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Should genes for non-syndromic hearing loss be included in reproductive genetic carrier screening: Views of people with a personal or family experience of deafness

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Abstract

Many commercial reproductive genetic carrier screening (RGCS) panels include genes associated with non-syndromic hearing loss (NSHL), however little is known about the general acceptability of their inclusion. Although some couples wish to avoid having a deaf child, there are effective interventions and supports available for deafness, and no consensus on whether it is appropriate to reproductively screen NSHL genes. This study explored views of people with personal experience of deafness regarding carrier screening for genes associated with NSHL. We interviewed 27 participants; 14 who identified as deaf and 13 hearing parents of a deaf child. Thematic analysis was undertaken on transcripts of interviews. The findings reveal the complexity of attitudes within these groups. Some vacillated between the wish to support prospective parents' reproductive autonomy and concerns about potential harms, especially the expression of negative messages about deafness and the potential loss of acceptance in society. While some participants felt carrier screening could help prospective parents to prepare for a deaf child, there was little support for reproductive screening and termination of pregnancy. Participants emphasized the need for accurate information about the lived experience of deafness. The majority felt deafness is not as severe as other conditions included in RGCS, and most do not consider deafness as a disability. People with personal experience of deafness have diverse attitudes towards RGCS for deafness informed by their own identify and experience, and many have concerns about how it should be discussed and implemented in a population wide RGCS program.

KEYWORDS
attitudes, deafness, genetic testing, lived experience, reproductive carrier screening, stakeholder views

1 | INTRODUCTION

Reproductive genetic carrier screening (RGCS) is widely available as a genetic screening method that enables a population-based offer of information to all prospective parents, prior to conception or in early pregnancy. It provides information about their chances of having a child with an autosomal recessive or X-linked recessive condition (Edwards et al., 2015). The aim of RGCS is to inform reproductive decision-making. The offer is available regardless of a couple's a priori risk, which means many couples are making reproductive decisions about genetic conditions of which they have no lived experience. Internationally, RGCS is offered by commercial testing companies (Chokoshvili et al., 2018). Although pilot studies are being carried out in the Netherlands (Schuurmans et al., 2019), and in Australia (Kirk et al., 2021), there is yet to be a government funded RGCS program (Dive & Newson, 2021). While there is a significant body of evidence-based research supporting the offer of RGCS to enable informed choice for prospective parents (Edwards et al., 2015; Gregg et al., 2021), there is no consensus on which conditions should be included, how they should be selected, or which stakeholders should make such decisions. The current landscape for offering RGCS is often commercially driven, and providers make the decision on which conditions to include in an offer of RGCS. While population wide RGCS may promote reproductive autonomy for all prospective parents, it also raises ethical, societal and psychological concerns for society and people living with the genetic conditions included in screening (van den Heuvel et al., 2023).

The terms 'severe' and 'serious' are frequently used to describe genetic conditions or operationally to categorize conditions. However, they are vague, and the boundaries are difficult to define (Dive et al., 2021; Kleiderman et al., 2019) and are often dismissive of personal experience, instead drawing on the views of healthcare professionals to delineate seriousness based on age of onset, lifespan, variability of symptoms, or availability of effective treatment (Boardman, 2021a, 2021b; Ghiossi et al., 2018; Lazarin et al., 2014). The importance of including the perspectives of people living with genetic conditions in understanding the subjective nature of 'severity' or 'seriousness' is increasingly acknowledged (Boardman & Hale, 2019; McNeill et al., 2020; Nijmeijer et al., 2020; Roadhouse et al., 2018; Thomas et al., 2020). There are different aspects to determining severity: clinical symptoms, quality of life, need for healthcare across the lifetime (Rolland & Williams, 2005). As an example, deafness has been described using a medical model as a disability or health condition with management options available, or alternatively using a social model as a culturally and linguistically diverse group not in need of correction.

Indeed, genetic professionals have suggested that individuals with genetic conditions should co-produce definitions of seriousness (Wertz & Knoppers, 2002). There are many examples in the literature reporting how persons with an impairment generally perceive a better quality of life than is predicted by persons who do not have the impairment, suggesting differences between those with and without direct experience (Albrecht & Devlieger, 1999; Boardman et al., 2018; Boardman & Hale, 2018; Lacey et al., 2008; McNeill et al., 2020; Nijmeijer et al., 2020; Ubel et al., 2005). This 'experiential expertise and knowledge' is essential for the responsible implementation of population wide RGCS as it becomes increasingly available to people who do not necessarily have a personal or family history of a genetic condition and are therefore making reproductive decisions without experiential knowledge.

Involving people with genetic conditions and their families in discussions about the implementation of RGCS can provide important information, as they may perceive different issues than the general population (Boardman & Hale, 2018). Several authors suggest the perspectives of parents of children with inherited conditions as well as those of people with the condition should be included whenever possible, in policy decisions and discussions about the composition of RGCS panels (Boardman, 2021a; Boardman & Hale, 2018; Molster et al., 2017; Thomas et al., 2020). Attitudinal studies suggest that families with experiential knowledge of cystic fibrosis (Janssens et al., 2016), spinal muscular atrophy (Boardman et al., 2017), and mucopolysaccharidosis type III (Nijmeijer et al., 2020) generally have positive views on RGCS for these conditions. More recently, a study from the Netherlands reported a majority of parents of children with a recessive disorder had a positive attitude towards population-wide RGCS, including screening for their own or the child's genetic condition, but that the perceived severity of the condition made the greatest contribution to their views (Woudstra et al., 2022). These findings cannot therefore be generalized to less severe conditions.

What is known about this topic

- There is no consensus on which conditions should be included in RGCS or who should make such decisions.
- Experiential knowledge is important for responsible decisions about which conditions should be included in RGCS.
- Concerns have been raised about possible negative impact of RGCS on people living with the genetic conditions being screened.

What this paper adds to the topic

- People with a personal or family experience of deafness have diverse attitudes towards RGCS for deafness informed by their own identity and experience, and many have concerns about how deafness should be discussed and implemented in population wide RGCS.
- Inclusion of genes for NSHL may have negative societal consequences, including a decrease in empathy and acceptance of disability; and de-valuation of people who are deaf.

Deafness is an example of a condition that is sometimes considered neither a disability nor a pathology in need of correction, with some D/deaf[1] people arguing instead that they are part of a distinct cultural community sharing common values and language (Ladd, 2005; Lane, 2005) rather than disabled. A recent review by our group reported that deafness is not necessarily seen as a limiting or unfortunate condition by D/deaf individuals or hearing parents of deaf children and hearing children of deaf adults (Freeman et al., 2022). Several earlier studies reported that these groups feel that the availability of genetic testing for deafness in the reproductive setting could express a negative view of deafness (Guillemin & Gillam, 2006; Mand et al., 2009; Steinberg et al., 2007). Nevertheless, in 2021 a study reported that most (18/23) of the published and commercial carrier screening panels included at least one gene associated with NSHL (Kirk et al., 2021).

