

III. Comparative empirical bioethics of reproductive practices and their social contexts

6. Views on Disability and Prenatal Testing Among Families with Down Syndrome and Disability Activists¹ A Comparative Analysis of Interviews from Germany and Israel

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Over the last decade, non-invasive prenatal testing/screening (NIPT/NIPS) has become part of prenatal care in many countries. The technology is based on the presence of cell-free foetal DNA in maternal plasma and can be used early – from 9–10 weeks of gestation – and without the risk of miscarriage associated with invasive prenatal testing such as amniocentesis. However, being a screening test, a positive result requires confirmation by a diagnostic test, usually amniocentesis. Currently NIPT is used primarily to detect chromosomal abnormalities – trisomies 13, 18 and 21, with or without sex chromosome aneuploidies – with highest accuracy in the detection of Down syndrome (DS) resulting from trisomy 21 (Mackie et al. 2017).

Due to its special characteristics, NIPT has heightened the social and bioethical debate that on the one hand argues that prenatal testing supports the autonomy of prospective parents (Chen/Wasserman 2017), and on the other criticises it as a new form of eugenics (Thomas/Rothman 2016). The current controversy is by no means new and has accompanied prenatal testing since its introduction in the 1970s (Löwy 2017; Meskus 2012). The ethical debate about prenatal testing is constantly evolving, thereby providing a dynamic

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standard against which to appraise lay ethical opinions. Various perspectives are brought to the debate, including foetal rights, disability rights, feminist and medical perspectives, and parental autonomy (Bayefsky/Berkman 2022; Löwy 2018; Perrot/Horn 2021; Rehmann-Sutter 2021; Stapleton 2017). Little is known about how the changes in prenatal care are perceived by families who already have a child with one of the conditions for which NIPT tests. DS is especially sensitive in this regard, since it is a condition that is compatible with life. The experience of having a child with DS might influence parents' images of what it means to have such a disability and – as a result – how the practice of prenatal testing, and in particular NIPT, is to be evaluated. This article presents results from a qualitative study in Israel and Germany – two countries with divergent public views on and regulation of genetic testing – based on in-depth interviews with family members of individuals with DS and with disability activists.

Objectives

Since many perceive NIPT to be mainly targeting DS, and because of the test's potential to significantly reduce the birth rates of individuals with DS and to affect society's views of DS, DS organisations and families of individuals with DS are prominent stakeholders in the debates about testing. One example is the "Don't screen us out" campaign, which was launched in the UK in response to the decision to publicly fund NIPT in pregnancies at high risk of trisomy 21, 13 or 18 (Ravitsky 2017). The aim of our study is to explore the views of activists and family members of individuals with DS regarding prenatal testing in general, and NIPT in particular.

Previous studies have shown a spectrum of attitudes toward prenatal testing among parents and siblings of children with DS (Bryant et al. 2005; Inglis et al. 2012). In a study by Kellogg et al. (2014), North American mothers acknowledged the impact NIPT might have, i.e. that it might lead to increased rates of terminating affected pregnancies, reduce the availability of services for persons with DS, and increase social stigma. However, more than half the participants said they would consider using NIPT in future pregnancies. The study by van Schendel et al. (2017) of Dutch parents' views of NIPT showed positive attitudes linked to the test's accuracy and safety. The test was appreciated for reducing false reassurance, reducing unnecessary invasive procedures, and enabling preparation for a child with special needs. Early uptake of the test was

seen positively when termination of pregnancy is sought, due to reduced maternal-foetal bonding. However, some feared that this would result in less considered terminations that could eventually lead to regret. Dutch parents also shared expectations of a rise in abortion rates, leading to less acceptance of individuals with DS and fewer resources available to them.

One critique raised repeatedly in these studies concerns inaccurate and imbalanced information about DS provided by medical professionals (Kellogg et al. 2014; van Schendel et al. 2017). Balanced information is necessary to make considerate and responsible decisions – as early as the stage of deciding whether to take the test, and when deciding how to act following anomalous results (Asch/Wasserman 2009; Kellogg et al. 2014; Skotko et al. 2011). As many authors have stressed (an authoritative statement can be found in Nuffield Council on Bioethics 2017), “balanced” means including direct experiences and views of people with DS and their families.

Parents raising a child with DS described both positive and negative experiences (Cuskelly et al. 2008; Farkas et al. 2019). For some, the personal experience strengthened their existing views, further underlining the desire to avoid disability in order to prevent suffering. Others reported a drastic shift away from concern and rejection to acceptance of disability and appreciation of its positive effects on their lives and its contribution to social diversity (Nov-Klaiman et al. 2019).

