2019). In Cohort 1, a specific disability identification question asked: '*Can you please tell me if you identify as someone who has a disability?*'. In Cohort 2, an indirect disability identification question asked: '*Do you require additional assistance or support?*'. Other questions explored women's views on disability identification. Component two consisted of an audit of the medical records to compare disability documentation in the medical records of the women who participated with women's disability self-identification status.

*Results*: 371/467 (79%) of eligible women that were approached participated in Cohort 1 and in Cohort 2, 295/346 (85%) of eligible women that were approached participated in the study. In Cohort 1, 5% (17/371) of women self-identified with having a disability. In Cohort 2 16% (46/295) of women reported needing additional assistance/support, however of these, only nine women viewed this as a disability. In Cohort 1, of the women who self-identified as having a disability, 82% had this recorded in their medical record. An additional 12% (43/354) of women in Cohort 1 who may have had a disability according to the Australian Bureau of Statistics classification, did not self-identify as having a disability. In Cohort 2, 37% (17/43) of women who self-identified as needing additional support did not have these needs documented in the medical record. Less than a quarter of women in both cohorts were asked about their disability status during their maternity care. Women with a disability status, and their responses were similar to women who did not self-identify with having a disability status, and their responses were similar to women who did not self-identify with having a disability status, and their responses were similar to women who did not self-identify with having a disability or additional support needs.

*Conclusions:* Disability prevalence data is highly dependant on the wording of the disability identification question. It may be appropriate to ask about disability both indirectly, in terms of additional support needs, and directly, to enable disclosure for those who do identify with a disability. Disability questioning should be routine and standardised guidelines around disability identification should be developed to allow for tailored adjustments to care on an individual level.

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# Introduction

The estimated disability rate amongst women of childbearing age is 10% globally, with numbers forecast to increase (World Health Organization, 2011). In Australia, the proportion is estimated to be similar, with 9% of women of between the ages of 15 and 44 reporting that they are living with a disability (Australian Bureau of Statistics 2019). Women with a disability are at an increased risk of coexisting health conditions during pregnancy (lezzoni et al., 2014) and poorer maternal and infant outcomes, (Mitra et al., 2015; Smithson et al., 2021; Tarasoff et al., 2020) compared to women without a disability. However, a challenge in understanding and exploring the association between disability status and maternal and perinatal outcomes is a lack of accurate prevalence data (Signore et al., 2011).

National reporting on pregnancy and childbirth in Australia is based on the National Perinatal Data Collection (NPDC), which gathers population-based, cross-sectional data on all Australian births of at least 20 weeks gestation, or at least 400 g birthweight (Australian Institute of Health and Welfare, 2014). Currently, disability status is *not* included in the list of mandatory reporting items as specified by the NPDC despite it having a potential impact on health outcomes for both mothers and babies (Smithson et al., 2021; Tarasoff et al., 2020). There is currently no comprehensive approach to national data collection on disability status in pregnancy and there are many variations on how disability is defined, how disability is perceived by individuals, how disability status is collected, and how it is reported.

Defining disability is complex. It has been defined specifically in terms of impairments in functioning, or from a broader social perspective, that results from environmental, attitudinal and organisational factors (Walsh-Gallagher et al., 2013). The International Classification of Functioning, Disability and Health (ICF), considers the biopsychosocial model of functioning and disability, whereby it combines the medical and social models of disability, and recognises that treatment may be needed at the individual level, but also looks beyond the individual at the environment itself (Fortune et al., 2021; ÜStÜN et al., 2003; World Health Organization, 2002). This is echoed by the United Nations (UN) Convention on the Rights of Persons with Disabilities (2007) who argue that disability is a result of an interplay between individuals with impairments and environmental and attitudinal barriers that limit their complete and effective participation in society as equal with others. The majority of the literature focuses on the impairment itself as opposed to the overall limitations in social participation that may be experienced by individuals and this can lead to a limited understanding of the lived experience of individuals with a disability (VicHealth, 2012).