Although a number of older studies reported on attitudes of D/deaf individuals or parents of a deaf child towards prenatal diagnosis (PND) and termination of pregnancy (TOP) for deafness, there is a paucity of more recent research. This is a concern given the advancement of new technologies such as preimplantation genetic testing (PGT) and changes in social attitudes. This qualitative study examines the perspectives of individuals who identify as D/deaf or who are a parent of a child who is deaf, on the inclusion of genes associated with NSHL in RGCS.

2 | MATERIALS AND METHODS

The conduct, design and reporting of this study follow the Consolidated Criteria for Reporting Qualitative Studies (COREQ) checklist (O'Brien et al., 2014; Tong et al., 2007; Appendix S1). The Sydney Children's Hospital Human Research Ethics Committee granted ethics approval for the study (2020/ETH01583).

2.1 | Participants and recruitment

Participants were recruited from deafness-related organizations across different sectors, including Deaf community organizations, support organizations for people with hearing loss, and a hearing support clinic at The Sydney Children's Hospital, Randwick, NSW Australia. In addition to recruiting from these sites, a process of snowball recruitment was also used in which participants were asked to pass on information about the project to others they thought might be interested in participating. Specific strategies were used to ensure a sensitive and safe research design and guard against potential distress to participants (Liamputtong, 2009). The recruitment strategy required participants to make the initial contact with the researcher and further information about the study was provided so that the choice to participate was informed. By providing this pathway, we expected that participants would feel confident to share their views.

[1]Throughout this paper Deaf with a capital D is used to describe those who identify as culturally Deaf, with deaf with a lower case d indicating audiological deafness.

2.2 | Data instrument and collection

Recruitment and data collection were conducted between November 2020 and November 2021 by the primary author, LF, a PhD candidate and genetic counselor with experience in qualitative research and in working with clients who are deaf and families with a child or relative who is deaf. Interviews were conducted by telephone or online (using video conferencing) according to participants' preferences. All participants were informed of the study aims and potential data uses. Interview participants provided written or verbal consent prior to commencing the interview. All interviews were conducted by LF who was not previously known to the participants. Australian sign language (Auslan) interpreters were available if requested. Given the method of recruitment including snowballing and the possibility of participants being known to one another, particular care was taken to protect the anonymity of those involved. A professional transcription agency transcribed the audio-recorded interviews. LF verified and deidentified all the transcripts, replacing names with pseudonyms. All participants were offered the opportunity to review their de-identified transcript and two participants accepted, although neither provided any comments.

The interview guide was developed by the investigators after review of the literature about RGCS, reproductive choices, genetic testing for deafness in the reproductive setting, and disability studies' critiques of prenatal testing and selection (Appendices S2 and S3). The questions were refined after review by several genetic counselors and one author, JLS, a bioethicist with personal experience of hearing loss. Interviews covered participants' experience of deafness, their perceived quality of life, any reproductive decisions made or anticipated, general views on reproductive decisions, and attitudes towards the use of RGCS specifically for deafness as well as for other conditions.

2.3 | Data analysis

We used inductive thematic analysis supported by NVivo v12 (QSR International, NVivo) to code transcripts and develop themes relevant to the research question (Braun & Clark, 2006, 2019). LF led the analysis. JLS co-coded several transcripts and engaged with LF on data interpretation and resulting coding themes. Analysis began with open coding, a 'line-by-line' technique where specific ideas as the smallest unit of information were assigned a code. As analysis progressed, codes were connected into broader themes using interpretive description. Interpretive description involes going beyond the initial themes identified and dynamically engaging with them in an inductive approach to thematic analysis that allows the gradual conceptualisation of a framework based on the

experiences and insights of the participants (Braun & Clark, 2006, 2019). After initial 'open coding', higher level hierarchal coding was undertaken through a repeated process of coding, refinement of concepts through data interpretation and insights from the literature, and as this progressed, codes were conneceted into broader themes using interpretive description. We revised codes over several iterations before organizing them into themes until thematic saturation (i.e. the point where no new information is emerging) (Given, 2008). LF and JLS organized codes into themes using interpretative description allowing us to synthesize themes and conceptualize them in relation to one another in a cohesive process. Discrepancies in coding were discussed between the researchers until agreement was reached. This paper presents the core themes derived from the final reflexive coding framework of the qualitative analysis. The data from all participants contributed to the final coding framework.

2.4 | Consent

Participants were provided with full information about the aims and procedures of the study before participating. Consent was provided either in writing or verbally at the start of all interviews after the aims of the study had been repeated.

2.5 | Validity

The complete data set, which includes accounts from 27 participants, reached thematic saturation and was sufficient to address our study questions.

3 | RESULTS

3.1 | Participant characteristics

The sample consisted of 27 participants who had a lived experience of deafness, either as a hearing parent of a deaf child ($N=13$) or as a D/deaf individual themselves ($N=14$) (Table 1). The majority of interviews with parents were with mothers alone ($n=9$), with one set of mother and father choosing to be interviewed together and another set of parents where the mother and father were interviewed separately. One interview was conducted over the telephone whilst the rest used videoconferencing. Nine participants elected to use an Auslan interpreter: all these participants requested an interpreter known to them and provided a list of preferred interpreters with whom they had previously worked and who understood their distinctive use of Auslan. Interpreters were booked through the Deaf Society and all participants were allocated an interpreter from their own list. While interpretation introduces the risk of some bias as interpreters are 'constructers of knowledge in the interpreting act' (Simcock, 2017), all interpreters adhered to the Australian Sign Language Interpreter's Association Code of Ethics and Guidelines for Professional Conduct (ASLIA, 2020) as required for registration with the Deaf Society.

The mean length of interviews was 47 min (range 21–66 min). There were 13 D/deaf individuals between 21 and 64 years of age and 14 parents of at least one child born deaf (children ranging between 6 months old and early adulthood). Most were female ($n=20$), had a high level of education ($n=25$ had a graduate certificate or higher), and had lived in Australia their entire life ($n=22$). Four participants identified as culturally Deaf in their report of ethnicity in the participant demographic details.

Some participants had genetic counseling after a child was identified as deaf by newborn hearing screening, others had genetic counseling in preparation for starting a family. The majority of D/deaf adults had not engaged with any genetic service.

