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# **It's just so bloody hard': Recommendations for improving health interventions and maternity support services for disabled women.**

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# Background

- Paucity of information about Aotearoa/New Zealand disabled women's experiences of becoming mothers and the enablers and barriers they may face.
- Overseas studies show that disabled women do encounter physical, attitudinal barriers.
- Studies have also indicated that health professionals lack the knowledge and experience to provide appropriate care.
- 2014 Maternity Consumer Survey found that disabled women were less satisfied overall with their maternity care in comparison to non-disabled women.



# Study aims

1. To investigate the experiences of women with either physical disabilities or sensory impairments in choosing whether to become mothers, including the barriers and facilitators to positive experiences of disabled motherhood;
2. To investigate the perspectives of health care professionals regarding the facilitators and barriers to providing best quality maternity and child care services for disabled women; and
3. To seek consensus on priority actions and strategies towards our overall aim of improving health outcomes for disabled women during pregnancy, childbirth and early childcare.

# Method



- Three phased, mixed methods study.
- Phases One and Two were semi-structured individual interviews and focus group interviews with 71 disabled mothers, and 28 health professionals involved in the care of disabled mothers from throughout Aotearoa/New Zealand.
- Phase Three a modified Delphi survey
- 20 of the 38 who had consented to taking part in Phase Three, ranked the 11 recommendations in order of priority.

# Delphi participants



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Pseudonym	Age in Years	Disability	No. of Children
Annette	25	Other*	None
Barbara	38	Muscular Dystrophy	None
Beth	38	Rheumatoid Arthritis	1
Clare	36	Other*	2
Donna	36	Spinal cord Injury	2
Grace	33	Epilepsy	2
Jan	31	Paraplegia	1
Jane	30	Multiple Sclerosis	1
Judith	44	Multiple Sclerosis	3
Katie	42	Multiple Sclerosis	2
Linda	43	Rheumatoid Arthritis	None
Manaia	36	Other*	1
Megan	44	Multiple Sclerosis	1
Natasha	37	Hearing Impairment	1
Nicola	39	Profound Deafness (Acquired)	2
Olivia	34	Motor Neuron Disease	2
Raewyn	38	Severe Traumatic Brain Injury	2
Rosie	38	Muscular Dystrophy	2
Serena	34	Severe visual impairment	Pregnant with first child
Suzie	33	Multiple sclerosis	3

# Ranked recommendations

• Recommendation	Mean ranking
• 1. Make relevant information more accessible for women and health professionals	3.65
• 2. Address professional knowledge deficits	3.90
• 3. Address home help provision	4.55
• 4. Ensure appropriate funding resources to reduce inequity	5.40
• 5. Foster better inter-sectorial communication and improved cohesion of services	5.75
• 6. Address professional attitudinal barriers (i.e. discrimination and prejudice)	5.90
• 7. Address physical barriers	6.25
• 8. Support the accessibility of Plunket [child health] nurses	7.10
• 9. Keep birthing choices as open as possible	7.45
• 10. Devise appropriate care and communication strategies for women who have sensory disabilities	7.95
• 11. Support mother's infant feeding options	8.10

# 1. Make relevant information more accessible for women and health professionals

Sarah:... just a website that's got a lot of knowledge about different things and where you can go to access the knowledge or where you can .... and with input by different disciplines ... [It should also include] what you might be entitled to as a disabled parent, what you might [not] know ... (aged 40, mother, other ).

Robyn: I would have benefitted from, I guess, a New Zealand based website ... about pregnancy and disability (aged 30, mother, visual impairment).

Tessa: Why can't we have a central hub on a computer? .... you'd feel more informed ... you'd feel more empowered to deal with it (aged 35, mother, multiple sclerosis).



## 2. Address professional knowledge deficits

Robyn:... for medical professionals, they need to have sort of frequent [disability] awareness training] ... for all disabilities ... just being able to up-skill.... [and] educate and train the professionals ... (aged 30, mother, visual impairment).

Maria:... I would have said training, training, training, and keep retraining ... going through the HR recruitment procedures, I think there should be mandatory training about disabilities .... ideally, I think it needs to be fixed strategically at a policy level (aged 35, mother, muscular dystrophy).