In Australia there is no consistent method of disability identification within maternity services (Benzie et al., 2023). In 2014 The National Woman-Held Pregnancy Record (NWHPR) was developed following the review of Australian Maternity Services, which recommended more comprehensive and consistent national data collection on maternal and perinatal mortality and morbidity (Commonwealth of Australia, 2009). Within the NWHPR there is a specific disability question that asks both women and their partners/support people whether they require any assistance with hearing, speech, literacy, vision, mobility or any other areas. However, despite the development of the NWHPR, states and territories use different standardised pregnancy records, which have a range of disability identification questions (Benzie et al., 2023). This is problematic, as in order to obtain an accurate understanding of the prevalence of disability amongst women accessing care in maternity services, disability identification must be consistent (Benzie et al., 2023).

There is little evidence to date regarding the optimal way to collect information about disability status (Morris and Hasnain-Wynia, 2014). The Washington Cohort on Disability Statistics was formed to facilitate the formulation of internationally comparable data on persons with disabilities (Washington Group on Disability Statistics, 2017). The Cohort developed a short set of questions, structured within the framework of the ICF, to identify people at greater risk of experiencing limited or restricted participation in society. The short set of questions were developed primarily for use in surveys and census' and therefore are not designed specifically for the healthcare system (Washington Group on Disability Statistics, 2017). The United Kingdom's National Health Service developed the Reasonable Adjustment Flag, which is a record that can be taken by services to ensure that health services are accessible for individuals with disabilities, for example longer appointment times or providing easy read materials (Moloney et al., 2021: National Health Service Digital, 2021).

In Australia, data on the health of individuals with a disability, and their use of health services comes predominantly from health and disability surveys rather than from health services directly (Madden et al., 2022). The Australian Survey of Disability Ageing and Carers (SDAC) has been used to provide an estimate of the prevalence of individuals with a disability (Fortune et al., 2021). It uses an operational definition of disability as "any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months" (Australian Bureau of Statistics 2019). A Standardised Disability Flag has also been developed with the intention to use a set of questions within mainstream services, such as education and employment, to enable consistent information within data collection (Australian Institute of Health and Welfare, 2016). However, this tool was not designed specifically for healthcare services. It is imperative that disability identification questions are designed with health services and the needs of those accessing health services in mind. Disability identification questions should be sensitive, and easily used by health care professionals, to enable accurate identification of women with a disability accessing care.

There is limited knowledge about how individuals feel about being asked about disability and how they would like to be asked. It has been suggested that there are negative connotations associated with the word "disability" as it signifies permanence and dependence (Schneider, 2009). A study conducted in the United States explored the views of patients from rehabilitation and primary care outpatient clinics regarding the collection of disability status by health care organisations (Morris et al., 2017). Overall, most participants were supportive of healthcare organisations collecting data on disability status (Morris et al., 2017). To the best of our knowledge there have not been any Australian studies that have explored individuals' perceptions on disability identification and none within the maternity setting. In order to improve the identification of women with disabilities within maternity services, and therefore enable accurate data collection to measure prevalence, outcomes and inform service provision, it is important to gain the perspectives, views and experiences of women accessing maternity care to inform policy and practice.

The primary aim of this study therefore was to explore the prevalence of women with a disability receiving maternity care using a direct and indirect disability identification question. Secondary aims were to explore how women would like to be asked about their disability status and to examine the difference between self-reported and clinician-documented disability status within medical records.

### Methods

# Study design

A descriptive exploratory design was used.

# Aims

- 1 To measure the prevalence of women accessing maternity care at the study site who self-identified as having a disability
- 2 To compare two disability self-identification questions
- 3 To obtain women's views about questions related to disability identification
- 4 To explore the difference between self-reported and cliniciandocumented disability status within the medical record

# Study components

There were two study components. *Component one*: face to face surveys with women on the postnatal ward conducted in February 2019 (Cohort 1) and December 2019 (Cohort 2), using two different disability identification questions. *Component two*: an audit of the medical records of the women who participated in the study to compare women's disability self-identification with disability documentation in the medical records.