The key findings presented here are the four overarching themes relating to views on the inclusion of genes associated with NSHL in RGCS. Quotes from interviews have been selected to illustrate the data coded to that theme particularly clearly.

3.2 | Theme 1—RGCS promotes reproductive autonomy and severity is a key criterion for selecting conditions to include

RGCS garnered support from all participants across the dataset for severe, childhood-onset, life-limiting conditions. Only two participants (both of reproductive age planning a family) had previously heard about RGCS. For the other participants, this type of screening was new. After having it explained they acknowledged the benefit this screening could offer prospective parents.

> ***Soren, deaf:*** "I think there's real value in this type of testing in terms of severe condition, life-or-death type situations".

References to RGCS promoting reproductive autonomy emerged spontaneously and frequently across the combined data set. All participants saw this type of screening as empowering and facilitating informed choice for prospective parents who may not want to have a child with a genetic condition. Many participants think that screening provides prospective parents with choice that is aligned with their own values and beliefs.

> ***Linda, a parent:*** "I think the more information you know, the better … I think being able to choose … people are always going to be different, but I think giving people an option … anything that could help people is never a bad thing".

Severity of the condition was mentioned most often as the key criterion for deciding which conditions should be included in an offer of RGCS. Participants also recognized that there is subjectivity in how different people view the severity of different conditions, and in turn whether the condition is "severe enough" to include in a RGCS

TABLE 1 Participant demographics ($N = 27$).

	Pseudonym	Sex	Age	Relationship to deafness and self-reported description of deafness	Education level	Ethnicity/cultural identity
1	Yazmin	F	28	Deaf—severe	Postgraduate	Middle Eastern
2	Anabel	F	64	Deaf—profound	Certificate	European
3	Maya	F	37	Deaf—Moderate	Bachelor	European
4	Soren	M	50	Deaf—severe	Postgraduate	European
5	Kareem	M	32	Deaf—severe	Bachelor	European
6	Lily	F	34	Deaf—profound	Postgraduate	European
7	Ella	F	29	Deaf—profound	Bachelor	European CALD deaf
8	Anisa	F	51	Deaf—severe	Diploma	European CALD deaf
9	Blake	M	30	Deaf—severe	Bachelor	South East Asian
10	Chad	M	53	Deaf—profound	Postgraduate	European CALD deaf
11	Tali	F	60	Deaf—profound	Certificate	European CALD deaf
12	Ida	F	38	Parent, child with mild hearing loss	Postgraduate	European
13	Mary	F	39	Parent, child with severe hearing loss	Certificate	Mediterranean
14	Elizabeth	F	32	Parent—child with severe to profound deafness	Bachelor	European
15	Linda	F	38	Parent, child with profound deafness	Certificate	European
16	Alice	F		Parent—child with moderate to severe deafness	Bachelor	European
17	Omar[a]	M	32	Parent, child with severe hearing loss	Bachelor	European
18	Grace[a]	F	30	Parent, child with severe hearing loss	Bachelor	European
19	Hazel	F	48	Parent—child with severe to profound deafness	Not reported	European
20	Mia	F	27	Parent, child with mild to moderate hearing loss	Not reported	European
21	Tori[b]	F	39	Parent, child with profound deafness	Bachelor	European
22	James[b]	M	40	Parent, child with profound deafness	Bachelor	European
23	Emi	F		Parent, child with mild to moderate hearing loss	Diploma	European
24	Mei	F	31	Parent, child with moderate hearing loss	Bachelor	European
25	Hassan	M	40	Deaf—profound	Postgraduate	European
26	Macy	F	35	Parent, child with profound deafness	Diploma	European/Indigenous Australian (child)
27	Pranee	F	21	Deaf—profound	Bachelor	European

Note: There were two sets of parents who were recruited.

Abbreviations: CALD, culturally and linguistically diverse group; F, female; M, male.

[a]Omar and Grace elected to be interviewed together.

[b]Tori and James participated in their own interview separately.

panel. Views on what constitutes a severe condition varied, with several mentioning that it was related to one or more of the following: (i) individual life experiences, (ii) availability of treatment, (iii) presence of suffering or pain, (iv) capacity to live an independent life, working and earning an income, and (v) ability to engage in and connect to community.

Macy, a parent: "The more serious conditions that affect a parent's lifestyle, potentially the child becoming independent or having a bad quality of life, essentially. I think if that's something the parents want to look at, absolutely, I think it's great testing."

Alice, a parent: "I'm in two minds about [screening for severe conditions] … you may not be coming from a place that understands what that means … it's about your own personal experience".

Several deaf participants suggested it may be unrealistic to aim for consensus on severity for all conditions to include in RGCS.

Whilst participants had varying ideas about the criteria for inclusion in RGCS, all participants do not believe that deafness fits the criterion of 'severe enough' to include in RGCS. Often using hypothetical scales in their descriptions, participants would position deafness at the lower end of severity for health conditions.

Maya, deaf: "…of all the illnesses you can faced with, hearing loss can be dealt with and is by far and away not the worst thing".

David, a parent: "[deafness] is almost just a bit beyond eye colour or something, yeah eye colour or hair colour".

Parents of deaf children shared the view that deafness is not a severe condition. Some parents however said that it took them some time to come to terms with their child's deafness and perceive it as not severe.

Elizabeth, a parent: "if [deafness is placed] in the same category as [severe conditions] then I think that would paint a very grim picture of what hearing loss actually is in reality."

Mia, a parent: "It seemed like a really big deal and now four years on you think, of, this is totally doable. This is not the end of the world; this is manageable and I'm hopeful for her future ….[I] wouldn't say profound deafness is what [I] would categorize as life-limiting or affecting real quality of life because they can go down the cochlear route or they can choose to embrace the deafness and the deaf community and live that way".

3.3 | Theme 2—Defining deafness: Identity, severity and stigma

Most participants in both datasets highlighted positive experiences associated with their own identity, connections with the deaf community and achieving life goals. One Deaf participant who has a positive view of her deaf identity however said her adolescent deaf children did not share this same view. Participants acknowledged that whilst they may have had a positive self-image of their deafness, they also perceived negative attitudes in others associated with their deafness. The perceived negative associations were often felt to be restrictive, a source of frustration and disappointment based on the views expressed in the wider society.

Their experience is that hearing people place a negative value on being deaf, but they themselves do not see it as a serious or severe problem. Several noted that deafness forms an important part of their identity. Many D/deaf individuals expressed that their views are inextricably linked with their own positive identity for themselves.

Maya, deaf: "my hearing is more part of who I am rather than a health condition".

Many deaf participants did not describe being deaf as a disability. Some however said they used the term *disability* solely to access funding for services, although they would not use it when describing themselves.

