


ORIGINAL ARTICLE

Australasian genetic counselors' attitudes toward disability and prenatal testing: Findings from a cross-sectional survey

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Abstract

Diagnostic genetic testing and non-invasive prenatal testing (NIPT) for conditions associated with disability are becoming increasingly available to consumers. This genetic information can be used in the disability setting to inform factors such as prognosis, management, and reproductive decision-making. Genetic counselors (GCs) play an important role in the provision of genetic testing and NIPT, and their attitudes toward disability can influence how genetic information is communicated and shape patients' responses. This study aimed to evaluate and describe Australasian GCs' experience with and attitudes toward disabilities to identify potential biases and training needs. A cross-sectional survey was distributed to 400 GCs registered with the Human Genetics Society of Australasia. Of the 106 respondents (participation rate: 26%), a significantly greater proportion were more comfortable interacting with individuals with physical disability as compared to intellectual disability ($p < 0.001$). GCs with personal experiences with disabilities reported significantly greater comfort interacting with people with intellectual disability than those without experience ($p = 0.012$). Qualitative analysis revealed discomfort was less reflective of bias than inexperience and apprehension about communicating disrespectfully. GCs believed people with disabilities experience discrimination and that having a disability could make a person stronger, wiser, and more motivated. Most GCs viewed prenatal testing for disabilities positively as it allowed for decisions regarding continuing the pregnancy and/or provided opportunity to prepare. Challenges identified for prenatal counseling included negative societal attitudes and the low visibility of disability. GCs felt that 'personal beliefs' was the primary factor influencing the decision to terminate a pregnancy affected by disability. These findings highlight important education and training needs for GCs to improve preparedness and comfort when communicating with people with a disability.

KEYWORDS

attitudes, disability, education, genetic counselors, genetics services

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1 | INTRODUCTION

On average, 2%–5% of children are born with a congenital difference and/or manifest neurodevelopmental disorders in childhood (Ropers, 2010; Sheridan et al., 2013). Within the last two decades, the probability of these children receiving a genetic diagnosis has increased due to significant advances in genetic technology. Approximately, 10%–15% of these children will have missing or duplicated genetic information detectable by a microarray (Miller et al., 2010) and a further 42% will have a causal genetic variant identified on exome sequencing (Deciphering Developmental Disorders Study, 2017). Furthermore, prenatal screening through non-invasive prenatal testing (NIPT) has led to earlier, more accurate and improved detection of some chromosomal conditions, compared to traditional screening methods (Gil et al., 2015; Mokhtar et al., 2022). Given the higher diagnostic yields, the expansion in the number of genetic diseases that can be detected, and the testing shorter turn-around-time, genetic testing is increasingly utilized in reproductive planning and prenatal testing (Kraft et al., 2019; Van Den Bogaert et al., 2021; van der Meij et al., 2019; Wang, Tang, et al., 2021). Reported benefits to improved genetic testing include reduced uncertainty through provision of genetic diagnosis, provision of earlier treatment and personalized therapies, information to guide family planning decisions, and greater access to support services (Madeo et al., 2011; Makela et al., 2009; Rosenthal et al., 2001). However, there is concern that increased availability of genetic testing brings an increased risk of discrimination and stigma for individuals with disabilities (Bayefsky & Berkman, 2022; Madeo et al., 2011; Parens & Asch, 2003).

Historically, the Disability Rights community has voiced concern regarding the sequelae of offering genetic testing, namely the prevention of the birth of babies with disabilities (Parens & Asch, 2003). They propose that genetic testing sends a message regarding what constitutes a worthwhile life and threatens to reduce the frequency, and thus, visibility of disability in our society. The introduction of non-invasive prenatal screening (NIPT), in the United States, United Kingdom and Australia in 2011–2012 reignited these concerns (Allyse et al., 2015). Studies of parents of children with Down syndrome found that most participants felt that NIPT would result in increased termination of pregnancies, increased social stigma, and decreased availability of services for individuals with disabilities (Kellogg et al., 2014; Nov-Klaiman et al., 2022; van Schendel et al., 2017). Indeed, this is substantiated by research findings. In Europe, the estimated average reduction rate of Down syndrome live births following the introduction of prenatal screening was 54% (de Graaf et al., 2021). Participants stressed the importance of quality counseling with balanced information and felt that in some instances healthcare providers gave biased or incorrect information about Down syndrome, which would increase the risk of termination of pregnancies (How et al., 2019; Kellogg et al., 2014; Nov-Klaiman et al., 2022; van Schendel et al., 2017). While some studies reported the value of

What is known about this topic

Genetic counselors play an important role in the provision of genetic testing for disabilities, and their attitudes can influence how genetic information are communicated and shape patients' responses. However, few studies have explored genetic counselors' attitudes and experiences regarding disability.

