

# Genetic selection for deafness: the views of hearing children of deaf adults

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## ABSTRACT

The concept of selecting *for* a disability, and deafness in particular, has triggered a controversial and sometimes acrimonious debate between key stakeholders. Previous studies have concentrated on the views of the deaf and hard of hearing, health professionals and ethicists towards reproductive selection *for* deafness. This study, however, is the first of its kind examining the views of hearing children of deaf adults towards preimplantation genetic diagnosis and prenatal diagnosis to select for or against deafness. Hearing children of deaf adults (or CODAs, as they call themselves, and are widely known in the deaf community) straddle both the deaf and hearing worlds, and this dual perspective makes them ideally placed to add to the academic discourse concerning the use of genetic selection for or against deafness. The study incorporated two complementary stages, using initial, semistructured interviews with key informants (CODAs and health professionals) as a means to guide the subsequent development of an electronic survey, completed anonymously by 66 individuals. The participants shared many of the same views as deaf individuals in the D/deaf (or "culturally deaf") community. The similarities extended to their opinions regarding deafness not being a disability (45.5% believed deafness was a distinct culture rather than a disability), their ambivalence towards having hearing or deaf children (72.3% indicated no preference) and their general disapproval of the use of genetic technologies to select either for or against deafness (60% believed that reproductive technologies, when used to select for or against deafness, should not be available to the community).

If parents were to forcibly cause a hearing child to be deaf, they would face a tide of moral indignation and severe legal consequences. How, though, should we view parents who, through the use of genetic technologies, would choose a deaf child in preference to a hearing child?

In 2002, this hypothetical scenario, setting modern medical science, bioethics and the disability rights movement on a collision course, became a reality when deaf couple Sharon Duchesneau and Candice McCullough set out to maximise their chances of giving birth to a deaf child.<sup>1</sup> The couple approached a friend with five generations of congenital deafness in his family to be the biological father of their child through sperm donation and in vitro fertilisation. Although this approach could not guarantee deafness, there was a 50 per cent chance that their child would be deaf. Their son, Gauvin Hughes McCullough, was diagnosed at 3 months of age as having only partial hearing loss that, without early use of hearing amplification, would prevent normal

speech development. Against a doctor's advice, the couple decided not to fit their baby with a hearing aid and justified their decision on the basis that it was not their choice to make, but rather the decision of Gauvin when he was older.

This paper informs the debate over such uses of technology by exploring the views of hearing children of deaf adults (CODAs, as they refer to themselves and are widely known) on the use of reproductive technologies to select for or against deafness.

## DEAFNESS

Approximately one in every 1000 children is either born deaf (congenital deafness) or develops profound hearing loss during the first few years of life, defined as pre-lingual deafness.<sup>2</sup> Deafness can occur as a result of a variety of genetic and environmental causes. Approximately half of all congenital deafness is due to single gene mutations.<sup>3</sup> Deafness can be characterised according to two distinct frameworks: a medical model (d/deaf) and a social model (D/deaf). Under the medical model, deafness is defined as a category of disability. In the social model, the deaf are understood to be a cultural group who form a linguistic minority, not a people with a disability.<sup>4</sup> The pure medical model and the pure social model are, in a way, the two extremes of a spectrum of views about deafness. In reality, most people in the discussion locate themselves somewhere between these two extremes.

## Reproductive options

Currently, there are two theoretical options for a deaf couple wishing to have a deaf child, where the cause of deafness is genetic. The first involves prenatal diagnosis (PND) and then pregnancy termination if the fetus has not inherited the genetic mutation(s) that will result in deafness. The second is in vitro fertilisation together with preimplantation genetic diagnosis (PGD), selecting for embryos that have inherited the genetic mutation(s) causing deafness, and transferring only these embryos into a woman's uterus. Any embryos that have not inherited the mutation(s) are discarded. The second is more often cited as the preferred option, as many people believe it is worse to terminate a fetus than to discard an embryo.<sup>5</sup> There is a third option, namely choosing a deaf partner. Couples who are genetically deaf have a greater chance of having a deaf child than do couples who are not deaf or than couples where deafness is not genetic in one or both parent(s). However, this will not guarantee a deaf child; hence the focus on reproductive technologies.