Blake, deaf: "when I'm dealing with NDIS [National Disability Insurance Scheme] or Centrelink, I would identify as disabled, but within myself and within the Deaf community I do identify strongly as being normal".

Many parents in the study shied away from labelling their child's deafness as a 'disability' as they feel it could stigmatize their child. Some parents also consider the use of hearing aids and/or cochlear implants as technology that allows their child to hear, i.e. that stopped their child being disabled, but this concept was not expressed by any of the deaf participants.

Mia, parent of a deaf child: "if [my daughter] didn't have access to hearing aids, I would probably consider it a disability".

Several participants said that they felt society has categorized the deaf experience as a problem for those who are deaf. There is particular resentment of the hearing world controlling the concept of deafness by defining it as a disability. Some participants felt this was emphasized by the provision of information coming from hearing people in the medical profession and feel it could be improved by including a deaf person in the preparation of information.

Grace, a parent: "It's just society that makes people think that there's something wrong with [being deaf], but there's not".

Isabelle, deaf: "It's funny that the medical sector assume they should be the ones giving information about culture and, and what it is like to be deaf … I think from the very beginning [the couple] should meet a deaf person, because you can't talk about deafness without having somebody who's deaf with lived experience … medical professionals do not have the expertise regardless of their degree".

Considering genetic testing for deafness in the reproductive setting, participants are concerned that it would influence reproductive decisions without due attention to the powerful views of those who have lived experience of deafness. They worry that only the medical view would be available to couples making reproductive decisions.

Anisa, deaf: "I feel the medical model only has that one view, the medical, the cost, the value, the economy, just all of that stuff around raising a deaf child".

Participants expressed caution at the availability of reproductive options that enables couples found to have an increased chance of having a deaf child to avoid having a child born deaf. There was a universal lack of support among the deaf participants for prenatal testing with TOP for non-syndromic deafness, i.e. where deafness is the only effect. It was clear that the participants' experience of being deaf or having a deaf child influenced their views on TOP for deafness.

Ella, deaf: "to abort because they're deaf, that's heartbreaking". She found the idea of termination of pregnancy for deafness

harrowing: "you're wanting to abort something that's so cultural to us and so meaningful."

Views on the use of PGT to avoid having a deaf child were more divided in the deaf participant group. For some, this technology represents a more acceptable advance in medicine because it does not involve pregnancy termination. Other D/deaf participants felt there is no difference between PGT and PND as both aimed to achieve the same outcome.

Yazmin, deaf: "I would be more comfortable with couples doing [RGCS] pre-pregnancy so they could use IVF rather than termination of pregnancy".

Several parents were also more supportive of using PGT to avoid having a deaf child than PND with potential pregnancy termination if the fetus is found to have the genetic predisposition to deafness.

Participants usually identified the most negative impacts of deafness in their lives as social and related to discrimination, attitudes and accessibility. Reflecting on the stigmatization of people who are deaf, participants wondered whether including deafness in an offer of RGCS may imply a devaluation of their lives. Some participants felt that the existence of these broader negative attitudes and perceptions would influence couples making reproductive decisions. There was also concern that the availability of RGCS for deafness might *exacerbate* existing negative attitudes towards deaf people or perpetuate the view that deafness is something that should be avoided, rather than (as they saw it) an acceptable difference in life.

Isabelle, deaf: "there is more awareness about some deaf people, but there's still this stigma … that unconscious bias, or, you know, patronizing attitude towards deaf people".

Macy, a parent: "I think a lot of people still have that perception, deaf and dumb, like old school days. Because the deaf community isn't huge as such you could say, and because it's an invisible condition you don't see … I think there just isn't enough information".

Ida, deaf: "if we include hearing loss [in RGCS] then I feel like that will put even more stigma on the whole aspect of hearing loss … there's enough stigma about it, but it may put so much more that it's now".

3.4 | Theme 3—Inclusion in RGCS may send a signal that deafness is something to avoid

Many deaf participants felt that including these genes in RGCS sends a 'signal' that deafness is something that the average person/couple would want to avoid. They expressed frustration at what they saw as society finding it easier to 'eliminate' deafness than to change societal attitudes or address barriers to inclusion. This was felt to be akin to promoting eugenics in the general population, i.e. the view that it would be preferable to eliminate deafness in future generations. For many D/deaf participants the possibility of reducing the number of deaf people in the world produced strong emotional reactions. Similarly, many parents of deaf children also felt that a line needs to be drawn and that eliminating deafness through inclusion in RGCS could cause harm.

Blake, deaf: "there is underlying discrimination that affects the deaf community in Australia [and] if there's genetic testing for deafness I believe there would be the potential for the loss of the deaf community and deaf babies to be aborted".

Anabel, deaf: "if we lose deaf people in the population, I feel that's very sad. I think it's a huge loss … hmmm … that type of diversity that deafness brings, … the language we have … the neurocognitive adaptions that a deaf person makes … it's important to have all of this".

Macy, a parent: "Where's the line, it needs to stop somewhere and I think being deaf shouldn't be one of them. It's such a beautiful community … so I just don't think that should be something that we get to choose".

Some participants saw inclusion as way to make the world more homogeneous and, more specifically, reduce diversity. Deafness as a form of diversity is seen by some deaf participants and some parents of a deaf child as worth preserving. Looking to the future, a few see RGCS for deafness as a first step on a slippery slope towards elimination of other traits, some drawing parallels with the eugenics movement.

Tali, deaf: "It doesn't feel correct to me, to be selective … if you want to rid the world of deafness, blindness, people who are short, where do you stop? I would reject that premise and that possibility not only because of deafness, because I'm deaf, but also because parents would start shopping for the perfect baby. And I do not want to see that … I think it's important for us to have diversity".

Some deaf participants projected an imaginary future in which there is reduced empathy towards and acceptance of children who are deaf or have another difference or disability. Many participants expressed a feeling that including deafness in RGCS was part of a drive towards perfection in reproduction, reflecting a desire to control characteristics and traits in future children. The belief that society is better for the presence of deaf people was common among participants. Both groups often argued that deaf people should be valued in society and that including deafness in RGCS emphasizes perfectionism rather than acceptance.

Soren, deaf: "imagine if you created a world of perfect human beings. There'd be no empathy because there'd be nothing to—everybody would be perfect. There'd be nothing wrong with anybody".

Alice, a parent: "I feel like the world would be a lesser place if people made a decision not to carry on with having deaf children, really I think it would a less rich place".

Some parents who chose not to undertake any genetic testing in subsequent pregnancies emphasized the message PND or PGT that would send to their first child.