What this paper adds to the topic

We conducted a cross-sectional survey to evaluate Australasian genetic counselors' experience with and attitudes toward disabilities. This paper provides insights regarding the impact of experience with comfort regarding disability and highlights the importance of education and training for genetic counselors to improve quality of care for people with a disability.

an early diagnosis without a risk of miscarriage (How et al., 2019; van Schendel et al., 2017), there was also a fear that increased use of NIPT would result in a decrease in diversity in society and a negative impact on the acceptance of individuals with Down syndrome (Nov-Klaiman et al., 2022; van Schendel et al., 2017). A systematic review found that knowledge, familiarity, and contact with individuals with disability were associated with positive attitudes toward persons with a disability (Wang, Xu, et al., 2021). Genetic counselors (GC's) were also cautious about the introduction of NIPT, but their concerns centred around the test accuracy and the provision of adequate counseling (Alexander et al., 2015).

In Australia, provision of genetic testing is primarily overseen by genetic healthcare providers (i.e., GCs and clinical geneticists). Genetic healthcare providers play a key role in the delivery and interpretation of genetic testing, and support patients in understanding, coping, and adapting to their genetic diagnosis (Devers et al., 2013; Resta et al., 2006). Given the prominent role genetic healthcare providers have in communicating genetic probability information, it is imperative to understand their attitudes toward disability. Such attitudes are likely to influence how providers communicate genetic information and shape patients' responses to this information (Gould et al., 2019; Madeo et al., 2011).

Few studies have evaluated healthcare providers' attitudes toward and biases against disabilities. Prior studies have reported that although healthcare providers had little explicit prejudice or biases, they had implicit biases favoring nondisabled people (Aaberg, 2012; Satchidanand et al., 2012; VanPuymbrouck et al., 2020). A study of physicians' attitudes toward individuals with Down syndrome showed that being a pediatrician, working in a hospital setting, and having previously known a person with Down syndrome were positively associated with comfort with disabilities (Pace et al., 2011). Studies of US physicians revealed a

lack of confidence, with reported discomfort and frustration stemming from inexperience and uncertainty regarding how to best interact with, and care for, individuals with disability, which has been consistent over the last decade (Iezzoni et al., 2021; Wilkinson et al., 2012). Furthermore, only ~50% of physicians strongly agreed that they would welcome patients with disability into their practices which the authors felt could be a possible indication of negative bias (Iezzoni et al., 2021).

Research has shown that GCs may often be the first person to discuss detailed information regarding disabilities with parents and families (Roberts et al., 2002). However, to our knowledge, there has only been one study assessing GCs' attitudes toward disability. This research found an implicit positive bias toward ability among counselors in the USA, in all areas of clinical genetics practice (i.e., pediatric, parental, and familial cancer) (Gould et al., 2019). There have been no studies evaluating attitudes and comfort of Australasian GCs toward disabilities. Thus, the present study aims to evaluate and describe Australasian GCs experience with and attitudes toward disabilities.

2 | METHODS

2.1 | Overarching study

The "We Need to Talk: Social and ethical dialogue around genomics and disability" project was funded by the Australian government's Medical Research Future Fund Genomic Health Futures Mission Grant. The study was subsequently reviewed by The University of Queensland Human Research Ethics Committee, who approved the research (HREC number: 2021/HE002305 2021/HE002305). This study aims to evaluate the ethical, legal, and social implications of genomics for people with disabilities. The project strives to capture input from key stakeholders including (i) individuals with disabilities, (ii) their family members and carers, (iii) healthcare providers, and (iv) the general public. Findings will be used to inform future genomics policy, research, education, and practice. This sub-study focuses on GCs' experiences with, attitudes toward, and explicit biases regarding disability. The aim of this study was to capture Australasian GCs' experiences with disability, and to evaluate their attitudes toward and comfort with disabilities.

2.2 | Study design

A cross-sectional survey was used to evaluate Australasian GCs' experiences with and attitudes toward disability. Individuals were eligible to participate if they were a GC working in Australia or New Zealand. GC students were eligible to participate as their attitudes may reflect those of the future workforce. To capture a wide range of views, there were no exclusions based on institutional settings (e.g., public/private hospital and university) and specialty areas.

2.3 | Participant recruitment

Recruitment occurred via the Human Genetics Society of Australasia (HGSA), which includes over 400 GCs and students. An invitation email was sent to the secretariat of the HGSA who then sent the study notification to their membership via the monthly virtual newsletter. A follow-up reminder was sent approximately 4 weeks after the initial invitation. An invitation to participate was also published via X, formerly known as Twitter, and other social media by the study investigators. Lastly, a passive snowballing approach was applied by providing a link to the online questionnaire to participants at the completion of the study for them to share with colleagues via email or social media. The survey was administered for a total of 3 months between November 30, 2021, and March 4, 2022.

The participant information sheet was provided at the start of the survey and consent was implied by completion of the anonymous survey. Upon completion of the survey, participants were given the option to follow a link to a separate site to enter a draw to win a one-year professional membership for the HGSA.