Comparing German and Israeli interviewees allows us to explore the effects of culture and societal context (Melhuus 2002) on the lived experiences and perceptions of family members of persons with DS, as well as disability activists, regarding disability and prenatal testing. Inter-cultural comparisons, particularly of societies with contrasting regulation, are a strong tool to explore the shared vs. local factors, whether historical, cultural, financial, or religious, affecting usage of genetic services. Moreover, the specific case of an Israeli-German comparison contributes to a perspective that goes beyond the Eurocentrism characterising much of western science (Poshali 2020). Indeed, previous studies have shown substantial differences between Germany and Israel, e.g. the attitudes of laypeople towards genetic testing for late-onset diseases or testing of adults (Raz/Schick Tanz 2009a; b). Other work, however, has mainly studied the views of genetic professionals (Hashiloni-Dolev 2007; Hashiloni-Dolev/Raz, 2010; Hashiloni-Dolev/Weiner 2008; Wertz/Fletcher 2004). Both the findings from these works and the legal and regulatory frameworks in these countries indicate that Israel adopts a relatively liberal and supportive approach to genetic testing, whereas Germany is rather restrictive.

The attitudes towards genetic practices in Germany and Israel cannot be considered without acknowledging their historical roots. Advances in genetic technology and the ever-growing testing options that come with it have been related to eugenics, although in different ways, by the general public as well as in the clinical or the bioethical discourse. Hashiloni-Dolev and Raz (2010) found that German genetic counsellors regarded Nazi eugenics as setting moral limits for contemporary practices, and highlighted the value of diversity in society. Interestingly, while the Holocaust is considered a primary defining element in Israeli culture (Zertal 2005), many Israeli genetic counsellors have dismissed the idea that the lessons learnt from Nazi eugenics should guide their current work and have detached their practice from historic atrocities (Hashiloni-Dolev/Raz 2010).

The very event that drove Germany to its restrictive approach is arguably the same event that underlies Israel's contrasting outlook. This culture, still bearing the powerful memory of victimhood in the Holocaust, emphasises survival (Chemke/Steinberg 1989) and prioritizes strong Israelis, thereby leaving little room for disability. Weiss (2004) has suggested that both the Zionist movement, which aspired to the rehabilitation of the Jewish body, and the Jewish religion, which is not tolerant of severe physical and mental disability, are further reasons for the Israeli aspiration to competent and whole bodies. In Germany, the Holocaust is a collective trauma of guilt experienced by descendants of a generation of perpetrators (Bar-On 1989) who must distance current practices of "selective" termination of pregnancies from eugenics (Foth 2021; Rubeis 2018).

The aim of this study is to explore the views of disability activists and family members of individuals with DS. It would be particularly interesting to understand this group of concerned people, since they might have insight into the ambivalence towards testing for DS, or might be offended by DS screening programmes such as NIPT. Expert ethical evaluation offers only one layer for the comparison of cultures. Moral reasoning provided by laypeople, although informal and ambivalent, is the one we 'live by' (Raz/Schickltanz 2009a). We draw on interviews with laypeople belonging to these groups for a descriptive analysis rather than an evaluative one. Previously (Nov-Klaiman et al. 2019), we have studied qualitative interviews with this group in Israel. Now we present a comparative interpretation and evaluation of an Israeli-German sample. In the comparative analysis we focus particularly on how participants made sense of the relation between parental responsibility, views on disability and NIPT/pre-natal testing. This analysis will hopefully contribute to a better understanding

of the perceptions of those who are particularly concerned with DS in Israel and Germany.

Methodology

As part of a larger project to compare prenatal diagnosis in Israel and Germany that began in 2017, semi-structured interviews were conducted with different stakeholders in both countries, following IRB approval from the research ethics committees at the authors' respective universities. Interviewees included health professionals specialising in obstetrics and gynaecology and/or genetics; women without unusual medical family history; parents or other close family members of children with DS; and disability activists. In total, 42 interviews were conducted in Germany and 52 in Israel. Stark differences in themes between Germany and Israel emerged from the interviews with family members of children with DS and DS organisation representatives, who are the focus of the comparative analysis conducted for this article. Data reported in this work reflect interviews conducted throughout the project. Over this period, two relevant changes in healthcare policies took place. In Germany it was decided in 2019 that NIPT would be covered by public health insurance in individual cases. In Israel, in 2018 parents of children with DS became eligible for a 100 per cent social security disabled child allowance, which until then had been determined on a case-by-case basis.