# Setting

The study was conducted at the Royal Women's Hospital, a large tertiary maternity hospital in Melbourne, Australia.

# Participants

Women were eligible for inclusion if they were admitted as a public patient to the postnatal ward (after giving birth) during the periods of recruitment and were at least 24 hours post-birth (unless earlier discharge was planned, in which case they were approached earlier), and prior to discharge from hospital. They were excluded if they or their infant were seriously ill or if their infant had died.

#### Data collection tools

<u>Component one.</u> Questionnaires were developed specifically for the study, with input from a disability advisory group comprised of disability advocates and women with a range of disabilities who had used maternity services. We explored disability identification using a specific disability identification question (Fig. 1, Cohort 1), as well as how women felt about the question that was used, and to find out if women had been asked about their disability status during their maternity care, and if so, when they were asked. They were also asked how they would like to be asked about disability. Demographic information was collected. The questionnaires contained both open- and closed-ended questions. The questionnaire was piloted with three women in the advisory group and four other women with similar characteristics to those eligible to participate to check the language, content, appropriateness of questions and length. Minor changes were made following piloting in relation to the wording of the questions, then the survey entered onto the (electronic) REDCap data management system (Harris et al., 2009).

Initially the study was planned to be conducted as a single cross-sectional survey using the direct disability identification question. Due to the number of women that *did not* self-identify with a disability but had a condition that could have been considered to be a disability within the medical record (further discussed in the results section), it was decided to repeat the questionnaire on a second cohort of women using an indirect disability identification question. The questionnaire was repeated using the same eligibility criteria and processes, and the alternate disability identification question was taken from the National Women Held pregnancy record (Fig. 1, Cohort 2).

#### Sample size considerations

Given there is very little literature on which to base sample size calculations, a one-month period was pragmatically chosen for recruitment, to provide a potential sample of approximately 625 women. This number was used as a basis to do a precision-based sample size estimate for the single proportion that was being measured. The estimate was based on the best available data available, i.e. the rate of women of childbearing age (between 15 and 44) in Australia that had a reported disability, which was 9% when we commenced the study (Australian Bureau of Statistics 2019). Using this, and the cii command in STATA 14, our expected sample size of 625, with an estimated prevalence of 9.6%, provided a 95% confidence interval of 0.07 to 0.12. If as few as 500 women agreed to participate the precision estimate 95% confidence interval would be 0.07 to 0.12 (i.e. virtually no precision will be lost). Ideally sample size calculations would be based on current disability data from public maternity services, but this was not possible due to disability status not being included by the NPDC.

# Recruitment

*Component one.* Cohort 1 – All eligible women on the postnatal ward were approached by a research midwife from Monday to Friday over a four-week period throughout February 2019. The research midwife reviewed the computer-generated handover sheets of all women who had given birth in the previous 24 to 48 hours to determine eligibility. A telephone interpreter was used for women that did not speak English and an Auslan interpreter was used for women who were hearing impaired.

Verbal consent was obtained. For women with intellectual disabilities who had impaired capacity to give consent, a person who was known to the participant and was understanding of her condition, usually her next of kin, was able to consent on her behalf. If an advocate or authorised person by the law was appointed, consent was requested on the woman's behalf. The research midwife completed the questionnaire with the woman and entered her responses onto the online survey within the REDCap database on an iPad at the bedside.

Cohort 2 – A second questionnaire, with the second, indirect disability identification question was administered face to face in the same manner throughout December 2019 (Fig. 1).