2.4 | Survey instruments

Development of the survey content was informed by the literature and used validated measures where appropriate. The survey was administered using the Qualtrics platform. One item was included at the start of the survey to determine if individuals met the study eligibility criteria. This was followed by a biomedical model definition of disability, in accordance with The Australian Institute of Health and Welfare (Australian Institute of Health and Welfare, 2022):

"Disability is an umbrella term for impairments, activity limitations and participation restrictions, all of which can interact with a person's health condition(s) and environmental and/or individual factors to hinder their full and effective participation in society on an equal basis with others.

People experience different degrees of impairment, activity limitation and participation restriction. Disability can be related to genetic disorders, illnesses, accidents, ageing, injuries, or a combination of these factors."

The survey measures included (Table S1):

- *Experience with disability:* Six items were adapted from Gould et al. (2019) to evaluate providers' experience with disabilities, including personal experience ("Do you have a disability, or are you a carer for someone with a disability?") and work-related experience (e.g., does part of your current role involve counseling about disability?).
- *Attitudes Toward Disability Scale (ADS):* A validated measure of personal attitudes toward physical and intellectual disabilities

developed by the World Health Organization Quality of Life Group was included (Palad et al., 2016; Power & Green, 2010). The scale comprises of 16 items across four domains: inclusion (relationships, inclusion, burden to society, burden to family), discrimination (ridicule, exploitation, irritation, ignorance), gains (emotional strength, maturity, achievement, determination), and prospects (sexuality, underestimation, optimism, future prospects). Items are rated on a five-point scale, ranging from completely disagree to completely agree. A score for each sub-scale was calculated by summing responses for each domain, with higher scores indicating less inclusion, more discrimination, more perceived gains, and fewer prospects (sub-scale range 4–20).

- *Comfort with disability*: Two items were adapted from VanPuymbrouck et al. (2020) to evaluate comfort with physical and intellectual disability. Participants were asked to rate their level of comfort with interacting with people with severe physical or intellectual disability on a five-point scale ranging from very uncomfortable to very comfortable.
- *Attitudes toward termination of pregnancy affected with disability*: Participants were asked to rank the statements that best described how they felt about prenatal testing for disabilities and the most important deciding factors around termination of pregnancy for disabilities. The initial wording of this question asked respondents to select the single factor most likely to influence the decision. However, there was feedback after the survey went live alerting the researchers to the fact that this was too difficult. Thus, the question was changed to a ranking. As explained later, only the ranking results have been reported, and earlier responses were excluded from the analysis.
- *Case scenarios*: Three scenarios, adapted from Gould (Gould et al., 2019), presented cases involving newborns, where one was diagnosed with Down syndrome (primarily associated with intellectual disability), the second was diagnosed with achondroplasia (primarily associated with physical disability), and the third with Lesch–Nyhan syndrome (a progressive metabolic disorder). Participants were prompted to estimate time spent during a typical 1-hour, pediatric session discussing the following: medical complications, diagnostic process, social and lifestyle behaviors, and psychosocial counseling.
- *Demographics*: included role as a genetic healthcare provider, primary field of practice, and years of clinical practice.

2.5 | Data analysis

Descriptive statistics including frequencies, means, and standard deviations were used to describe the sample and attitudes toward disability. Data from Likert scale responses and binary scale (e.g., yes or no) responses were summarized using descriptive statistics including number and percentages of observations in each category. Due to the limited sample sizes, responses were dichotomized where appropriate. Open-ended responses to experience with disability were reviewed. For the purposes of data analysis, participants were

categorized as followed: (i) close experiences with disability (e.g., personal experience, carer of someone with a disability or long-term volunteering role), (ii) distant experience (e.g., a distant family member or acquaintance with a disability), and (iii) no experience. Basic univariate analyses (e.g., chi-squared, one sample *t*-test, and one-way ANOVA) were used to evaluate associations between experience with disability, self-reported attitudes toward disability, the ADS scale, and area of practice. Using independent samples *t*-test, the mean score for the ADS was compared to published data of nurse educators (Lyon & Houser, 2018) to determine how GCs' attitudes toward disabilities compare with other healthcare providers. Narrative data from open-ended questions were analyzed using qualitative content analysis.

3 | RESULTS

3.1 | Demographics

Of the 125 individuals who accessed the survey, 14 did not complete any survey responses. Of the remaining 111 responses, 5 were ineligible (identified as non-GC's), 17 were partially complete, and 89 completed the entire survey. All partially completed responses were included in the analysis for the purpose of describing the cohorts' experiences with disability ($n=106$), attitudes toward disability ($n=103$), comfort with disability ($n=98$), and attitudes toward prenatal testing ($n=94$). Of the 89 who completed the entire survey, most were GCs ($n=73$, 82%), with the remainder GC students ($n=16$, 18%) (Table 1). Thus, our participant cohort represents approximately 27% of 400 individuals with HGSA GC membership. Most of the cohort worked in cancer ($n=23$, 33%) and had around 0–5 years of experience ($n=35$, 39%).