Participants

The inclusion criteria for interviewees selected for the current study were having a child or a close family member with DS or being a DS organisation representative, i.e. stakeholders with a direct experience of DS who are therefore those arguably most concerned by the possible effects of prenatal testing. The term 'activists' refers to office holders and representative of DS-related organisations and self-help groups. Some respondents were both parents and activists. Israeli participants were Jewish individuals belonging to a spectrum of religiosity – secular, modern Orthodox and ultra-Orthodox – and they varied in their ages and number of children. The recruitment process began by contacting five representatives of Israeli DS organisations – of whom four are also parents of children with DS – who agreed to participate in the study.

These representatives assisted us, through their social networks, in recruiting additional participants. Using the snowballing method, 21 interviews were conducted with Israeli organisation representatives and parents of children with DS. In some cases, the child with DS was born before NIPT was available. Sixteen German participants were recruited via information brochures distributed at obstetric/gynaecological and midwifery practices and pregnancy counselling centres, through online posts and snowball sampling. Twelve of the German interviewees have a family member with DS. Four interviews were conducted with disability activists (one of them parenting a child with DS).

All respondents received a recruitment letter describing the study. They agreed to participate and signed an informed consent form. Interviews in Israel were conducted by the first author (a PhD student in medical sociology with training in qualitative methodology), and in Germany by two medical anthropologists trained in qualitative methodology. There was no professional relationship between the interviewers and the interviewees. Consistency between interviewers was maintained by using the same interview guide and comparing interview analysis in team workshops.

Instrumentation and procedures

The research team used an interview guide, which was structured to probe participants' experiences and views of disability, the impact of having a child with DS on subsequent pregnancies and their management, attitudes toward prenatal testing (with a focus on NIPT), and the consequences of these technologies, for the respondents and for society at large. DS organisation representatives were also asked about their organisation's official position. Some questions explicitly probed moral views, e.g., "Does prenatal testing carry in your opinion any specific message to individuals with DS or other disabilities and their families? If so, what kind of message?", and "What do you think of the decision of some prospective parents to terminate pregnancies diagnosed with DS?". Additional questions considered broader frames of influence, for example "How would you describe the influence of your community in deciding about taking the test?". Data were collected in both countries through semi-structured interviews in the local languages (German in Germany and Hebrew in Israel). Interviews were carried out in person or over the telephone and lasted between 45 and 90 minutes. They were transcribed

verbatim and anonymised. Thematically selected quotes were translated from these languages into English and given pseudonyms.

Data analysis

This study pursued a descriptive rather than an evaluative analysis. Classifying statements as ethical was discussed by team members during the thematic analysis. We were looking for references of the respondents to the benefits and harms of prenatal testing and whether they considered them good or bad.

In each country, interview transcripts were coded and analysed thematically, based on the grounded theory approach (Strauss/Corbin 1990). Coding served to identify recurring discursive themes and categories of themes within and across groups of participants (e.g. users and non-users of NIPT, secular and religious, and German and Israeli) (Denzin/Lincoln 1994). Interviews were translated to English to enable their reading by both German and Israeli team members. The research team discussed the first few interview transcripts together, examining the relevance of the themes and agreeing on needed modifications and reclassifications. The first author then continued with the coding, discussing new findings as they appeared and their relationships to the codes in team meetings, where agreements were reached to prevent the potential bias of a single rater. The iterations stopped when all authors agreed on all the themes and no new themes were identified, suggesting that theoretical saturation of the sample was achieved, taking place after analysing about half of the interview transcripts (Corbin/Strauss 2008). Preliminary codes, such as views about disability, and arguments supporting and opposing NIPT, were established following a review of the literature prior to the interviews. Further themes – mainly those related to the social context which is characteristic of each location and associated with decision-making about pregnancy management – were identified from the transcripts. As interview transcripts were read and discussed together by both German and Israeli team members, foci of comparison emanated from this dual juxtaposition of cultural perspectives, exoticising “the familiar” and familiarizing “the exotic” through mutual reflection (Sørensen 2010).

Results

The views of parents and activists are presented together since we did not find differences between these groups. Respondents who are both parents and activists presented comparable views in both their roles. In addition to presenting themes on views about disability (ii) and arguments supporting and opposing NIPT, which were drawn from the preliminary literature review, we focus on the emerging theme of responsibility as (future) parents (i). We also describe three additional themes that were commonly found to form the argumentation for the respondents' views on NIPT: (iii) eugenics, (iv) guilt, and (v) perceptions of how prenatal diagnosis and disability are publicly seen.