David, a parent: "if I had to explain later on to my son that the second child was an IVF baby to rule out the deafness, then it's basically saying he's not good enough".

3.5 | Theme 4—If deafness is included in RGCS it needs to be done responsibly

There was a sense among participants that it is necessary to recognize and overcome their own feelings of discomfort about making this information available to prospective parents in order to be consistent with their belief in promoting autonomy and respecting the freedom of couples to make their own informed choices. This tension was also expressed by parents of deaf children, who felt deafness is not severe enough to include in screening but could see that it could help facilitate choice. A number of D/deaf participants recognized that some parents may not have the capacity or resilience to provide care for a child born deaf. Some parents noted that caring for a child born deaf is hard and that this could justify the inclusion of deafness in RGCS.

Mia, a parent: "I wouldn't say it should be part of normal screening, but I think if someone knows that parent's going to be hard for them and something that could really push them over the edge, they should be able to seek it out … I think it's absolutely valid that someone can seek out that information."

Some participants felt that knowing this information early could also be an opportunity to engage with the Deaf community and learn about early interventions, and others that hearing parents may benefit from knowing this information in order to come to terms with their grief at having a deaf child. Parents of a deaf child supported giving an option even if they would not do it themselves, citing 'choice' and 'information' as key drivers.

Linda, a parent: "I think it's a good thing. I think being able to choose that … people are always going to be different, but I think giving people an option, I don't think that's a bad thing at all".

Participants indicated that high quality, unbiased information about lived experience of deafness is a vital resource to support a decision about RGCS for deafness at the time of screening.

Kareem, deaf: "I don't see any issue with it being part of a test, it would just need to be alongside a lot of information"

Elizabeth, a parent: "I think definitely the right information needs to be given and needs to inform the parents of what [having a deaf child] actually looks like".

Notably, for most deaf participants their support for inclusion of NSHL-associated genes in RGCS was positioned in terms of helping parents plan and prepare for the possibility of having a child born deaf.

Soren, deaf: "I would like to say if we screen for hearing loss, it's only to give you an idea of the chances that your child might have a hearing loss, and so you can be better prepared … if I had my preference, you only get the information. You don't get to do anything about it, except learn more and be prepared."

Some participants queried whether the level of information required for 'good' decision making is a realistic goal for the general population. They felt that many people today may not know or have ever met a deaf person and are on the whole uninformed about lived experiences of deafness. Participants across both groups emphasized that the information should come from deaf people.

Isabella, deaf: "I think [the couple] have to have that conversation with deaf people about the benefits of a deaf child".

Concern was expressed that the lack of exposure to accurate information about deafness in fact constitutes a failure of informed consent: accessible and accurate information about deafness is essential for prospective parents to make a genuinely informed decision about screening for their family planning. Participants did acknowledge the subjectivity of living with deafness and that it may not be possible to provide all aspects to prospective parents. Whilst the information is important it is equally important to consider how it is presented to people making decisions.

Tori, a parent: "I think that the information can be good, but it's how people are presented with that information, how they're counselled through that".

Some participants were concerned that if deafness is included in RGCS, couples may feel implicit pressure to act on this information to avoid having a child born deaf. Participants said they feel uncomfortable at the possibility that the autonomy of prospective parents could be compromised if screening becomes part of 'routine' pregnancy care. Participants felt this becomes more likely if RGCS and access to selective reproductive technologies in general is funded by the government, further legitimizing the use of these pathways to avoid having a child born deaf. When considering the inclusion of deafness in a larger panel of conditions being screened, concern was compounded.

Anabel, deaf: "I feel that many parents, if they had this choice in a pregnancy they would terminate because the screening test is quite overwhelming".

Kareem, deaf: "[the couple] might be overwhelmed with all this information about different conditions … and if it is free, they might just be like, 'we'll just get tested for everything'".

4 | DISCUSSION

To our knowledge, this study is the first to examine the attitudes towards RGCS of people who are deaf and those of parents of a deaf child. By elucidating and clarifying the perspectives of those with a personal connection to deafness, this study contributes to an increased understanding of the challenges of responsible inclusion of genes for NSHL in RGCS. It was assumed that participants' views on RGCS for deafness can be understood in the context of their personal experiences, beliefs, sense of identity, as well as reflections on wider society. The themes identified were equally supported across parents of a deaf child and D/deaf adults, the main difference between the groups being that parents, unlike D/deaf adults, felt that cochlear implants meant their children were not deaf and considered them hearing. There was a small increase in support for PGT among parents of deaf children compared to D/deaf adults, and D/deaf adults also expressed stronger sentiments around deaf identity.

Our study found that those living with deafness, and parents of a child who is deaf, do not feel deafness is severe enough to include in an offer of RGCS. They particularly resented that the severity of deafness is defined by hearing people rather than those who are deaf. This response may reflect the fact that for many people born deaf, deafness is something they have incorporated into a positive self-identity. Many deaf people say they are Deaf (with a capital D) reflecting their cultural identity as a member of a culturally and linguistically diverse group. In a study reporting on perceptions of severity by people living with conditions, those with early onset conditions held more positive views of their health and quality of life and were more likely to see their condition as part of their identity than participants with later-onset conditions (Boardman & Clark, 2022). The findings of this study echo previously published work that demonstrates many people living with genetic disease perceive their quality of life to be rich and diverse and often higher than those living without the condition assume they would experience (Boardman, 2021a, 2021b; Boardman & Hale, 2018; Hoffman-Andrews et al., 2019; Redgrave & McNeill, 2022).

The concern that inclusion of deafness in RGCS could contribute to a societal climate hostile to having less than 'perfect children' has previously been reported as a potential harm from RGCS, especially when 'mild' conditions might be included in the test panel (Conijn et al., 2021; Henneman et al., 2016; Janssens et al., 2017; Matar et al., 2016, 2019a). Participants in this study raised concerns that inclusion of deafness may increase stigmatization of deaf people, resulting in discrimination and a future society lacking diversity and less acceptance of difference. Whilst we are not aware of empirical evidence of increased stigmatization or discrimination following uptake of RGCS, the potential negative implications of offering population-wide RGCS have previously been raised (Matar et al., 2019a, 2019b; van den Heuvel et al., 2023). Parents who continued a pregnancy where a genetic condition was detected or suspected prenatally have reported receiving negative and discouraging comments from both family and healthcare professionals (Hickerton et al., 2012). The risk that stigmatization will encourage the perception that there is no place for people with disabilities in our society, or that the lives of people with genetic conditions have less value. is part of the 'disability critique' of prenatal screening (Boardman, 2014a, 2014b; Dive & Newson, 2021; Edwards, 2004; Parens & Asch, 1999, 2003).