3.2 | Experience and comfort with disability

Nearly half of the cohort ($n=48$, 45%) reported having no experience with disability (Table 1). Among those with experience with disability ($n=58$), most reported having a distant relative or acquaintance with a disability ($n=29$, 27%), having a disability themselves or being a carer for someone with a disability ($n=22$, 21%), or volunteering at a disability support group ($n=7$, 7%). In relation to clinical practice, over a third ($n=70$, 67%) were in a role that involved counseling about disability, which occurred most frequently more than two times per week ($n=23$, 34%). Similarly, most participants ($n=70$, 68%) reported counseling individuals with a disability in their current role. However, half the cohort ($n=34$, 49%) reported counseling individuals with a disability less than once a month.

Participants were significantly more likely to indicate they were very/somewhat comfortable interacting with individuals with a severe physical disability ($n=80$, 82%) as compared to individuals with a severe intellectual disability ($n=65$, 66%) (χ^2 (4,

TABLE 1 Genetic Counselors demographic characteristics and experience with disabilities.

Demographic characteristic	N (%)
<i>Profession (n = 89)</i>	
Genetic counselor	73 (82)
Student/trainee	16 (18)
<i>Field of practice (n = 69, students excluded)</i>	
Cancer	23 (33)
Pediatric	13 (19)
Prenatal	12 (17)
Adult	10 (15)
Non-clinical (i.e., research and laboratory roles)	11 (16)
<i>Years of experience (n = 89)</i>	
0–5	35 (39)
6–10	18 (20)
11–15	13 (15)
More than 15	23 (26)
Experience with disability	N (%)
<i>Experience with disability (n = 106)</i>	
Has close friend or family members with a disability	29 (27)
Has a disability themselves or is a carer for someone with a disability	22 (21)
Volunteering experience with support groups	7 (7)
No experience	48 (45)
<i>Does part of your current position involve counseling about disability (n = 105)</i>	
Yes	70 (67)
No	35 (33)
<i>How often do you counsel patients or clients about disability? (n = 68)</i>	
>than 2 times per week	23 (34)
1–2 times per week	14 (21)
1–2 times per month	13 (19)
>than one time per month	18 (27)
<i>Does part of your current job involve counseling individuals with a disability? (n = 103)</i>	
Yes	70 (68)
No	33 (32)
<i>How often do you counsel patients or clients with a disability? (n = 70)</i>	
>than 2 times per week	4 (6)
1–2 times per week	10 (14)
1–2 times per month	22 (31)
<than one time per month	34 (49)
<i>Comfort interacting with people with severe physical disabilities (n = 98)</i>	
Very/somewhat uncomfortable	13 (13)
Neither	5 (5)
Very/somewhat comfortable	80 (82)
<i>Comfort interacting with people with severe intellectual disabilities (n = 98)</i>	
Very uncomfortable	20 (20)
Neither	13 (13)
Very comfortable	65 (66)

$N = 98$) = 63, $p < 0.001$). Comfort interacting with people with intellectual disability was significantly higher among individuals with close experiences with a disability (83% reported being comfortable/very comfortable) as compared to those with distant or no experiences (48% and 67% reported being comfortable and very comfortable, respectively) (χ^2 (4, $N = 98$) = 12, $p = 0.021$). Comfort level was comparable when interacting with individuals with severe physical disability across those with close, distant, and no experiences, 86%, 74%, and 83% very/somewhat comfortable, respectively (χ^2 (4, $N = 98$) = 8, $p = 0.09$). Similarly, area of practice (i.e., cancer, prenatal, adult general, pediatric, and non-clinical role) did not impact comfort with intellectual (χ^2 (8, $N = 85$) = 7, $p = 0.55$) or physical disability (χ^2 (8, $N = 85$) = 7, $p = 0.55$). As there was only one significant predictor of comfort (degree of prior experience), a regression analysis was not performed.

Responses in open-ended text fields suggested that many participants felt they did not have biases against people with disabilities (Table 2). However, many participants reported a lack of experience working with people with disabilities and a lack of confidence in knowing how best to communicate with people with intellectual disabilities. In addition, many participants commented on the challenges of using a broad definition of disabilities and highlighted a need to acknowledge that people with disabilities have their own unique personalities and ambitions, which should be acknowledged and considered during GC sessions.

3.3 | Attitudes toward disability (ADS)

Descriptive information for each domain of the ADS is reported in Table 3. There was acceptable internal consistency reliability across the cohort for the Inclusion and Gains domains (Cronbach's alpha 0.71 and 0.78, respectively), and satisfactory internal consistency for the Discrimination or Prospects domains (Cronbach's alpha 0.61 and 0.62, respectively). When distributing the survey, the last item of the Prospects domain was inadvertently omitted. Given the satisfactory internal consistency of the Prospects sub-scale, a decision was made to include this domain in the study analysis.