*Component two*. Two audits of medical records were undertaken following data collection for Cohorts 1 and 2 to compare hospital documentation with women's verbal reports of their disability status. The Australian Bureau of Statistics (ABS) disability classification was used to determine if there was anything in the

Cohort 1	Cohort 2			
Can you please tell me if you identify as someone who has a disability?	Do you require additional assistance or support in the following areas?			
( <i>lf yes</i> ) How would you describe your disability?	<ul><li>Vision</li><li>Hearing</li></ul>			
<ul> <li>Intellectual</li> <li>Specific learning/Attention Deficit Disorder</li> </ul>	<ul><li>Speech</li><li>Communication or literacy</li></ul>			
<ul> <li>Autism (including Asperger's syndrome)</li> <li>Physical</li> </ul>	<ul><li>Mental health</li><li>Other (please describe)</li></ul>			
<ul><li>Acquired brain injury</li><li>Neurological (including epilepsy)</li><li>Vision</li></ul>				
<ul><li>Hearing</li><li>Deafblind (dual sensory)</li><li>Speech</li></ul>				
<ul><li>Mental health</li><li>Other</li></ul>				

Fig. 1. Disability identification questions used within questionnaires.

medical record that could be considered to be a disability, that is, *if there was a limitation, restriction or impairment which has lasted or is likely lasted for at least six months and restricted everyday ac-tivities* (Australian Bureau of Statistics 2019). The medical record of each participant regardless of their disability status was examined to identify any women that had any conditions that were likely to be considered a disability and this was compared with women's verbal reports within the questionnaire.

# Data analysis

Data were downloaded from REDCap (Harris et al., 2009) and transferred into STATA version 17 (StataCorp, 2021) for data cleaning and analysis. Data cleaning included range and logic checks and any inaccuracies that were identified were corrected where possible. Descriptive analyses were undertaken for the quantitative data, and frequencies and proportions presented. Content analysis was used to analyse responses to open-ended questions (Liamputtong, 2016). Two of the authors (CB and HM) conducted the content analysis separately and then compared codes to reach consensus on the grouping of responses into codes and then themes. To ensure anonymity, direct quotes are shown as the study identification number followed by whether they self-identified with a disability/additional support needs (e.g. ID 1000, self-identified with a disability).

Ethical approval to conduct the study was granted by the Royal Women's Hospital Research Ethics Committee on 1 December 2017 (Approval number: 17/25) and La Trobe Human Ethics Committee on 21 December 2017 (Approval number: 17/25).

# Results

# Participant characteristics

In the initial four-week recruitment period in February 2019 (Cohort 1), 711 women were admitted to the postnatal ward following birth, of whom 467 (66%) were approached and invited to participate, with 371 (79%) agreeing (Fig. 2). This represented 61% of eligible women in Cohort 1. For Cohort 2, 502 women were admitted to the postnatal ward following birth during the four-week recruitment period in December 2019, of whom 346 (69%) were invited to participate, and 295 (85%) did so (Fig. 2). This represented 70% of eligible women in Cohort 2.

Characteristics of women in each survey are presented in Table 1. Respondents were similar in most characteristics, with more women in Cohort 1 reporting that English was their first language (64% vs 55%).

# Disability identification processes

We asked women whether they were asked during their maternity care episode (i.e., including pregnancy, labour, birth and postpartum) about whether or not they had a disability, and if so, when they were asked (Table 2). Almost three quarters of women in both Cohorts (Cohort 1: 273/371, 74%; Cohort 2: 217/295, 74%) reported that they were *not* asked about their disability status during their episode of care. If they were asked, the majority in both Cohorts (Cohort 1: 51/71, 72%; Cohort 2: 42/51, 82%) were asked at the first pregnancy booking visit. For the second survey (Cohort



Fig. 2. Participant recruitment Cohorts 1 and 2.

Table 1
Participant characteristics.

Characteristic	Cohort 1 $(n = 371)$		Cohort 2 $(n = 295)$	
	n	%	n	%
Maternal age (years) (n=371/294)				
<20	6	2	2	1
20–30	111	30	90	31
31-40	238	64	192	65
41–50	16	4	9	3
Married or living with partner (n=371/293)	342	92	266	91
Education level graduate degree or higher	236	64	197	67
Household annual income pre-tax (SAUD)				
Less than \$37,000	16	4	33	11
\$37,001 - \$87,000	32	9	42	14
\$87,001 - \$180,000	136	37	107	36
More than \$180,000	63	17	61	21
Unsure	89	24	33	11
Declined to answer	35	9	19	6
Pension/Government benefit main income	35	9	27	9
Born in Australia	181	49	129	44
Identifies as Aboriginal and/or Torres Strait Islander	4	1	2	1
First language - English	239	64	163	55

# Table 2

Disability identification processes.