Concerns about the potential for RGCS to 'shape society' have been expressed by healthcare providers and those offered population-based carrier screening (van den Heuvel et al., 2023). Offers of RGCS that includes genetic conditions with a wider range of severity in their presentation have been criticized for expressing a discriminatory view of those living with the conditions screened for. Our study also shows participants' concern about the possible routinisation of screening for deafness, evidenced by the wide acceptance of other types of reproductive screening like NIPS; once a condition is included on an RGCS panel, it may become the social norm to screen for that condition and to expect that prospective parents will take steps to avoid having a child with it (Dive et al., 2023).

In parallel with previous work (Guillemin & Gillam, 2006), participants in this study emphasized the need for accurate and contemporary information about life as a deaf person, but also that prospective parents should be offered opportunities to speak with a deaf person. This study provides further support to the argument that those making reproductive decisions about deafness, and no doubt other conditions, require access to diverse experiences of the qualitative aspects of living with those conditions.

RGCS aims to provide prospective parents with information to inform their reproductive decision making. In this study participants identified value in including deafness as it may provide important information for planning for the birth of a child born deaf, supporting prospective parents to explore management options before a child is born. This is a valid reproductive choice and whilst this group did not support access to PND for TOP for deafness it would be logistically challenging for a healthcare system, and would also contradict the aim of supporting reproductive autonomy, to limit reproductive options available to prospective parents.

Our study highlights that support for inclusion of deafness in RGCS does not imply support for all reproductive options, such as PND followed by TOP. This has been previously reported in a study of adults with hemophilia and their relatives: despite support for population-wide RGCS, 90% of the respondents did not agree with pregnancy termination for hemophilia (Boardman & Hale, 2018). Whilst there is support for RGCS to provide information and choice, participants would prefer that choice not be for TOP for deafness alone. Similar findings were reported by Boardman: largely positive lived experiences and supportive attitudes towards prenatal screening but also a resistance to the associated practice of selective termination for patients living with a serious genetic condition (Boardman & Clark, 2022). A study by Redgrave and McNeill (2022)

also reported persons living with a genetically caused visual loss objected to termination of pregnancy for the condition but were supportive of PGT and PND being available, even though they did not think they would use the technologies themselves (Redgrave & McNeill, 2022). A recent study of people with a range of genetic conditions, and their parents, found strong support for the statement "[RGCS] ensures that (future) parents can better prepare for a child with a genetic disorder" (Woudstra et al., 2022). Offering prospective parents RGCS with restrictions on reproductive choices or offering an expanded panel which includes 'mild' conditions may, however, conflict with obtaining fully informed consent or respecting reproductive autonomy. Whilst this was not explored further in this study, future work could consider the nuances of a system that supports TOP for a range of personal reasons but not for a specific diagnosis such as hearing loss or deafness.

5 | STRENGTHS AND LIMITATIONS

One strength of this study is the inclusion of D/deaf participants with different experiences of communication methods (spoken English and signing Auslan). In qualitative semi-structured interviews, the necessarily small sample size is counterbalanced by the richness of data gained. Nevertheless, the recruitment methods used impose certain limitations on the sample. Participants with strong views may have self-selected to participate, and recruitment using snowballing may have biased the sample towards participants who share similar views. The majority of participants were university educated which is not necessarily generalisable to the population nor the Deaf population. Explanatory material was available in written English and not in Auslan, which may have excluded D/deaf individuals who are not confident in communicating via written English. Participants who found the topic too sensitive to explore in interviews may have chosen not to participate. Some nuances may have been lost in translation in interviews conducted in Auslan with an interpreter. These findings are made within an Australian context and their generalisability to other cultures may be limited; attitudes towards disability and the social contexts in which they operate vary greatly across cultures. Factors such as availability of early intervention, cost of any management or intervention and the possibility of coercion may also be viewed quite differently in countries with different types of healthcare systems.

6 | PRACTICE AND RESEARCH IMPLICATIONS

Policy stakeholders and commercial organizations can use these findings to reflect on the ethical and responsible implementation of RGCS when deciding whether to include genes associated with NSHL. While not directly generalisable, our findings suggest significant themes could be tested in a larger, quantitative study and across groups of individuals with mild or moderately severe genetic conditions.

7 | CONCLUSIONS

Understanding the perspectives from 'experiential experts' is essential for the responsible implementation of population-wide RGCS. Our findings suggest that views regarding reproductive choices around deafness are intertwined with the identity of being deaf and part of a Deaf community. Whilst participants in this study felt that offering RGCS promotes reproductive autonomy they also raised concerns that including genes for NSHL could lead to further stigmatization for people who are deaf, and decreased acceptance of and empathy towards them. Our findings underline the growing complexity of arguments on the inclusion of deafness, and similar conditions, in RGCS, and how different reproductive options are viewed from different perspectives. For deafness to be included in RGCS, there should be a consensus from all stakeholders that the benefits outweigh the harms, and this was not clearly indicated in our study.

AUTHOR CONTRIBUTIONS

LF: Conceptualization; formal analysis; investigations; methodology; project administration; visualization; writing—original draft; writing—review and editing. **JLS**: Conceptualization; formal analysis; methodology; supervision; validation; writing—review and editing. **LB**: Recruiting; writing—review and editing. **MD**: Conceptualization; methodology; supervision; validation; writing—review and editing. **EK**: Conceptualization; methodology; supervision; validation; writing—review and editing.

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CONFLICT OF INTEREST STATEMENT

The authors declare that they have no conflict of interests.

DATA AVAILABILITY STATEMENT

The data are not publicly available due to privacy or ethical restrictions. Further information is available by contacting the corresponding author.

ETHICS STATEMENT

Human studies and informed consent: This research study was approved by the Sydney Children's Hospital Network Research (2020/ETH01583). The research was undertaken in compliance with the Australian Code for the responsible Conduct of Research and National Statement on Ethical Conduct in Human Research. Informed consent was obtained from all study participants. Participant identifiers have been removed so the persons described are not identifiable.

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

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REFERENCES

Albrecht, G. L., & Devlieger, P. J. (1999). The disability paradox: High quality of life against all odds. *Social Science & Medicine*, *48*, 977–988.

ASLIA. (2020). *Australian sign language interpreters Australia*. Code of Ethics.

Boardman, F. (2014a). Experiential knowledge of disability, impairment and illness: The reproductive decisions of families genetically at risk. *Health (London, England)*, *18*, 476–492.

Boardman, F. K. (2014b). The expressivist objection to prenatal testing: The experiences of families living with genetic disease. *Social Science & Medicine*, *107*, 18–25.