The highest mean scores were for the Discrimination ($M = 14.4$, $SD = 2.7$) and Gains domains ($M = 14.3$, $SD = 2.4$) (out of a total of 20). This indicated that GCs believed that people with disabilities were more likely to be discriminated against, yet felt that a person with disability could be stronger, wiser, more motivated, and/or more determined because of their disability (Power & Green, 2010). The lowest mean score was for Prospects ($M = 4.3$, $SD = 1.8$), but the significance of this is unclear given that one item was missing from this subscale. When compared to nurse educators (Lyon & Houser, 2018), GCs in this cohort had significantly different scores across all domains, including greater inclusion (t (103) = 3.1, $p = 0.002$), discrimination (t (103) = 5.4, $p < 0.001$), and gains (t (103) = 21.3, $p < 0.001$). The Prospects mean could not be compared to the nurse educator group as the mean reflected three survey items and not four due to human error.

TABLE 2 Qualitative comments from open-text fields.

Topic	Theme	Quote
Experiences and comfort with disability	Wanting to be respectful	<p>"I am not uncomfortable - but I can find it hard to find the correct balance in my style of communicating without being disrespectful."</p> <p>"I feel I have the skills and empathy to engage with people with severe intellectual or physical disabilities. My discomfort is more around not having much experience in these situations and being worried that I will offend them inadvertently through ignorance by how I act or what I say."</p>
	Each person with a disability is unique	<p>"Moderate to severe disability does not define the person, they have their own personality and dispositions just like everybody else."</p> <p>"Interacting with people with severe intellectual disability can be very challenging. One cannot make a generalized statement about every encounter being comfortable."</p>
Attitudes toward prenatal testing	Societal attitudes toward disability	"Disability is not a burden, lack of support services and inclusive culture in society is the burden. However, I absolutely believe that people should be able to have access to health care like prenatal tests to make informed decisions about their life and what they can handle as a parent. Until there are shifts in society to support people with disability create a more inclusive culture where all individuals can thrive and be celebrated, it will remain extremely difficult for parents (depending on the disability) to raise their child in an unsupportive world. It is not up to anyone but the parent to make that very difficult decision."
	Lack of visibility of disability	"...As a prenatal genetic counselor, I am aware that the information I provide may influence a person's perception of the result they receive during a pregnancy and so I do my best to ensure the information is balanced and inclusive. On the one hand, I believe that pregnant couples have the right to be informed about what to expect with their pregnancy and also the right to choose to request termination of pregnancy for any reason, including the finding of a condition in which disability is expected. On the other hand, the lack of visibility of disability in the community has a detrimental effect on the acceptance of disability and many people make a decision based on their lack of experience with disability and the unknown..."
	Case dependent	<p>I found this survey difficult ... I put neither agree nor disagree for most of the questions as there is so much nuance that is completely situation and person specific.</p> <p>Some of these questions are very difficult to answer for disability as an umbrella term because my answers would be different for different types of disability.</p>
Scenarios	Customize session depending on clients' needs	"Session would be guided by what the couple need at the time. The foundation of the session would most likely come under "psychosocial counseling". Other topics in this list would be covered in response to whatever the couple indicate they need from this session."
Impact of completing the survey	Increasing reflectiveness	<p>I appreciate how these questions have helped me reflect on this further. I do not have a lived experience with disability - I'm not sure if this makes me less biased or more ignorant to the concerns that may come up.</p> <p>I think most genetic counselors I know acknowledge that the knowledge from prenatal testing is important to individuals and couples in making decisions in the world as it exists today but also that at a societal level, identifying more pregnancies with disabilities at earlier stages makes it more likely that more couples will terminate because there is not currently enough support and societal acceptance of disability.</p>

One-way ANOVA did not identify any association between self-reported experience and each of the four domains of the ADS (Table 3). Similarly, there was no significant difference in score for each subdomain based on area of practice: Inclusion ($F(2, 95)=1.4, p=0.25$), Discrimination ($F(2, 95)=0.65, p=0.52$), Gains ($F(2, 95)=0.94, p=0.40$), and Prospects ($F(2, 95)=0.57, p=0.67$).