	Cohort 1		Cohort 2	
	(n = 371)		(n = 295)	
	n	%	n	%
Asked about disability status				
Yes	71	19	51	17
No	273	74	217	74
Unsure	27	7	27	9
When asked about disability status				
(n=71/51)**				
First booking visit	51	72	42	82
Another time during pregnancy care	11	16	3	6
Labour and birth	3	4	1	2
After the baby was born	2	3	2	4
Other (on a form)	2	3	2	4
Not sure/can't remember	7	10	6	12
Comfort level when asked about				
disability status				
Very comfortable	299	81	N/A	N/A
Somewhat comfortable	47	13	N/A	N/A
Neither comfortable nor	20	5	N/A	N/A
uncomfortable				
Slightly uncomfortable	4	1	N/A	N/A
Very Uncomfortable	-	-	N/A	N/A
Asked about additional assistance/sup	port during	care (n=371/295)		
Yes	N/A	N/A	140	48
No	N/A	N/A	125	43
Unsure	N/A	N/A	29	10
When asked about				
assistance/support* (n=140)				
First booking visit	N/A	N/A	90	64
Another time during pregnancy care	N/A	N/A	55	39
Labour and birth	N/A	N/A	34	24
After the baby was born	N/A	N/A	55	39
Other (on a form)	N/A	N/A	1	1
Not sure/can't remember	N/A	N/A	8	6
Comfort level when asked about assist	tance/suppo	rt		
Very comfortable	N/A	N/A	246	84
Somewhat comfortable	N/A	N/A	22	7.5
Neither comfortable nor	N/A	N/A	22	7.5
uncomfortable				
Slightly uncomfortable	N/A	N/A	2	0.7
Very Uncomfortable	N/A	N/A	1	0.3

\* may add to >100% as could tick all that apply. \*\* This question was only asked of women who stated they were asked about their disability status during their episode of care.

Table 3	
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Self-identified disability type/area of additional support.

	Cohort 1 Self-identified with a disability (n = 17)		Cohort 2 Self-identified with additional support needs (n = 46)	
	n	%*	n	%*
Type of disability/ area of additional supp	ort			
Mental health	5	30	27	59
Neurological (including epilepsy)	3	18	0	0
Vision	3	18	7	15
Hearing	2	12	3	7
Physical disability/mobility	2	12	10	22
Specific learning/Attention Deficit	1	6		
Disorder (Cohort 1)				
Literacy/communication (Cohort 2)			6	13
Speech	1	6	1	2
Other	2	12	2	4

 $^{\ast}$  may add to>100% as could tick all that apply.

2), we asked women who identified as having a disability, about additional support needs. Almost half (48%) said they were asked about their additional support needs during their episode of care (i.e., during pregnancy, labour, birth or postnatally), during their pregnancy booking visit (64%) (Table 2).

Women in both Cohorts were asked about their comfort level with the way that they were asked about their disability status / additional support needs within our survey. In Cohort 1, 81% of women said they were 'very comfortable' with the way they were asked about their disability status (Table 2). In Cohort 2, 84% of women reported being 'very comfortable' with the way they were asked about their additional support needs (Table 2).

# Disability prevalence

Women were asked about disability identification using the two different questions at the different timepoints (Fig. 1). In Cohort 1, 17/371 (5%) of women self-identified as having a disability, with mental health conditions being the most common disability type identified (Table 3). In Cohort 2, 46/295 (16%) of women identified as needing additional support or assistance in one or more areas. Similar to Cohort 1, the most common area women identified as needing additional support was mental health (Table 3). These women were also asked if they viewed these additional support requirements as a disability. Nine (20%) women responded that they did, 36 (78%) did not and one (2%) was unsure. In terms of prevalence therefore, only 9/295 women (3%) perceived their support needs as a disability. Of the 36 women who did not see their additional support needs as being a disability, 22 (61%) identified that their additional needs were in relation to their mental health.