*Abbreviations:

IL=Israel; GE=Germany; P=Parent/family member of an individual with DS; A=Activist

(i) Responsibility as parents

Many Israeli respondents linked testing with parental responsibility, arguing that there is a duty to avoid suffering by preventing disability. This was a recurring theme, as clearly described by Efrat:

A friend of mine was pregnant around the same time I gave birth to my child and she decided not to have the tests, and I remember that in my view it was "How can you be a friend of mine, see what happened to us and decide not to have the tests?" It was extremely irresponsible in my view. (IL, P, Efrat)

Anna-Lena, a German parent of a child with DS, made a parallel reference to other women who use prenatal screening tests, however in a completely opposite sense:

I also notice that when I talk to other pregnant women, if they say they are going for a nuchal fold scan, I think, "Why are you really doing this?" I mean, "Would you not want a child if it had something like this? And you know my child!" (GE, P, Anna-Lena)

While Efrat questioned the responsibility of her friend's decision not to test, Anna-Lena questioned other women's decision to test. Both critiques are motivated by their own situation with a disabled child, which in each of their views

clearly demands a different decision. While having a child with DS can evidently entail very different experiences for parents, we found that the view in favour of testing was common amongst the Israeli respondents while the view against taking the tests for granted was more common amongst the German respondents. Both women essentially argued: How can you see me and my child with DS and still make the decision you have? In their respective socio-cultural contexts, it seemed appropriate to reach opposite conclusions from observing the situation parents of children with DS are faced with. This is a strong recurring signal throughout the interviews.

Within the Israeli secular community, aiming for a healthy child is considered an accepted norm and the expecting parents' right, perhaps even their duty. Using testing and pregnancy termination to avoid disability is therefore clearly articulated and not a taboo. In contrast to the common secular Israeli perception of a duty to test in order to "ensure" healthy children, German parents emphasised their perceived duty to accept the child no matter what. Parents did not see themselves as being entitled to perfect children.

I don't think you have a right to a healthy child. Well, I don't think you have any right to it. I mean, you get pregnant and I think you simply accept that things won't all go smoothly. (GE, P, Lena)

Holding the view that responsibility during pregnancy is exercised through testing, especially in light of their personal experience, some of our Israeli interviewees expressed their wish to maximise the detection of possible abnormalities in subsequent pregnancies. That is, they would not "settle" for a screening test such as NIPT because it can only detect a limited scope of conditions and can produce false results.

N: If I were pregnant now, I would have performed chorionic villus sampling at the beginning of the pregnancy.

I: So NIPT is no longer an option for you?

N: Of course not. Come on, you don't fall into the same pit twice. It wasn't a minor tumble. It isn't, you know, a tiny scratch on your little finger. (IL, P, Noga; had a False Negative result with NIPT)

In comparison with the Israeli sense of duty to eliminate uncertainties in pregnancy through testing, accepting the uncertain nature of pregnancy was more characteristic of the German respondents. This could be related to a general

acceptance that one cannot – and therefore should not – make all efforts to protect oneself from the risks associated with pregnancy and childbearing. The tests are often regarded as providing false reassurance, as explained by Paula:

Well, it really is outrageous. What kind of security is there during pregnancy that everything will be okay in the end? It just doesn't exist. [...] The tests make us go into things completely naively in the hope that afterwards I'll be safe and know that everything is fine. (GE, P, Paula)

In Germany, “disability and responsibility” were connected too, though in a different way than for the Israeli respondents, due to their alternative interpretations of these concepts. A common German rationale that we found was that testing is a means to detect disability, which responsible parents need so they can prepare themselves and their environment for the child. Some respondents saw this as crucial. An understanding environment of family and friends would provide parents with the support and love they felt they needed in their time of difficulty. Interviewees described, in contrast, the difficulties experienced by other parents who were unable to build on supportive environments.

The preparation enabled by NIPT came in the form of emotional readiness as well as practical arrangements. The following quote from Tanja demonstrates how testing enables emotional preparation – a topic that was repeatedly mentioned by our German respondents:

So I gave birth and I knew that my child had Down syndrome and I was glad that he was there. I know a lot of other women who didn't know it and had children with Down syndrome [...] and fell into a very deep hole. No, well, all the grieving I did in the decision-making phase, when I was going through prenatal diagnosis. They had to do all that grieving after the birth. (GE, P, Tanja)

Practical preparation included choosing a suitable hospital in which to give birth according to the diagnosed condition or choosing appropriate health insurance. The following quote demonstrates how knowing in advance helps in making the necessary healthcare arrangements for the future child.