3.4 | Attitudes toward prenatal testing

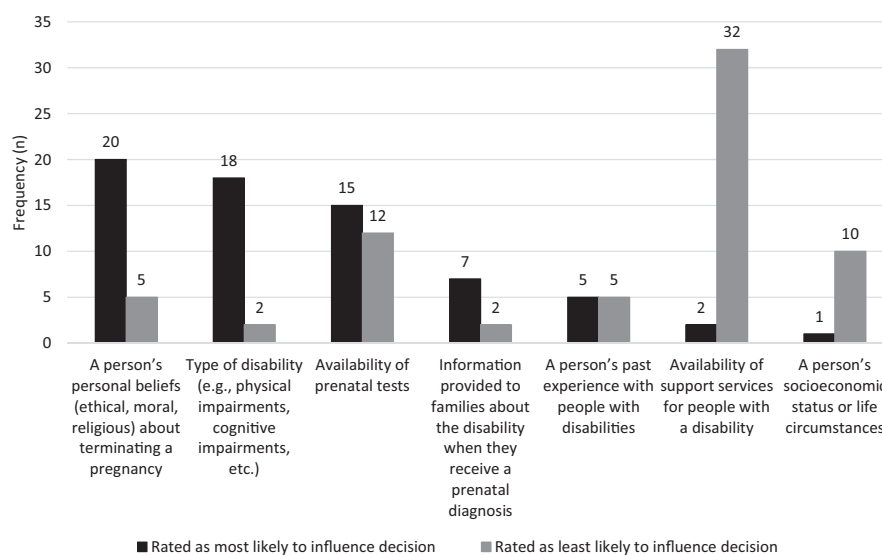
Most participants felt positively about prenatal testing being available for disabilities ($n=90/94, 96\%$), with few being unsure about their attitudes toward prenatal testing for disabilities ($n=4/94, 4\%$), none of whom worked in the prenatal field. When asked about the

TABLE 3 Genetic counselor scores from the attitudes toward disability scale relative to previously published scores for nurse educators ($n=98$).

	Mean (SD)	Range	Cronbach's alpha	Mean scores for nurse educators (SD) (33)	t-test
Inclusion	11.0 (2.7)	6–18	0.71	10.15 (2.7)	($t(103)=3.1, p=0.002$)
Discrimination	14.4 (2.7)	9–20	0.61	13.2 (2.7)	($t(103)=5.4, p<0.001$)
Gains	14.3 (2.4)	8–20	0.79	9.4 (2.4)	($t(103)=21.3, p<0.001$)
Prospect	4.3 (1.8) ^a	3–14	0.63 ^b	6.2 (1.9)	–

^aThe fourth item was omitted from this survey due to a printing error. Based on the average response for the other three questions (1.43), it is likely that the total mean score for this subscale would have been ~ 5.7 . As this data is not complete, no t-test analysis was performed for this subscale.

^bFor the incomplete subscale.

FIGURE 1 Genetic counselors' ratings of the factors most and least likely to influence the decision to terminate pregnancies affected with a disability ($N=68$).

benefits of prenatal testing, half indicated that prenatal testing provided information about whether to continue with pregnancies and provided more time to prepare oneself to care for a child with a disability ($n=48/90$; 53%). The remainder of the participants who reported a positive view of prenatal testing selected a single benefit: either providing information on whether to continue a pregnancy ($n=10/11$; 11%) or providing more time to prepare oneself to care for a child with a disability ($n=32/36$; 36%).

The first 25 participants selected a single response, as per the initial instructions. The remaining respondents completed a ranking. Given the challenges of analyzing two divergent answer types, only the ranking answers were included ($n=68$) in our analyses. The factors were selected as being MOST likely to influence the decision included personal beliefs ($n=20$, 29%), the type of disability ($n=18$, 26%), and the availability of prenatal testing ($n=15$, 22%) (Figure 1). The factor ranked as LEAST likely to influence the decision was availability of support services ($n=32$, 47%) (Figure 1).

Responses to open-ended text fields identified additional considerations for prenatal testing for disabilities (Table 2). Many participants reflected on the complex decision-making process related to termination of pregnancies, and described additional factors that can influence decisions, such as personal beliefs and experiences with disabilities. Overall, participants viewed prenatal testing

positively as it provided people opportunities to make informed decisions about their pregnancy. However, participants also reflected on the societal attitudes toward disabilities, the lack of visibility of disabilities in society and how these could potentially influence prenatal decision-making.

3.5 | Counseling scenarios

Ninety-five participants answered questions related to patient scenarios that involved three different conditions. Summaries of mean time spent for each scenario are reported in Table S1. On average, across all three scenarios, participants indicated they would spend the longest part of the session reviewing psychosocial issues, when compared to other aspects of the session ($p<0.001$). There was no difference in time spent for each aspect of the case between the different cases. Similarly, there was no impact of participant field of practice on time spent in each session. Review of responses to open text questions indicated that many participants felt they were guided by the parent, and thus felt the question was difficult to answer without knowing the parent's background. Additional areas for the session included: time spent building rapport, exploring the family experiences with the condition, and linking the family with

relevant support services and support groups. Lastly, some participants noted that completing the study survey provided them with an opportunity to reflect on their experiences and attitudes toward disabilities.