# Medical record audit

In Cohort 1, most women (14/17, 82%) that self-identified as having a disability also had their disability recorded in the medical record. Of the women that did not self-identify as having a disability, 43/354 (12%) could have been considered to have a disability using the ABS disability classification, with most of these (33/43, 77%) being mental health conditions.

In Cohort 2, of the women who self-identified as needing additional support, 17/43 (37%) did not have a disability recorded in their medical record. The remaining 29/43 (63%) had a disability recorded in their medical record. Ten out of 249 (4%) women who did not self-identify as having additional support needs had a condition in the medical record that could have been considered a disability using the ABS disability classification. How women would like to be asked about disability status

We asked both cohorts of women how they would like to be asked about disability status using an open-ended question, regardless of whether they identified as having a disability or whether they had additional support needs (Table 4). Around half of the women (30/58) who reported that they had a disability or additional support needs indicated that they would like to be asked directly about their disability status. One commented: "Ask directly - it's nothing to be ashamed of!" (ID 1011, self-identified as having a disability), and another: "Having the choice of saying if you identify is a good thing." (ID 1016, self-identified with a disability). Another stated: "I am fine being asked the question about if I have a disability directly" (ID 3021, self-identified as needing additional support). Conversely, many women (26/58) offered suggestions for non-direct methods of asking about disability such as asking in terms of additional support needs with one respondent commenting: "Probably additional support needs is a nice way of asking. Because "disability" might not make someone think of areas needing support." (ID 3032, self-identified as needing additional support). Another stated: "I'd like to be asked if I had additional support needs rather than the word disability." (ID 3031, self-identified as needing additional support). Other non-direct methods of asking also included asking as part of a list on a medical form with one respondent commenting: "It's good when it's on the initial form, generalised with other questions is good too." (ID 3044, self-identified as needing additional support). A small number of women (2/58) commented on the importance of asking about disability identification routinely.

Women who did not identify as having a disability or needing additional support had similar responses. Over half (57%; 294/516) indicated that they would like to be asked directly about their disability status. One commented: "Ask directly. How else can you ask? Sometimes you just have to ask." (ID 2249, self-identified as not having a disability). Another stated: "Ask directly if I had something I could express my very specific needs or wants." (ID 4234, self-identified as not needing additional support). Many women (191/516) however offered suggestions for non-direct methods of asking about disability such as asking in terms of additional support needs with one respondent commenting: "Do you need any special assistance in areas would be a better way to ask." (ID 2024, self-identified as not having a disability). Another stated: "Whether additional support is needed - not use the word disability." (ID 4140, self-identified as not needing additional support). Other nondirect methods of asking also included asking as part of a form with one respondent commenting: "On a form would be best. Then I can explain further if needs be. That ensures I won't feel

#### Table 4

ow	women	would	like	to	be	asked	about	their	disability	status.
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Theme	Self-identified wineeds $(n = 58)$	th a disability	/additional support	Did <i>not</i> self disability/ac (n = 516)	Did not self-identify with a disability/additional support needs (n = 516)		
		n	%	n	%		
Ask directly		30	52	294	57		
Non-direct methods of asking about disability		26	45	191	37		
Ask routinely		2	4	42	8		
The way the hea asks is importa	alth professional nt	-	-	20	4		
May feel differe disability	ntly if I had a	-	-	12	2		

uncomfortable." (ID 4006, self-identified as not needing additional support).

Some women (42/516) commented on the importance of asking about disability identification routinely, with one respondent commenting: "It can be a sensitive topic but it needs to be asked. So I think asking directly is ok as long as its polite and everyone is asked routinely." (ID 2262, self-identified as not having a disability). Some women (20/516) also suggested that the way in which the health professional asked about disability identification was important. One commented: "As long as you're sensitive when asking the question then it's fine" (ID 2054, self-identified as not having a disability). It was also suggested by some women (12/516) that they may feel different if they had a disability with one respondent commenting "I don't have a disability so I can't say. If I had a disability I may have been more sensitive to the question." (ID 2126, self-identified as not having a disability).