The detailed diagnosis, which we did with both children, is something that for me can perhaps influence the decision about which hospital to give birth in. You can also fix some things before the birth. I mean it also has a curative aspect, so not just a selective one. (GE, P, Beate)

Testing was appreciated by both Israeli and German respondents because it provided knowledge, and not just for practical reasons: it also gave expecting parents peace of mind when the results were normal, or certainty when there was an indication of anomaly in pregnancy. Tirzah from Israel explained why she chose diagnosis by amniocentesis following an ultrasound that suggested DS:

[Confirmation by amniocentesis] allowed me to prepare. I had the time to think what I wanted to do. I think it was very good for me to know this. It gave me the option to choose and later to remind myself that this was my choice [to give birth to him]. Knowing that it was my choice helped a lot. This feeling that it didn't "fall" on me, but it was my own choice. A choice made with logic and with the will to deal with something different. (IL, P, Tirzah)

Lisa from Germany also described in her words the benefits of knowing. For her, testing was a key to eliminating uncertainties and their associated discomfort and potential shock at birth.

And then it was somehow so clear to us that we just wanted to know. I mean, I didn't want to go through this whole pregnancy – mhm – [I didn't want to] wander around with such an uncomfortable feeling, is it like this or isn't it, and somehow it was also clear that we didn't want our first greeting of this child when it's born to be perhaps shock or something like that. (GE, P, Lisa)

In addition to these positive effects of NIPT, German respondents also conveyed a great deal of criticism beyond that relating to an erroneous sense of security and control. Similar to a common argument among Israeli ultra-Orthodox respondents, a repeated rationale of the German respondents who criticised the tests was the emotional distress they provoked, and the agony related to the decision-making that followed. Even if the results are correct, the tests are blamed for putting women in situations where they have to make decisions they would rather not. Interviewees like the activist Liselotte emphasised the right not to know.

The more tests you do, the more decisions you have to make. I mean, the famous right not to know [...]. I mean, the easier it is to carry out a test, the easier it is for you to take the test, and afterwards the woman is left with a decision that she may not have wanted to make. (GE, A, Liselotte)

This message is in line with the following, conveyed by another German activist – Dora – who also argued in favour of reducing testing:

I would say: have as few tests as possible. Because I believe that you never know what something would be like for you and that the tests are, so to speak, always certain or not certain to some extent, and I think that, a lot in pregnancy is aimed at, I mean it leads to generating more worry than you would have if you didn't do all of that. (GE, A, Dora)

Dora's message is especially interesting when compared with that of Dvora's, an Israeli activist:

I think life isn't simple and that preventive medicine is the proper medicine. Whatever is preventable, you should prevent. Therefore, do all the possible tests to prevent any problem in the future. (IL, P+A], Dvora)

A different understanding of responsibility is not the only explanation for this contrast, as was shown earlier. It also stems from different perceptions of disability and its effect on disabled people and their families.

(ii) Views about disability

Rather than being a source of suffering, many of our German respondents perceive DS to be a special condition of existence, associated with special needs. DS in itself was not considered a disease. In fact, the manifestations of the syndrome are often disassembled and viewed separately. The structural defects, such as the heart conditions that are common in children with DS, are considered separately, and as something that may be treated by surgery, whereas the untreatable manifestation – the cognitive impairment – is what they consider as DS, but without considering it a devastating trait.

He's just, he has a disability, but he is HEALTHY, he has no diseases or anything. (GE, P, Anna-Lena)

What was at the forefront for us wasn't the Down syndrome at all, but the heart defect. Because you don't die of Down's, but you can die of the heart defect. (GE, P, Sabrina)

Beate stressed that families who have children with DS are just as normal and happy as other families:

I think if you dive into the subject of Down syndrome and trisomy and also get to know people, they are just normal happy families, I mean, they maybe worry a bit more about their health, but otherwise [...]. (GE, P, Beate)

However, German respondents did not describe bringing up a child with a disability as carefree. The difficulties associated with raising such children were claimed to be the result of the obstacles that society puts in front of the families. The interviewees spoke more about suffering because of social stigmatisation and a lack of acceptance, and less because of the DS itself. DS was not found to be inherently connected to suffering in Germany as much as it was in Israel.

There is even an emphasis on the positive characteristics of these children in the way some German interviewees describe them. Some interviewees pointed out what a positive impact their children have on other people. Hanna said:

Life with a child with a disability is so, so enriching. Well, that always sounds such a platitude, but it really is like that. It's something very special because you can think through your own values again and what is practically grafted onto you from outside by this system of having to perform, you can somehow really shake yourself free of it. And there is this saying "Once your reputation is ruined, life gets a lot more relaxed." (GE, P, Hannah)

Among Israeli parents too there were less typical voices echoing German ones, where DS was not seen as inherently disabling and instead the positive aspects of the direct experience of DS were emphasised. Society was seen as the source of these children's difficulties.