## Current arguments surrounding genetic selection for and against deafness

There are a range of views about the ethics of using reproductive technologies to produce, or avoid, deaf children. Apart from concerns about the moral status of the embryo and fetus, there are also strongly differing views about what life is like for a deaf person, and hence how bad it is to be deaf. Those arguing against selection for deafness hold that a child's open future is denied at the outset when parents decide to eliminate one of the five senses.<sup>6</sup> They argue that from day one a deaf child is not equal with a child who has all senses. For example, Shenfield and colleagues<sup>7</sup> argue that, "the request of disabled parents to replace embryos with a disability (e.g. deafness) can only be defended if the welfare of the child is strictly considered within the familial boundaries or subculture. However, the functioning of this child within society at large would be severely impaired due to the imposed disability."

Those arguing in favour of selection for deafness generally come from the deaf community, and hold a strong social model of deafness. They view deafness as a "culture that should be celebrated and conserved," albeit one that is not understood by the hearing world,<sup>8</sup> rather than a disability that necessarily diminishes quality of life. Munzo-Baell and colleagues<sup>9</sup> exemplify this social model in arguing that "deaf people are disabled more by their transactions with the hearing world than by the pathology of their hearing impairment". Sharon Duchesneau and Candice McCullough believed they were acting in the best interests of their child, and preserving the child's autonomy, in enhancing the probability that it would be born deaf. They contended that they would be content with whatever choices their child makes in life so long as the child is happy.

Some deaf couples seeking to select for a deaf child draw attention to their right to reproductive autonomy rather than to the quality of life of a deaf person, arguing that those in the wider community should respect their decision and the reproductive choices they choose to make.<sup>8</sup> However, there is a widely held view that the right to reproductive autonomy is limited and does not extend to choosing to create a child whose life will be more difficult or have fewer options than would otherwise have been possible.<sup>10</sup> Assessments of deafness from those outside the deaf community who regard selection for deafness as ethically inappropriate are not necessarily bleak in themselves. Savulescu,<sup>11</sup> for example, comments that "deafness is not that bad". However, in his view, a life with deafness is not the best life that a parent could give a child and, on his principle of procreative beneficence, would not be the ethically right choice for parents to make (although imposing one's own ethical evaluation of reproductive choices on others is also not ethically right, according to Savulescu).

Several studies have assessed key attitudes towards genetic selection both for and against deafness.<sup>12–16</sup> Middleton and colleagues,<sup>13</sup> seeking to gauge potential demand for PND for inherited deafness, surveyed 527 hearing individuals who had a deaf parent or child. They found that 49% of hearing individuals would consider PND to select against deafness. The authors, however, failed to separate out the views of those with a deaf parent as opposed to a deaf child. These two perspectives are extremely different. CODAs have a unique life experience. CODAs experience deafness as a normal part of their family life right from the start, not as a shock in adulthood, as is the case for hearing parents of a deaf child. These different experiences are likely to affect attitudes towards selection for or against deafness.

To date, no study has attempted to specifically examine the views of the CODA population towards the use of reproductive technologies to select for or against deafness.

## This study

This paper has two unique features: it examines the views of CODAs, and it includes their views about the reproductive technology PGD. Previous research has focused on the views of deaf, hard of hearing, and hearing individuals towards prenatal and paediatric testing for deafness, yet no study has explored views about PGD as a method of selection. This is an important omission because PGD does not involve the termination of pregnancy and hence is commonly seen as a much more acceptable method of selection. There is literature concerning the life experiences of CODAs, but it is general in nature and does not address views about selection for deafness. Preston,<sup>15</sup> for example, using in-depth interviews, explored the experience of 150 adult hearing individuals with deaf parents but did not examine their views on genetic technologies. CODAs are ideally placed to provide insight into this issue, as they straddle the deaf and hearing worlds. The aim of this study was therefore to add a new dimension to the selection debate by gaining insight into the views and attitudes of CODAs towards the use of genetic technologies (including PGD) to make selective reproductive choices regarding deafness.

## METHODS

This study features two complementary phases: interviews and a survey. Participation in both phases was restricted to hearing CODAs over the age of 18 years who had one or both parents who could not hear.