4 | DISCUSSION

Genetic counselors have an important role in providing education and counseling regarding the genetic contribution to conditions associated with physical and intellectual disabilities. As there is the potential for GCs to influence patients' decision-making and perceptions of disabilities (Madeo et al., 2011), it is important to evaluate attitudes toward disability in this profession and to explore the experiences of GCs counseling individuals with and about disability. Australasian GCs were more likely to feel comfortable with individuals with physical disabilities, compared to individuals with intellectual disabilities. The half of our cohort which had experience with a disability, reported greater comfort interacting with individuals with intellectual disabilities than those reporting no experience. Personal experience was not associated with attitudes toward disability, as assessed by the ADS. Genetic counselors felt that individuals with disability were more likely to experience discrimination, but strongly believed their disability could make them stronger, wiser, and more determined. Nevertheless, the view of the disabled as having attributes of fortitude, which others in the community do not, has been challenged as ableist. Ableism is defined as "A network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human" (Campbell, 2001). By attributing strength or determination to people with a disability could be reflective of the desire to fit them within a "normal" construct, yet "normality and normalcy is achieved through an unsaying: an absence of descriptions of what it is to be normal" (Campbell, 2009). Addressing this view of disability among those who counsel families about disabilities would appear to be an important area of professional learning need (Young, 2014).

Genetic counselors' high levels of comfort interacting with individuals with physical disabilities were consistent with a systematic review of healthcare students' and professionals' attitudes toward individuals with physical disabilities (Satchidanand et al., 2012). Genetic counselors with close experience with disability reported higher levels of comfort interacting with individuals with intellectual disability than those without close experiences. This finding is congruous with prior studies of healthcare providers, which identified that greater interactions with individuals with intellectual disability were associated with more positive attitudes (Rose et al., 2012). Qualitative comments supported the theory that discomfort stemmed from inexperience and apprehension regarding unintentionally disrespectful communication rather than overt bias. Genetic counselors' attitudes toward individuals with disabilities, as

captured by the ADS scale, were positive. Genetic counselors were keenly aware of the fact that individuals with disabilities experienced discrimination (Inclusion and Discrimination subscales) and recognized that having a disability might drive a person to achieve more (Gains subscale). Furthermore, the GCs low scores on the Prospects subscale reflected their belief that individuals with disability have great potential, though the omission of one item from this subscale compromises the ability to compare this to previous studies (Lyon & Houser, 2018). Caution should be taken in interpreting these comfort and attitudes results given that they represent explicit views, which are not always reflective of implicit attitudes in healthcare providers (Aaberg, 2012; VanPuymbrouck et al., 2020). A previous study of North American GCs found a strong implicit bias toward ability, and interestingly while explicit attitudes were influenced by personal experience, implicit attitudes were not (Gould et al., 2019).

Responses to the scenario questions produced identical results in terms of the perceived time allocated to discussing medical complications, diagnostic processes, social and lifestyle behaviors, and psychosocial counseling, regardless of the condition in question. While this may reflect GCs perceptions regarding their practices, given the homogeneity of the responses, it is important to consider that responses may have been biased by psychological reactions and survey construction limitations. Self-reported behaviors are vulnerable to bias as there is a natural tendency to gravitate toward the answer that is considered socially desirable or socially conforming (Andersen & Mayerl, 2019; Richman et al., 1999). The similar structure of three sequential questions raises the possibility that the survey construction could have introduced assimilation and consistency biases. Assimilation bias reflects respondents' tendency to use the response to the first question to inform the response to the subsequent questions (Sumer & Knight, 1996). Furthermore, respondents often wish to ensure that there is consistency in the rationale of their choices across questions, and thus the similar responses could reflect consistency bias (Rasinski et al., 2012). Recording and assessing real-time genetic counseling sessions may be able to accurately capture time spent in these various topics while counseling individuals with or about disability. Nevertheless, if the responses are accurate and genetic counselors spend more time on psychosocial counseling, there are implications that need to be considered. Research exploring experiences of parents with children affected by rare diseases highlighted the need for assistance coordinating and accessing required specialist and local services, connecting families with common experience to provide peer support (Baumbusch et al., 2018). Spending more time addressing these practical concerns may also be of when counseling individuals and/or families affected by disability.

Genetic counselors in our study valued prenatal testing as it allowed parents to make the decision regarding whether to continue with a pregnancy and/or prepare for the future. To our knowledge, only one study has evaluated how GCs discussed disability in a prenatal setting (Farrelly et al., 2012). In that study, analysis of transcripts showed that GCs more frequently discussed the physical

aspects of the disability, as opposed to social aspects. Fewer than half asked patients about their personal experience with disability. While most mentioned termination of pregnancy, fewer discussed continuation of the pregnancy and/or adoption (Farrelly et al., 2012). An earlier study evaluated the experiences of women who had undergone prenatal genetic counseling after being identified as being at increased likelihood of having a child with a disability (Roberts et al., 2002). Although women reported that genetic counseling was beneficial, they reported that they would have appreciated more information about future quality-of-life issues and more information regarding the positive, as well as negative impacts of having a child with disability (Roberts et al., 2002).