Some people say that these kids are a birth defect. But we say no. They are the light of the house. [...] My son taught me a lot. He taught me what is patience, he fine-tuned me, he improved me. [...] You need to understand that the child is not retarded, our child is not disabled. The ones that are still disabled and retarded are us, as society that doesn't know how to deal with them. (IL, P+A, Sivan)

A strong emphasis on the positive meanings of disability among Israeli respondents came mostly from the ultra-Orthodox community and carried religious meanings. In those instances, children with DS were described as "higher souls" that were "sent by God" to carefully chosen families.

I told the kids: “God chose us and gave us this special soul. A pure soul. God chose you to be his siblings and us to be his parents. And that means we will do it in the best possible way, and this is a privilege”. And I told them that if their friends say “Oh, poor you, you got a child with Down syndrome” with such pity, then they should know that they were not chosen. We were. It is an honour. (IL, P, Leah)

In interviews from both countries, then, DS was not always seen as an obstacle to a fulfilled life. However, even in Germany, where such ideas were more prevalent, some respondents opposed the clichéd positive view of children with DS. They felt uncomfortable with descriptions such as “sunny children” and claimed that this is not accurate and fair. As Lisa describes it:

It’s such a cliché, I have to say. There are many children who don’t fulfil that at all –always being so radiant and so sunny and sweet. There are some children who are quite aggressive. (GE, P, Lisa)

A similar rejection of the portrayal of children with DS as “sweeties” also came from an Israeli head of one of the DS organisations. She advocated a view that rejects seeing them as uniformly cute, and instead discerns their individualities and needs. She called for a society that provides for their needs accordingly:

Let me tell you a secret: not all Down’s children are sweet. They aren’t kittens! Each one is an individual. They have talents, needs, dreams and achievements. (IL, P+A, Bosmat)

(iii) Views about eugenics

In line with the widely shared goal of avoiding a life with disability, the idea that prenatal testing will result in a decline in the DS community or even its elimination was not perceived by many of the Israeli respondents as a negative outcome. This was justified by the value of the prevention of suffering, as demonstrated in the following two quotes. One is from an activist in an Israeli DS organisation and the other from a mother of a child with DS:

A child like this, even with all the advances in science and the available opportunities [...]. Still, a child with DS is a child that brings difficulties into the family that a regular family doesn’t have. Not everybody is able to deal with it. [...] Nobody wants a child with disability. If you can somehow prevent it and you know in advance about a disability – if you want you

can have an abortion – I am in favour of that. But I never tell the parents my opinion. Each parent is responsible for their own actions. (IL, A, Ofra)

[As a result of testing] fewer babies with DS will be born and I don't think that's not good. If there is anything I know about in advance, then why [stay pregnant]? But if you don't know, like me, then [...] there is nothing you can do. Then you have to cope with what you have. But if you know in advance, then I wouldn't keep it. I say that with real pain, because I gave birth to an adorable child. But not everybody is like him. There are many kids with very difficult problems. I am in touch with parents whose children spend most of the time in hospital [...] crying and really suffering. Poor children and poor parents [...]. (IL, P, Noa)

Other Israeli respondents, however, opposed the attempt to create a society without DS. Some respondents explained the futility of such attempts because disabilities will always occur for different reasons. Others articulated aspects of the disability critique and described diversity in society as an ideal.

There will always be [people with] special needs. There are so many things that can't be detected genetically. It's not that I think the world will suffer if Down syndrome didn't exist. But this desire to reach perfection, so that everything is according to the norm [...]. It doesn't make sense. But also, it will never happen that everybody is the same. That's why I think there is a problem with this desire to reach perfection, not specifically [in connection with] DS. (IL, P, Alona)

In contrast to Israel, explicitly eugenic views were rarely heard in Germany; instead, the fear of selection based on undesired traits was raised multiple times. Several respondents mentioned Nazi history in their interviews. In some cases, this was used to explain older people's views in favour of selection, i.e. arguing this was the result of their upbringing under an ideology that rejected disability. Others mentioned Nazi history to refer to processes that should be avoided. Even the argument of "testing enables preparation" was rejected by some who claimed that it is used simply to cover the true nature and aim of these tests, which is selection. The "slippery slope" argument was sometimes raised, reflecting the fear of an uncontrolled outcome.

I really think that these tests send a message: "It makes sense to avoid having children with trisomy." And I think that it isn't the job of the insurers to fund the selecting out of particular forms of life, and that's what these

tests do, or that's what these tests suggest, or that's the consequence of these tests in many cases, and I think what they always argue, that parents want to prepare for what awaits them, in the first place, I don't believe that you can. (GE, A, Dora)

Eugenic ideas are thus openly discussed in interviews from both countries – freely advocated for in Israel, and as a red flag in Germany.