### Phase 1—interviews

Interviews were conducted by CM with one paediatrician with expertise in deafness and four CODAs from the Victorian Branch of CODA International. Semistructured interviews were designed to cover a set of key subject areas, each with specific prompts to elicit relevant responses. Semistructured interviews were chosen because they allow flexibility to explore an individual's personal experience. The data from the interviews was used to inform the development of the survey used in phase 2.

### Phase 2—survey

There were four components to the survey (<http://www.mcri.edu.au/CODA/>): (1) demographics; (2) involvement in the deaf community; (3) ethics of genetic reproductive technologies to select for or against deafness; and (4) deafness as a disability. A combination of tick-box responses, Likert scales and open-ended questions inviting written responses were chosen to gather both quantitative and qualitative data from the survey. The final draft of the electronic survey was distributed to the interviewees who had participated in the first phase of the project, for their review and comments. No changes, however, were made to the questionnaire. A cover letter containing a plain-language project synopsis was then emailed to potential participants. Because of privacy considerations, the research team did not have direct access to potential participants. Emails were distributed on behalf of the research team by a member of CODA International. It is likely that those who access these listserves identify, at least to some extent, with the deaf community. The survey was placed on a website accessible only

## Clinical ethics

via a link sent in the recruitment email. Completed surveys were received anonymously by email.

Quantitative data analysis was performed using SPSS V.13 and Epi-Info 2002. Data are presented as frequency tables. To assess the level of evidence for differences in the responses to two questions from the same group of participants, McNemar tests for correlated proportions were used. For qualitative data, transcripts and written responses to open-ended survey questions were coded independently by different researchers (CM, RD and LG), and the codes were grouped into themes using standard processes of thematic analysis.<sup>17</sup> In this paper, data are presented from phase 2 only, not the initial interviews. Quotations are presented as they were provided, without corrections for spelling or grammar. The reference after each quotation refers to the code allocated to each survey (eg, S1:F:35 refers to survey number 1, female, aged 35).

This study was conducted with the approval of the Monash University Standing Committee on Ethics in Research Involving Humans (SCERH) (CF07/0299-2007/0086).

## RESULTS

Sixty-six responses were received. Approximately 300 individuals received an invitation, giving a response rate of approximately 22%. Table 1 provides demographic details of the sample group. In short, most participants were female, mostly under 50, came from the USA and had post-secondary education. Approximately half worked as a sign language interpreter, and all but one could use sign language.

The results of this study are provided in the four major areas addressed by the survey questions: (1) individuals' preference for hearing or deaf children; (2) views surrounding the use of

**Table 1** Demographic details of the cohort (numbers differ because not all questions were answered by all respondents)

Variable	No. of participants	Per cent
Age, years (n = 66)		
18–30	14	21.2
31–50	38	57.6
51–70	13	19.7
71–90	1	1.5
Gender (n = 66)		
Female	52	78.8
Male	14	21.2
Country (n = 64)		
USA	44	65.2
Australia	9	13.6
Europe	9	13.6
Canada	2	3.0
Highest completed level of education (n = 66)		
Primary school	0	0
High school	8	12.1
Diploma	12	18.1
College/university	27	40.9
Postgraduate	15	22.7
Other	4	6.1
Current occupation (n = 63)		
Sign-language interpreter	35	53.0
Other	28	42.0
Able to use sign language? (n = 66)		
Yes	65	98.5
No	1	1.5

**Table 2** Preference of CODAs for having hearing or deaf children

Preference	No. of participants (n = 65)	Per cent
Deaf children	0	0
Hearing children	18	27.7
No preference	47	72.3

genetic reproductive technologies; (3) experience of growing up as a hearing child of deaf adults; and (4) deafness as a culture versus as a disability.

### Preference for hearing or deaf children

Participants were asked to indicate whether they had a preference for having hearing or deaf children. The majority of participants had no preference (table 2).

### Views surrounding reproductive technology

Participants were asked to indicate their opinions about the appropriateness of using genetic technologies to increase or decrease the likelihood of having a deaf child, across a range of scenarios (table 3). Participants were asked to indicate in which circumstance(s), if any, they believed it was appropriate for a couple to undertake testing. Most respondents (77.2%) indicated that under no circumstances was either PGD or PND appropriate to select for either hearing or deaf children (table 3).