Despite most participants counseling about disability, less than half of the study cohort reported actually having experience with disability. In open-ended text responses, GCs reported a need for more education to empower them to engage with people with disabilities. While the United States Accreditation Guidelines for Master of Genetic Counseling mentions including a disability specific education program, the Australasian guidelines do not explicitly highlight this as a learning objective (Accreditation Council for Genetic Counseling, 2019; Human Genetics Society of Australasia, 2019). Previous studies evaluating training and educational interventions with healthcare students and providers have shown improvements in attitudes toward physical and intellectual disability (Moroz et al., 2010; Satchidanand et al., 2012). A review of interventions found that lectures by academics were less helpful in changing attitudes than interactions with people with disabilities themselves (Crane et al., 2021; Shakespeare & Kleine, 2013). Opinions and preferences elicited by individuals with an intellectual disability led to recommendations for educational support for genetic and non-genetic health professionals (Strnadová et al., 2023). Furthermore, education materials and resources including Easy Read booklets and best practice videos, should be co-produced by individuals with disability (Strnadová et al., 2023). Awareness of personal beliefs and learning about disability, in the absence of direct interaction, has been shown to be insufficient in reducing biases toward disability (Galli et al., 2015). Emerging work from the GeneEQUAL program in Sydney Australia suggests that education by individuals with an intellectual disability improves health care providers confidence and authentic engagement with people with disabilities. Interestingly, some participants noted that completion of the survey prompted them to reflect on their attitudes toward disability and increased their awareness and mindfulness of these issues. Therefore, it possible that this survey could be adapted to create a reflective tool for GCs, particularly given that reflective practice is a key competency standard for genetic counselors (Australasia, 2022). The tool would also need an educative aspect to avoid reflecting in ignorance.

While educating the genetic health workforce and non-genetic health professionals who interact with individuals about and with disability is important, there is a broader societal challenge regarding attitudes about disability. Our society is ableist, by and large, with both physical and attitudinal barriers limiting access, support,

resources, and adequate care for individuals with disabilities (Charmaz, 2020; Temple et al., 2018). These societal challenges add an extra layer of complexity to couples deciding whether to have a child with a disability. Raising a child with a disability comes with personal, financial, and psychological costs (Solmi et al., 2018; Wondemu et al., 2022). Simultaneously, parents describe the many positive impacts of having a child with a disability for themselves and their families (Niedbalski, 2022). In qualitative comments, genetic counselors recognized the importance of systemic and institutional change to create a more inclusive society for individuals with a disability. However, when asked about the most influential factors for decision making around terminating affected pregnancies, they still ranked “personal beliefs” as the most important factor, while downgraded systemic and societal influences such as “availability of support services for people with disability,” and “a person's socio-economic status or life circumstances.” This discordance may contribute to the idea that education is the most important intervention for counteracting bias in health professionals, when more focus should ideally be placed on influencing change at a societal level.

4.1 | Study strengths and limitations

To our knowledge, the present study is the first to report on Australasian genetic counselors' experiences, and comfort, with disabilities. As the study includes only GCs, it is not reflective of genetic healthcare providers more broadly. Additionally, most of the GC cohort who participated in the survey worked in the field of cancer and would have limited experience in the prenatal and disability setting. Prenatal GCs in the UK expressed concerns about NIPT, and its use and the way it is offered should be carefully considered (Alexander et al., 2015). As GCs who work in the general and prenatal space may communicate more often about disability, it is likely that our survey responses would have captured a view that is not representative of the entire GC workforce. It is possible that individuals who elected to participate had prior experiences with disability or were more interested in the topic. This study captured explicit attitudes only and not implicit biases. Initially, the study intended to include the Disability Attitudes Implicit Association Test (DA-IAT), but after consultation with the author group from the authors of Gould et al. (2019), it was decided that the visual images associated with that scale capture physical disability alone and was not capable to adequately capture disability. Thus, this measure was omitted from the study survey. Findings from this study provides a broad overview of attitudes, comfort, and experiences of Australian GCs toward disabilities. However, as identified in the responses to open ended questions, there are challenges in capturing the nuances of individuals' attitudes through quantitative measures. Future qualitative studies should be conducted to further explore experiences and comfort toward disability among genetic healthcare providers. Despite the study limitations, our study identified important findings in relation to education needs and the impact of experience with disability on comfort levels, attitudes, and clinical practice.

AUTHOR CONTRIBUTIONS

All authors helped conceived the project. Authors TY, VN, and AML contributed to data collection and analysis. TY and AML wrote the first draft of the manuscript and all authors contributed to the revision of the draft. Authors TY and AML confirm that they had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. All of the authors gave final approval of this version to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interests.

DATA AVAILABILITY STATEMENT

The datasets generated during and/or analyzed during the current study are available from the corresponding author upon request.

ETHICS STATEMENT

Human studies and informed consent: This study received approval from The University of Queensland Human Research Ethics Committee (HREC number: 2021/HE002305 2021/HE002305). Participants provided voluntary, and informed consent.

Animal studies: No non-human animal studies were carried out by the authors for this article.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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