(iv) Feeling guilty

These distinct attitudes are in line with the different kinds of guilt described by our respondents in relation to parenting children with DS, and the uptake of prenatal testing. In Germany, women felt guilty when they encountered abnormality in pregnancy and considered termination. In line with Simandan (2020), who elaborates on the process by which people can come to surprise their own selves, the discrepancy between the acceptance of disability, which they saw as an ideal, and what they actually felt in their situation, made them feel guilty. This demonstrates the impact of the social discourse about inclusion, which may prevent German women from choosing a different path – one of thorough testing and termination.

So, I surprised even myself, because I'd always thought, "well, I want to live in a colourful world with diversity and where people become happy in their own way and not in one of those things [where you're under pressure to succeed]" and "I don't want to love my child for being in some particular way, but for being at all" and so on. Those were my thoughts before, and I think they also had a basis in my heart, but when I was thrown into this medical-technical [world], I suddenly got to know a completely different side of myself. One that didn't want all this, that wanted more security, more normality. (GE, P, Hannah)

A minority of German parents also expressed guilt over the hardships a child with DS experiences and the associated burden on society as a result of the costs of treatments and care.

It always plays a role too when I see the costs my son actually generates, through all his health problems. We were constantly at the hospital, he needs a lot of aids and a lot of medication and so on. In some ways I do have a bit of a guilty conscience. (GE, P, Janine)

A parallel type of guilt present in Israel was associated with *not* detecting the condition and thus not sparing the child and the family a life of difficulty, as expressed here by Efrat, who did not have an amniocentesis after what later turned out to be a false negative NIPT:

Clearly I intensely regretted not having the amniocentesis. And all the time people told me, “You know, it isn’t certain that it would have been detected by amniocentesis because it is a case of mosaicism.” And each time I felt that people were telling me this even though it wasn’t true, just so I wouldn’t feel guilty. (IL, P, Efrat)

Another form of guilt was articulated by respondents from both countries and expressed here by Ilanit: realising that testing in subsequent pregnancies sends a negative message to the child with DS whom they already have.

There is great complexity here. And the issue of the test puts me in that zone. When I come to have the test, what am I actually trying to say as a mother of a child with DS, and who is thankful for having him? Am I saying that in reality I am not thankful? (IL, P, Ilanit)

(v) Public attitudes about disability and prenatal testing

Despite a clear emphasis in official statements in Germany against routinised selection practices (“Dieser Test ist keine Routineuntersuchung.” Gemeinsamer Bundesausschuss 2021: 11), even to the extent of eliminating an “embryopathic” indication in the German abortion law (§ 218 a, 2, German penal law) in 1996, interviewees in Germany described a society that is, in reality, often not receptive to disability. Swaantje said:

It’s absolutely not a free decision at the moment – first of all because of the stigma. A question which I have encountered quite often is: “Why didn’t you have an abortion?” (GE, P, Swaantje)

This quote indicates a discrepancy between the ideal, as described in the law, and real life. The official views emphasise a free choice and underline inclusion. In reality, parents report encounters with people that not only demonstrate acceptance of selective practices, but also the expectation of endorsing them.

In the Israeli secular community, respondents described frequent judgmental and negative reactions alongside instances of positive and embracing messages from society. As Alona says:

The biggest difficulty is this look of “How did this happen?” The feeling is that it is something extremely exceptional in our environment and I feel that people pity us. [...] In the current pregnancy I feel pressure from society and from people around us to get tested. People would have really raised an eyebrow had we not tested. [We face] all these questions of “This time you ARE getting amniocentesis, right?” (IL, P, Alona)

Discussion

Our findings portray two different logically coherent triangles of local views about parental responsibility, disability, and prenatal tests in Israel and Germany. Given all the nuances and contradictory evidence that we encountered even within each country sample, this depiction of contrasting logics is an idealisation. It over-emphasises and may exaggerate the contrast. However, it does reveal different *possibilities* for connecting experiences with disability, the power of testing and the concerns about responsibility in two different ways, which seem to form distinct tendencies among Israeli and German respondents. Although the sample is much too small to generalise across a whole population, we can identify some clear indications.