Insight into the thinking behind this view is provided by open-ended written responses given by some participants. For example, a woman in her 40s explained that

I think that life brings us many things. the same thing can be good and can be bad. I think that wishing to be Deaf or having Deaf children on purpose is egotistic and unnatural. If you'r Deaf or you have Deaf children You adapt yourself ... But beeing Deaf on purpose just because you want to preserve your culture or give continuity to a Deaf family is as strange as beeing a doctor or musician and forcing your children to choose the same career even if they'd prefer to be an actor or writer ... Beeing different is ok ... even if beeing different means being hearing ... or deaf. (S36:F:49)

Of the minority who thought it was sometimes appropriate to use genetic technologies, there was a slight trend towards hearing couples wanting a hearing baby and deaf couples wanting a deaf baby, rather than parents wanting a child of opposite hearing status. However, none of these differences were statistically significant ( $p > 0.05$ ) (table 3).

Participants were asked whether they thought the technologies should be available to the community regardless of their personal beliefs regarding their use. The majority indicated that they should not be available (table 4).

Open-ended text responses to the above questions demonstrated that there were a number of participants whose broader belief in reproductive choices guided their support for the availability of genetic technologies in this case, many referring to the parenting issues for deaf and hearing parents of deaf children:

I would rather that Hearing parents who feel strongly that they could not cope with a Deaf child abort than have a Deaf child that they did not expose to Deaf culture and sign language. I believe that Deaf parents have the right to select a Deaf child who will fully share their culture— Deaf children with signing Deaf parents are not at a significant disadvantage with respect to educational and social opportunities. (S51:F:39)

**Table 3** Deaf and hearing couples' judgements regarding appropriateness of use of genetic technologies (n = 66)

Technology	Couple's hearing status and preference	No. (per cent) who consider the technology appropriate	p (McNemar's test)
PGD	Deaf		
	Wanting a deaf baby (discard hearing embryos)	13 (19.7)	0.21
	Wanting a hearing baby (discard deaf embryos)	9 (13.6)	
	Hearing		
Wanting a hearing baby (discard deaf embryos)	12 (18.2)	0.46	
Wanting a deaf baby (discard hearing embryos)	9 (13.6)		
PND	Deaf		
	Wanting a deaf baby (termination of a hearing baby)	9 (13.6)	0.25
	Wanting a hearing baby (termination of a deaf baby)	6 (9.1)	
	Hearing		
Wanting a hearing baby (termination of a deaf baby)	9 (13.6)	0.69	
Wanting a deaf baby (termination of a hearing baby)	7 (10.6)		

Fifty-one of the 66 respondents (77.2%) did not indicate that *any* of these options were acceptable (ie, left all boxes blank). PGD, preimplantation genetic diagnosis; PND, prenatal diagnosis.

Some respondents also emphasised the importance of education in informing any choice:

People should have the choice. Education first is essential though. (S5:F:26)

Many responses appealed to fears of “designer babies” and discussed negative impacts on society broadly:

I don't think that it is ethically viable to go down this road—to design the babies that are born without letting them develop naturally removes the impact of nature, which has done a good enough job of evolving people thus far. Also to remove embryos because of their hearing status, something that is non-life threatening, is ridiculous, and in either case, (desiring a deaf baby or desiring a hearing baby) has fascist undertones. (S48:M:25)

Many responses also tapped into the discourse surrounding deafness as a disability, claiming the hearing status of an individual, deaf or hearing, is not life threatening and should not form the basis for potential termination of pregnancy or use of reproductive technologies such as PGD:

... Hearing loss is not a birth defect any more than red hair is. When my grandmother was born, having a baby with red hair was something to lament. Times have changed. People need to feel the same way about hearing loss. (S29:F:25)

Most respondents saw little difference between PGD and PND in selecting for or against deafness. There were echoes here of “pro-choice versus pro-life” themes, with many responses emphasising the fetus and embryo as living, viable humans.

**Table 4** Should PDG and PND be readily available to the wider community even if you personally disagree with their use?”