Boardman, F. K. (2021a). Attitudes toward population screening among people living with fragile X syndrome in the UK: 'I wouldn't wish him away, I'd just wish his fragile X syndrome away. *Journal of Genetic Counseling*, *30*, 85–97.

Boardman, F. K. (2021b). Whose life is worth preserving? Disabled people and the expressivist objection to neonatology. *Acta Paediatrica*, *110*, 391–393.

Boardman, F. K., & Clark, C. C. (2022). What is a 'serious' genetic condition? The perceptions of people living with genetic conditions. *European Journal of Human Genetics*, *30*, 160–169.

Boardman, F. K., & Hale, R. (2018). How do genetically disabled adults view selective reproduction? Impairment, identity, and genetic screening. *Molecular Genetics & Genomic Medicine*, *6*, 941–956.

Boardman, F. K., & Hale, R. (2019). "I didn't take it too seriously because I'd just never heard of it": Experiential knowledge and genetic screening for thalassaemia in the UK. *Journal of Genetic Counseling*, *28*, 141–154.

Boardman, F. K., Young, P. J., & Griffiths, F. E. (2017). Impairment experiences, identity and attitudes towards genetic screening: The views of people with spinal muscular atrophy. *Journal of Genetic Counseling*, *27*, 69–84. https://doi.org/10.1007/s10897-017-0122-7

Boardman, F. K., Young, P. J., Warren, O., & Griffiths, F. E. (2018). The role of experiential knowledge within attitudes towards genetic carrier screening: A comparison of people with and without experience of spinal muscular atrophy. *Health Expectations*, *21*, 201–211.

Braun, A., & Clark, V. (2006). Using thematic analysis in pyschology. *Qualitative Research in Pyschology*, *3*, 77–101.

Braun, V., & Clarke, V. (2019). Novel insights into patients' life-worlds: The value of qualitative research. *Lancet Psychiatry*, *6*, 720–721.

Chokoshvili, D., Borry, P., & Vears, D. F. (2018). A systematic analysis of online marketing materials used by providers of expanded carrier screening. *Genetics in Medicine*, *20*, 976–984.

Conijn, T., van Dijke, I., Haverman, L., Lakeman, P., Wijburg, F. A., & Henneman, L. (2021). Preconception expanded carrier screening: A focus group study with relatives of mucopolysaccharidosis type III patients and the general population. *Journal of Community Genetics*, *12*, 311–323.

Dive, L., Archibald, A. D., Freeman, L., & Newson, A. J. (2023). How should severity be understood in the context of reproductive genetic carrier screening? *Bioethics*, *37*(4), 359–366.

Dive, L., Archibald, A. D., & Newson, A. J. (2021). Ethical considerations in gene selection for reproductive carrier screening. *Human Genetics*, *141*(5), 1003–1012.

Dive, L., & Newson, A. J. (2021). Ethics of reproductive genetic carrier screening: From the clinic to the population. *Public Health Ethics*, *14*, 202–217.

Edwards, J. G., Feldman, G., Goldberg, J., Gregg, A. R., Norton, M. E., Rose, N. C., Schneider, A., Stoll, K., Wapner, R., & Watson, M. S. (2015). Expanded carrier screening in reproductive medicine-points to consider: A joint statement of the American College of Medical Genetics and Genomics, American College of Obstetricians and Gynecologists, National Society of genetic counselors, perinatal quality foundation, and Society for Maternal-Fetal Medicine. *Obstetrics and Gynecology*, *125*, 653–662.

Edwards, S. D. (2004). Disability, identity and the "expressivist objection". *Journal of Medical Ethics*, *30*, 418–420.

Freeman, L., Righetti, S., Delatycki, M. B., Scully, J. L., & Kirk, E. P. (2022). The views of people with a lived experience of deafness and the general public regarding genetic testing for deafness in the reproductive setting: A systematic review. *Genetics in Medicine*, *24*(9), 1803–1813.

Ghiossi, C. E., Goldberg, J. D., Haque, I. S., Lazarin, G. A., & Wong, K. K. (2018). Clinical utility of expanded carrier screening: Reproductive behaviors of At-risk couples. *Journal of Genetic Counseling*, *27*, 616–625.

Given, L. M. (2008). *The SAGE encyclopedia of qualitative research methods* (Vol. *1–2*, p. 413). University of Alberta.

Gregg, A. R., Aarabi, M., Klugman, S., Leach, N. T., Bashford, M. T., Goldwaser, T., Chen, E., Sparks, T. N., Reddi, H. V., Rajkovic, A., Dungan, J. S., & Acmg Professional Practice, and Committee. (2021). Screening for autosomal recessive and X-linked conditions during pregnancy and preconception: A practice resource of the American College of Medical Genetics and Genomics. *Genetics in Medicine*, *23*, 1793–1806.

Guillemin, M., & Gillam, L. (2006). Attitudes to genetic testing for deafness: The importance of informed choice. *Journal of Genetic Counseling*, *15*, 51–59.

Henneman, L., Borry, P., Chokoshvili, D., Cornel, M. C., van El, C. G., Forzano, F., Hall, A., Howard, H. C., Janssens, S., Kayserili, H., Lakeman, P., Lucassen, A., Metcalfe, S. A., Vidmar, L., de Wert, G., Dondorp, W. J., & Peterlin, B. (2016). Responsible implementation of expanded carrier screening. *European Journal of Human Genetics*, *24*, e1–e12.

Hickerton, C. L., Aitken, M., Hodgson, J., & Delatycki, M. B. (2012). "did you find that out in time?": New life trajectories of parents who choose to continue a pregnancy where a genetic disorder is diagnosed or likely. *American Journal of Medical Genetics. Part A*, *158A*, 373–383.

Hoffman-Andrews, L., Mazzoni, R., Pacione, M., Garland-Thomson, R., & Ormond, K. E. (2019). Attitudes of people with inherited retinal conditions toward gene editing technology. *Molecular Genetics & Genomic Medicine*, *7*, e00803.

Janssens, S., Chokoshvili, D., Vears, D., de Paepe, A., & Borry, P. (2017). Attitudes of European geneticists regarding expanded carrier screening. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, *46*, 63–71.

Janssens, S., Chokoshvilli, D., Binst, C., Mahieu, I., Henneman, L., De Paepe, A., & Borry, P. (2016). Attitudes of cystic fibrosis patients and parents toward carrier screening and related reproductive issues. *European Journal of Human Genetics*, *24*, 506–512.