Disability in Israel is perceived by many as a source of suffering that justifies prevention. The role of “responsible” parents is to prevent the suffering of a future child and the rest of the family. This practice of responsibility begins in pregnancy (and even before – in the elaborate pre-conception carrier screening offered to the general population, or premarital carrier matching for the ultra-Orthodox). The availability of the widely implemented pre-conceptional and prenatal testing programmes (Zlotogora 2014), which are funded by the state and recommended by medical professionals, implies that genetic testing is the responsible and expected thing to do before and during pregnancy. This, together with an abortion law that explicitly allows terminations based on embryopathy (*Penal Law Amendment (Interruption of Pregnancy) 1977*), arguably pushes for testing in order to terminate affected pregnancies. This has even been described as a local script of “responsible parenthood” in some studies (Hashiloni-Dolev 2007; Raz/Schicktan 2009a; Remennick 2006; Rimon-Zarfaty/Raz 2009). This outlook is shared not only by large parts of the population, but also by parents of children with disabilities (see also Raz 2004), including parents of children with DS (Nov-Klaiman et al. 2019), where a two-

fold view of disability is prevalent: supporting prenatal testing as a preventive measure while being committed to those already born with disability.

The respondents' views reflect an Israeli environment in which prenatal testing is expected, and pregnancy terminations on the basis of DS are seen as legitimate and, in some cases, even encouraged. No such views were found among the German respondents. According to the German interviewees, to act 'responsibly' primarily means accepting a child with DS and preparing properly. When not rejecting them, they see the tests mostly as a legitimate tool for preparation, rather than sharing the Israeli opinion of them as a legitimate tool for avoiding the birth of a disabled child.

The disability critique in Germany is stronger than in Israel: voices rejecting testing and their implementation in society are clearly audible. In line with the change in the German abortion law so that it no longer includes an "embryopathic" indication, the German public discourse is one that promotes inclusion rather than legitimising selection based on undesired traits. This, coupled with the lingering guilt and aversion related to Nazi history, perhaps explains this different logic. It may be harder for parents of children with DS to express difficult personal experiences which – as in the common Israeli voice – lead them to acknowledge the benefits of prenatal testing through the prevention of suffering.

Social discussions clearly have an impact on personal decision-making. Studies from other countries demonstrate the effect of the social environment on the decision-making process. In Denmark, where the termination rate for pregnancies in which DS is diagnosed is over 95 per cent, parents described the legitimising feedback they received from their social networks as highly valued when choosing to terminate (Lou et al. 2018). Perceived social expectations were found to have an impact in the other direction as well. Parents who decided to continue a pregnancy diagnosed with DS felt vulnerable, knowing that they were choosing a path very rarely taken by others in their society (Lou et al. 2020). This could well underlie decision-making in both Israel and Germany. In Israel prospective parents might find it very hard to decide to have a child with DS, whereas in Germany many find it both hard to decide to have a child with DS and hard to decide not to.

Our findings reflect the previously known contrasting public discourses and cultural differences between Germany and Israel. NIPT – a technology only roughly a decade old – demonstrates the persistence of cultural scripts – values and norms – over time, despite the potential effects of personal experience and global trends such as commercialisation.

This study has limitations. To generalise from the level of personal views to the level of cultural characteristics, we looked for statements that reflect common values and norms within and across the groups of respondents. Our sample, which started with activists and then used snowball technique to recruit further participants, may have created a biased sample and thus missed a broader range of viewpoints. Like all qualitative studies, our study's generalisability is limited by the small sample. Less typical interview statements were discussed by the research team and when deemed meaningful were mentioned as minority views in the findings.

Conclusions

Studying disability activists and parents of children with DS allows us to examine whether the lived experience of those who directly encounter DS changes their perceptions of disability, prenatal testing, and termination of pregnancy. By comparing those groups in two societies that are known to have contrasting views on these matters, we can assess the role society plays in the formation of such views. We might have expected that direct experience of DS would drastically change the views of those involved, thereby making them a unique group within their respective country. However, our findings suggest that in each case society has a strong influence. Many Israeli respondents expressed views that legitimise prenatal testing for pregnancy termination, while the major views amongst German interviewees emphasised prenatal testing primarily as a legitimate tool for preparation or rejected them altogether. This difference arguably reflects the different policies and public debates that broadly characterise these countries.

This study has combined two axes of comparison. The first compares German with Israeli respondents, and the second compares the respondents – disability activists and parents of children with DS – with their wider society. For the first axis, our study provides further evidence of the gulf between Germany and Israel already reported in previous studies (e.g. Hashiloni-Dolev 2007). The passing of time and the emergence of new technologies do not seem to have brought these societies closer to one another. Concerning the second axis, parents of children with DS and disability activists seem to reflect the norms of their socio-cultural environments, thereby emphasising the role society plays in shaping the views of those with direct experience of disability.

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