Response	No. (per cent) (n = 66)
No	40 (60.6)
Yes (for all requests)	18 (34.8)
Yes, but not for deafness	2 (3)
Yes, but only for knowledge, not termination	3 (4.5)
Not specified	3 (4.5)

PGD, preimplantation genetic diagnosis; PND, prenatal diagnosis.

A baby is a baby no matter what stage of development it is in. (S6:F:49)

Some (approximately 23%), however, disagreed with this blanket opposition to the use of technologies for selection purposes. Most of these responses favoured PGD as a moral choice over PND, though these participants mostly commented that they did not expect others to act according to their preference.

I feel as though an embryo is not yet a developing baby until it is in the womb thus I am not against PGD however I do feel strongly about PND and termination. Again, I feel it is an individual/couple's choice to decide what is best for them, given their own very personal and unique circumstance(s). Only s/he knows what is best. No one expert/law can dictate what is best applicable to the general population. (S8:F:36)

### Experience growing up as a child of deaf adults

Participants described a variety of experiences related to growing up as a CODA. Four broad themes emerged: (1) a negative experience either (a) because of identity confusion or (b) because of increased responsibility of acting as an interpreter for parents, with an associated loss of childhood; (2) a positive experience; (3) mixed feelings surrounding personal experience and (4) a neutral experience.

Commonly, participants described some negative experience associated with growing up as a CODA (theme 1). As well as difficulties during childhood and adolescence, some responses emphasised ongoing troubles into adulthood. Commonly, respondents touched on a sense of identity confusion (theme 1i) throughout their childhood, which sometimes continued into adulthood:

Conflicted. I felt more at home and preferred being with deaf people than hearing, using ASL instead of English. But I felt pushed to be one of “them” I also was very hurt when hearing people would ask stupid questions like ... your mom can drive?? I was constantly ashamed because of their ignorant perception of deaf and DUMB and being forced to be hearing, while being very proud of my deaf family and ashamed because the hearing people just didn't get it. I didn't want to be hearing, but didn't want to lose my hearing either. (S66:F:42) (theme 1i)



Feelings of having had an accelerated or incomplete childhood (theme 1ii) were common and were often mentioned as having continuing negative repercussions into adult life:

Many times you are relied on by adults to relay messages between the hearing and your parents, this makes you become very confused as to your place in the world and in your own family. It caused me a lot of emotional problems as a teenager and child which are yet to be resolved. (S5:F:26) (theme 1ii)

Some respondents emphasised positive experiences (theme 2), usually describing a sense of pride in their deaf family and the deaf community:

very positive rewarding as being empowered to have access to things normally others would never see fun (S35:F:44) (theme 2)

Mixed feelings (theme 3) were also described by some participants, describing, on the one hand, how what they experienced as a positive childhood and adolescence had left them ill-prepared for adulthood or, alternatively, how negative experiences growing up worked to shape them into well-adjusted adults:

I struggle as an adult trying to fit in within both worlds. I don't feel like ever quite fit in, in either world. It's very difficult and I try to hard to "fit in". As a child I felt like I fit in with the deaf world and felt very comfortable, warm and cozy but as an adult it changed for me, I had to TRY and fit into the hearing world, still trying to this day. (S8:F:36) (theme 3)

I think being a CODA has enriched my life. It was struggle with who I was growing up but now I know who I am. I have hearing parts, deaf parts and CODA parts and I know how to handle them. I'm proud to have deaf parents. (S55:F:37) (theme 3)

Only a small number of participants felt that growing up as a hearing child in a deaf family was a neutral experience, similar to that of a hearing child in any other family (theme 1):

We felt that we were completely normal and that having deaf parents was not really a big deal. It freaks hearing people out more than it really is. Deaf can do anything that hearing people can do except hear. (S2:F:48) (theme 4)

### Culture versus disability

Participants were presented with the statements that some people view deafness as a disability while others view it as a distinct culture, or simply a difference. They were then asked to indicate their own views on this question. Table 5 shows the range of responses, demonstrating that all participants recognised some level of distinct cultural significance in deafness.