Kirk, E. P., Ong, R., Boggs, K., Hardy, T., Righetti, S., Kamien, B., Roscioli, T., Amor, D. J., Bakshi, M., Chung, C. W. T., Colley, A., Jamieson, R. V., Liebelt, J., Ma, A., Pachter, N., Rajagopalan, S., Ravine, A., Wilson, M., Caruana, J., … Delatycki, M. B. (2021). Gene selection for the Australian reproductive genetic carrier screening project ("Mackenzie's Mission"). *European Journal of Human Genetics*, *29*, 79–87.

Kleiderman, E., Ravitsky, V., & Knoppers, B. M. (2019). The 'serious' factor in germline modification. *Journal of Medical Ethics*, *45*, 508–513.

Lacey, H. P., Fagerlin, A., Loewenstein, G., Smith, D. M., Riis, J., & Ubel, P. A. (2008). Are they really that happy? Exploring scale recalibration in estimates of well-being. *Health Psychology*, *27*, 669–675.

Ladd, P. (2005). Deafhood: A concept stressing possibilities, not deficits1. *Scandinavian Journal of Public Health*, *66*, 12–17.

Lane, H. (2005). Ethnicity, ethics, and the deaf-world. *Journal of Deaf Studies and Deaf Education*, *10*, 291–310.

Lazarin, G. A., Hawthorne, F., Collins, N. S., Platt, E. A., Evans, E. A., & Haque, I. S. (2014). Systematic classification of disease severity for evaluation of expanded carrier screening panels. *PLoS One*, *9*, e114391.

Liamputtong, P. (2009). Qualitative data analysis: Conceptual and practical considerations. *Health Promotion Journal of Australia*, *20*, 133–139.

Mand, C., Duncan, R. E., Gillam, L., Collins, V., & Delatycki, M. B. (2009). Genetic selection for deafness: The views of hearing children of deaf adults. *Journal of Medical Ethics*, *35*, 722–728.

Matar, A., Hansson, M. G., & Hoglund, A. T. (2019a). "A perfect society" – Swedish policymakers' ethical and social views on preconception expanded carrier screening. *Journal of Community Genetics*, *10*(2), 267–280.

Matar, A., Hansson, M. G., & Hoglund, A. T. (2019b). Values and value conflicts in implementation and use of preconception expanded carrier screening – an expert interview study. *BMC Medical Ethics*, *20*(1), 25.

Matar, A., Kihlbom, U., & Hoglund, A. T. (2016). Swedish healthcare providers' perceptions of preconception expanded carrier screening (ECS) – A qualitative study. *Journal of Community Genetics*, *7*(3), 203–214.

McNeill, A., Lewis, R., & Freeth, M. (2020). Views of adults with 22q11 deletion syndrome on reproductive choices. *American Journal of Medical Genetics. Part A*, *182*, 1284–1287.

Molster, C. M., Lister, K., Metternick-Jones, S., Baynam, G., Clarke, A. J., Straub, V., Dawkins, H. J., & Laing, N. (2017). Outcomes of an international workshop on preconception expanded carrier screening: Some considerations for governments. *Frontiers in Public Health*, *5*, 25.

Nijmeijer, S. C. M., Conijn, T., Lakeman, P., Henneman, L., Wijburg, F. A., & Haverman, L. (2020). Attitudes of relatives of mucopolysaccharidosis type III patients toward preconception expanded carrier screening. *European Journal of Human Genetics*, *28*, 1331–1340.

O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine*, *89*, 1245–1251.

Parens, E., & Asch, A. (1999). The disability rights critique of prenatal genetic testing. Reflections and Recommendations. *Hastings Center Report*, *29*, S1–S22.

Parens, E., & Asch, A. (2003). Disability rights critique of prenatal genetic testing: Reflections and recommendations. *Mental Retardation and Developmental Disabilities Research Reviews*, *9*, 40–47.

Redgrave, S., & McNeill, A. (2022). A qualitative interview study of the attitudes toward reproductive options of people with genetic visual loss. *Journal of Genetic Counseling*, *31*, 1231–1234.

Roadhouse, C., Shuman, C., Anstey, K., Sappleton, K., Chitayat, D., & Ignagni, E. (2018). Disability experiences and perspectives regarding reproductive decisions, parenting, and the utility of genetic services: A qualitative study. *Journal of Genetic Counseling*, *27*, 1360–1373.

Rolland, J. S., & Williams, J. K. (2005). Toward a biopsychosocial model for 21st-century genetics. *Family Process*, *44*, 3–24.

Schuurmans, J., Birnie, E., van den Heuvel, L. M., Plantinga, M., Lucassen, A., van der Kolk, D. M., Abbott, K. M., Ranchor, A. V., Diemers, A. D., & van Langen, I. M. (2019). Feasibility of couple-based expanded carrier screening offered by general practitioners. *European Journal of Human Genetics*, *27*, 691–700.

Simcock, P. (2017). Ageing with a unique impairment: A systematically conducted review of older deafblind people's experiences. *Ageing & Society*, *37*, 1703–1742. https://doi.org/10.1017/S0144686X16000520

Steinberg, A. G., Kaimal, G., Bain, L., Krantz, I., & Li, Y. (2007). Parental narratives on genetic testing for children with hearing loss: A qualitative inquiry. *American Journal of Medical Genetics. Part A*, *143A*, 1533–1545.

Thomas, L. A., Lewis, S., Massie, J., Kirk, E. P., Archibald, A. D., Barlow-Stewart, K., Boardman, F. K., Halliday, J., McClaren, B., & Delatycki, M. B. (2020). Which types of conditions should be included in reproductive genetic carrier screening? Views of parents of children with a genetic condition. *European Journal of Medical Genetics*, *63*(12), 104075.

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*, 349–357.

Ubel, P. A., Loewenstein, G., Schwarz, N., & Smith, D. (2005). Misimagining the unimaginable: The disability paradox and health care decision making. *Health Psychology*, *24*, S57–S62.

van den Heuvel, L. M., van den Berg, N., Janssens, A. C. J. W., Birnie, L., Henneman, W. J., Dondorp, M. P., Plantinga, M., & van Langen, I. (2023). Societal implications of expanded universal carrier screening: A scoping review. *European Journal of Human Genetics*, *31*, 55–72.

Wertz, D. C., & Knoppers, B. M. (2002). Serious genetic disorders: Can or should they be defined? *American Journal of Medical Genetics*, *108*, 29–35.

Woudstra, A. J., van den Heuvel, L. M., van Vliet-Lachotzki, E. H., Dondorp, W., Lakeman, P., Haverman, L., van Langen, I. M., & Henneman, L. (2022). Views of patients and parents of children with genetic disorders on population-based expanded carrier screening. *Prenatal Diagnosis*, *42*, 1201–1210.

SUPPORTING INFORMATION

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

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