# Discussion

This study explored the prevalence of women with a selfidentified disability receiving maternity care within a tertiary maternity hospital in Melbourne using a direct disability identification question compared with an indirect disability identification question. The study also explored how women would like to be asked about their disability status and explored the difference between self-reporting and clinician-documented disability status within medical records.

## Hospital disability identification processes

In this study, most women reported not being asked about their disability status during their episode of maternity care, and this was consistent amongst both cohorts of women. Of the women that were asked about their disability status, the majority were asked at the pregnancy booking appointment. These findings are consistent with a recent national study that explored disability identification practices within public maternity services in Australia which found that disability identification practices are inconsistent (Benzie et al., 2023). Gaps in disability identification have also been reported in health services in Australia with a recent large data linkage study conducted in New South Wales, that examined intellectual disability and hospital admissions, reporting that overall, there was low recognition of intellectual disability (Walker et al., 2022). This supports the need for the development of specific guidelines around disability identification within maternity services so that disability status is asked routinely and consistently.

In our study, the second cohort of women answered a followup question about if they were asked about any additional support needs during their episode of care. Whilst 73% of women said that they were *not* asked about their disability status during their care, 48% of women reported being asked about their additional support needs during their care. This suggests that many of the women viewed additional support needs and disability as two different things. This is similar to the findings of a Canadian mixed-methods study that examined how patients in a multi-site primary care organisation responded to being asked about disabilities as part of a routine, self-administered socio-demographic survey, with participants reporting that they experienced confusion around what constituted disability and chronic illness (Pinto et al., 2020). Asking in terms of 'additional support needs' as an initial question may reduce some people's concerns around what constitutes a disability and disability labels. It has been argued that by identifying individuals with disability in terms of the needs for "reasonable adjusted care" rather than the individual disability itself may be more effective in enabling individualised care (Moloney et al., 2021).

# Disability prevalence

The prevalence of women with a disability that was identified using the direct identification question in the first cohort was 5%, which is significantly less than the national estimated rate of 9% using data from the ABS (Australian Bureau of Statistics 2019). When comparing women's survey responses, most of these also had their disability status recorded in their medical history, however there were an additional 12% of women (mostly with mental health conditions) who could have been considered to have a disability according to the definition. This suggests that the direct disability identification question may not have been sufficiently effective in identifying women with a disability, particularly in the area of mental health. In contrast, the prevalence of women who self-identified as needing assistance or support using the alternate identification question, was 16% which is higher than the national estimated rate (Australian Bureau of Statistics 2019). When comparing the responses of this cohort of women with their medical records, 37% were not recorded in the medical record. Further, of the women who did not have additional support needs, only an additional 4% had a condition that could have been considered to be a disability. This suggests that asking about disability in terms of additional support needs could be an effective and more accurate way of being able to link women in with appropriate hospital and community supports and enable more individualised maternity care. It also demonstrates that the prevalence rate is highly dependant on the wording of disability identification questions are worded.

Defining disability is complex, and how individuals experience and interpret their own condition, and whether they view that as a disability is challenging. This appears to particularly be the case for mental health conditions. For example, we found that of the 46 women who identified that they had additional support needs, only 20% viewed this as a disability. The majority had additional support needs in the area of mental health which demonstrates that many women with mental health support needs do often not identify this as being a disability. Similar to our findings, a mixed-methods study conducted in Canada, which examined how patients responded to being asked about disabilities as part of a routine survey, found that there was a large discrepancy between self-reported disability and what was recorded in the Electronic Medical Record (Pinto et al., 2020). The largest discrepancy was in the area of mental health (Pinto et al., 2020). It has been identified that there is a gap between those living with significant mental health conditions and it being named as a disability. In 2017-2018 approximately 20% of Australians had a mental or behavioural condition (Australian Bureau of Statistics 2019). According to a recent report conducted on the National Disability Insurance Scheme and psychosocial disability, (Smith-Merry et al., 2018) there is a significant gap between the number of Australians living with mental health and needing ongoing support and those participating in the scheme. One of the suggested issues is around the language associated with disability, namely often considered as lifelong and permanent (Smith-Merry et al., 2018). This language directly conflicts with language used within the mental health system which focuses on recovery and wellness (Smith-Merry et al., 2018). It has also been reported that those with mental illness are often concerned about reporting this due to associated stigma and fear of labelling (Pinto et al., 2020).