### Hearing as a disability

Participants were asked to indicate whether they had ever had a personal desire to have been deaf at any stage of their life. Twenty-four participants (36.4%) responded that they had indeed had this wish at one time or another. Most frequently these desires were described in terms of wishing to be like their deaf family members and wishing to fit in with their community. This desire was most often experienced during childhood or adolescent years and disappeared in adulthood, when an appreciation of the ability to hear surfaced:

At times, as the saying goes, "ignorance is bliss". I hated that I could hear the hateful and hurtful things that were said about

my parents being deaf or being made fun of because they were deaf. Other than that, I am grateful that I am able to hear. (S8:F:36)

I think at times I wanted to be deaf as a child. I felt so comfortable being around my deaf family and friends. Being with hearing friends, I felt awkward and socially inept. I didn't know how to be "hearing". (S55:F:37)

Some participants explained that they had never had a desire to be deaf, expressing contentment with their state of hearing in a family affected by deafness. None of these participants described deafness as a disability, expressing more of a sense of ambivalence towards their hearing status:

I like being hearing with the ability to move within the deaf community if I wish to do so. I feel life is easier for me. (S52:F:66)

## DISCUSSION

There were four key findings to come out of this study: (1) the views of CODAs about deafness are similar to those of deaf adults; (2) CODAs have a similar (lack of) preference regarding the hearing status of their children as deaf adults; (3) CODAs have a high level of disapproval of genetic technologies to select for or against deafness; and (4) CODAs attach significance to the match between the hearing status of parent and child.

### CODAs have similar views on deafness to those of deaf adults

Most participants believed that deafness is not simply a disability, but a difference that is misunderstood by the wider, hearing world. Hearing individuals and some deaf individuals tend to view deafness as a restriction on a normal or optimal life experience. Conversely, those who view themselves as "culturally deaf" consider that deafness represents a distinct cultural and linguistic minority.<sup>4</sup> This is the first study that identifies the concordance between the views of CODAs and deaf individuals on the nature of deafness.<sup>14</sup>

### CODAs have similar (lack of) preference regarding the hearing status of children to deaf adults

In keeping with previous studies of other groups in the deaf community, 71.2% of participants in this study indicated that they had no preference for either a hearing or deaf child. As part of a broader study concerning attitudes towards genetic testing and prenatal diagnosis of hearing loss, Stern and colleagues<sup>16</sup> surveyed 337 deaf, hard of hearing and hearing individuals and asked a very similar question regarding preference for hearing or deaf children. The participants were divided for analysis into "culturally deaf", "equally involved" in deaf and hearing communities, and "hearing community". Stern and colleagues found the culturally deaf and "equally involved" groups disproportionately indicated no preference, "while the vast majority of those from the hearing community indicated they would prefer to have hearing children". Participants in our

**Table 5** How respondents see deafness: as disability versus culture

Response	No. (per cent) (n = 66)
Distinct culture/difference	30 (45.5)
Disability	0 (0)
Both	33 (50)
Unsure	0 (0)
Other	3 (4.5)

study cannot be divided into culturally deaf or “culturally hearing” groups, as no specific questions relating to this were included. However, as CODAs, all participants by definition have had a close personal experience of living in a family with at least one deaf member, and many participants referred to involvement in the deaf community in their text responses. It is reasonable, therefore, to draw comparisons between CODAs and Stern’s culturally deaf. In a separate study by Middleton and colleagues,<sup>14</sup> 87 deaf participants were asked their preference for hearing or deaf children; 74% indicated no preference.

In the present study, there were no participants who indicated a preference for a deaf child, though this appears to reflect a generalised ambivalence—antipathy for some—towards the concept of selection itself, whether for or against deafness. Most were content with the possibility of having a deaf child. Again, the views of CODAs in this instance are in line with the views of the culturally deaf. Considering the life experiences of most CODAs, these findings are not particularly surprising, but act as important evidence, since CODAs have close daily insight into the lives of people who cannot hear, while having the experience themselves of hearing.