## 2. cont'd. Address professional knowledge deficits

I think doctors should take each case on its merits. I think that if they're dealing with people with disabilities they need to listen a bit more carefully to that person because that person is more experienced on their disability as opposed to whatever their medical condition may be at the time because you cannot separate one from the other. We've lived with our disabilities from year dot, if you've had a congenital disability, and so we are more insightful on how to possibly deal with a situation

(Helen, aged 39, mother, spina bifida).



### 3. Address home help provision

Ellen: ... so that person [the home help] would come in and look after me but there was absolutely no support at all for [caring for] my baby. ... it was just ... heart-wrenching that my baby wasn't even considered at all. ...

Int: So you probably would have got the same support plan whether or not you had that baby?

Ellen: Yeah, definitely (Ellen, aged 43, mother, multiple sclerosis).

... They [home help] would put her [her child's] washing to the side and do my washing, 'cause the funding was for me. The funding's not for my child (Maria, aged 35, mother, muscular dystrophy).



## 4. Ensure appropriate funding resources to reduce inequity

I am basically at the end of my ability to use this hoist, so I need to look at other options in terms of driving. I drive from the wheelchair thing so you basically have to buy a car and get it modified. If I was an ACC [funded] person I would have a \$110,000 vehicle bought for me, but because I am a poor old Ministry of Health person, the only money I can get, and you have to jump through about a million hoops to get it, is \$11,000 of funding towards vehicle modifications when the bill is more likely to be \$40,000 for the modifications alone without the cost of the car. ... (Rosie, aged 38, mother, muscular dystrophy).



## 4. contd. Ensure appropriate funding resources to reduce inequity

... We went on a joint invalid's benefit and that pays about \$20,000 [per annum]. ... It pays the mortgage, it pays for food, mortgage and it pays towards insurance; it doesn't cover things like clothes. ... We tried applying to [a funding body] to see if they could help us out [but they couldn't]. ... We haven't received support from our families, financially, they haven't got it to give. There really isn't another place to go. So we've exhausted all avenues ... It really has been tough. ... An educated person like myself who has [worked in the poorer parts of the city she lives in], and worked with families there, I think I'm resourceful enough to say that I have tried everything, and there is nothing. ... I tried to top myself [commit suicide] last year 'cause it's just so bloody hard (Megan, aged 44, mother, multiple sclerosis).



## 5. Foster better inter-sectorial communication and improved cohesion of services

... it would be really good if there was a way that different services could talk to each other ... [engage in] information sharing. And you're never actually asked if you mind [your information being shared between agencies] or not, it's just, I mean privacy is great and it's really important ... but if you consent to that being done in the beginning, I can't see why there couldn't be that sharing of information (Judith, aged 44, mother, multiple sclerosis).

## 6. Address professional attitudinal barriers (i.e. discrimination and prejudice)

I had an obstetrician and I had an, I think a paediatrician, and .... I can't remember who, but one of them made the assumption that [her baby] was a mistake because she brought up contraception after he was born and she made the comment, 'So something like this doesn't happen again' ... and I can't remember what my response was but I assured her that he was planned and he wasn't a mistake. ... It was pretty shocking (Julia, aged 25, mother, spina bifida).



## 6. cont'd. Address professional attitudinal barriers (i.e. discrimination and prejudice)

My own GP, my own doctor, as soon as I told her that I was pregnant and I said it wasn't planned, the first thing she said to me was, 'Do you want to have a hysterectomy?', and that to a 22 year old woman. I'm sure she wouldn't be offering that to any other 22 year old! So, and that's a family doctor that I've had since I was eight so, yes, they [prejudices against women with disabilities having children] are still there (Michelle, aged 30, mother, other).



## 7. Address physical barriers

I wish the [obstetrician's examination] tables weren't so high, you know getting up and down off the examining table, cause I actually kind of fell off one and hurt my back in my pregnancy ... they should have had low tables (Virginia, aged 43, mother, other).



# Are midwives going to be barriers or enablers?

- Midwives play a vital role in the health and wellbeing of mothers during pregnancy, birth and postpartum period. As such midwives can make a difference to disabled mothers' experiences during this time by:
  - Becoming more disability aware
  - Advocating for disabled women at a local, regional and national level to bring about these changes towards a more fully accessible maternity system.

Thank you for attending this session.