#### How do women feel about disability identification?

A commonly cited barrier to collecting information about disability status is around the possibility of people feeling offended (Morris et al., 2021). Our study found that most women felt comfortable with being asked about their disability status, which was consistent in both cohorts using two different disability identification questions. This is similar to findings reported in a study conducted in the United States which examined patients' attitudes towards health care organisations collecting disability status information (Morris et al., 2017). Of the 303 participants, the majority (77%) felt either very comfortable or comfortable with this information being collected. Similarly, a recent pilot trial conducted in the United Stated which evaluated the effectiveness of collecting data on disability status within new patient registration found that patients did not report any concerns about their disability status being collected (Morris et al., 2021).

In our study, many women responded that they would like to be asked directly about their disability status with many also highlighting the need for this to be asked routinely. On the other hand, many women reported that they would prefer to be asked indirectly about their disability status, such as by being asked about additional support needs. One option could be to initially ask women about any additional support needs, and then subsequently ask women directly about their disability status. This would enable women who do not identify with a disability or wish to disclose this, to communicate their additional support needs, and for those who do identify with having a disability to disclose that to their health care providers.

## Considerations for practice and future research

Maternity services should routinely ask about maternal disability status to ensure that women have access to appropriate, individualised care. Further research conducted in partnership with women who have a disability should explore the development of a universal disability identification question specific for maternity services. Without routine disability identification it is not possible to understand women's experiences of maternity care nor ensure that maternity services can meet their needs.

# Strengths and limitations

To our knowledge this is the first study to explore disability identification from the perspective of childbearing women as well as to explore prevalence of disability status via self-report within maternity services in Australia. Given the lack of research in this area and the overall aims of the study, a cross sectional survey design was considered to be the most appropriate to address our aims. The study included over 650 women and provides important insights into disability prevalence and identification practices occurring in a tertiary level public maternity service in Australia. It has also provided new information regarding women's views on disability identification.

The exclusion criteria of serious maternal illness, infant death or a seriously ill infant may have meant that some women with a disability may not have been identified as they were not eligible to participate in the survey, which may have impacted on the prevalence in both cohorts. A further limitation was that this study was conducted at a single site and the site is a tertiary referral centre, so may not be representative of the broader population of childbearing women.

# Conclusion

This study has demonstrated that disability prevalence data is highly dependant on the wording of the disability identification question. Disability is personal and self-defined and therefore it may be appropriate to first ask about additional support needs and then subsequently ask about disability directly so that women who require assistance or support can identify their needs without fear of labelling their disability, and for those women who do self-identify with a disability, they are able to disclose that. Disability questioning should be routine and it is imperative that national guidelines around disability identification are developed and reporting disability identification data is mandatory within maternity services. This will allow for population-level surveillance and tailored adjustments to care on an individual level.

# **Declaration of Competing Interest**

None Declared

#### **CRediT** authorship contribution statement

**Charlie Benzie:** Conceptualization, Investigation, Methodology, Formal analysis, Writing – original draft. **Helen McLachlan:** Conceptualization, Methodology, Supervision, Formal analysis, Writing – review & editing. **Della Forster:** Conceptualization, Methodology, Supervision, Formal analysis, Writing – review & editing. **Michelle Newton:** Conceptualization, Methodology, Supervision, Formal analysis, Writing – review & editing.

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