### **CODAs have a high level of disapproval of genetic technologies to select for or against deafness**

Participants in this study showed a high level of disapproval regarding the use of genetic technologies for selection, whether for deafness or against it. Most participants responded that it was never appropriate to use these technologies and 60.6% said the technologies should never be available to the wider community. Most of those who thought the technologies were sometimes appropriate described their view in terms of assisting in preparation for the coming child rather than for possible termination of pregnancy. The findings in this study demonstrate only a small group of CODAs (9/66 for PND, 13/66 for PGD) who see genetic technologies as a legitimate tool to ensure the inheritance of deafness. Most in the deaf community, whether hearing or deaf themselves, are against the use of such technologies and fear they will do more harm than good,<sup>18</sup> threatening the future of the deaf community and invalidating what they perceive as a legitimate example of cultural diversity. If deaf people perceive genetic technologies as invalidating their own experiences and lifestyle, it is perhaps not surprising to find that participants in this study disapprove of the use of these technologies. However, it is again important evidence of the considered opinions of those who have experience of both worlds.

### **CODAs attach significance to the match between parent and child hearing status**

Participants focused very strongly on the parent–child relationship in their responses. Of those who thought it was sometimes appropriate to use genetic technologies, individuals tended to be more accepting of situations where technologies are employed to select for a child of the same hearing status as their parents. This may reflect the experiences, described by many participants, of having had the difficult experience of growing up as a hearing person in a deaf community and yet also living in a wider, hearing world. Individuals seem to have considered this far more important than whether or not a child is hearing or deaf per se.

### **CONCLUSIONS**

Currently, there are no consensus guidelines for the use of PGD and PND. This study has particular relevance to the development

of future policies, adding to the discussion concerning the circumstances under which technologies should be offered, or permitted, for deafness and other conditions.

Other authors have shown that there is a significant body of opinion within the deaf population that sees deafness as a distinct and valued form of cultural identification and expression, rather than as a limitation or disability. This is the first study to demonstrate that this position is supported by a significant number of hearing children of deaf parents. Having direct experience living within, and sometimes of acting as a bridge between, hearing and deaf communities, these CODAs do not consider deafness a disability and are deeply suspicious of those who seek to use genetic technologies to prevent deafness in future generations. For the medical model of deafness, this position is incongruous in that able individuals are not merely identifying with but are expressly endorsing a culture and lifestyle of supposed disability. These findings should sound a note of caution for governments, professional bodies and individuals working to develop frameworks for the appropriate use of emerging genetic technologies. Deafness is not necessarily seen as a limited or unfortunate life by hearing people who know most about it, and attempts to impose or enshrine a negative view of deafness in regulations for reproductive technology will not be welcomed by them. If CODAs do not see deafness as a condition that must be avoided, then the wider, hearing community should be cautious about jumping to conclusions.

The findings of this study may also be useful for informing the practice of genetic counsellors working with CODAs and families affected by deafness. Working with deaf individuals and their families necessitates an understanding of the ideals, experiences, motives and apprehensions that underlie the expressed wishes of members of this group. Understanding the life experience of CODAs entails understanding that CODAs have an ongoing connection with the deaf community, often sharing their views, and sharing the experience of suffering emotionally as a part of that community when deafness is defined by some as a disability to be prevented where possible.

Notwithstanding the relatively low response rate, small population size and our difficulty in accessing CODAs who do not belong to the CODA organisation (and hence may have a more negative view of deafness), we argue that the findings of this study add a new and important perspective to the complex debate concerning the use of genetic technologies for the selection of deafness. CODAs hold a unique and important perspective that straddles both the hearing and deaf worlds. Theirs will not be the final word in what is certain to be an ongoing discussion as genetic technologies becomes increasingly accessible, but is an important perspective, which ought to be taken into account.

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## Correction

There was an error in an article published in the August issue of the journal (Schick Tanz S, Schweda M. One man’s trash is another man’s treasure: exploring economic and moral subtexts of the “organ shortage” problem in public views on organ donation. *J Med Ethics* 2009;**35**:473–6). The first sentence at the top of p476 should read: “It seems to be based on a preconception of the situation formed from the point of view of demand, that is, of (former, potential or prospective) recipients, and thus takes sides with the perspectives, interests and concerns of only one of the parties involved in organ donation.”

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## Genetic selection for deafness: the views of hearing children of deaf adults

C Mand, R E Duncan, L Gillam, et al.

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