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‘We are all in the image of God’: reproductive imaginaries and prenatal genetic testing in American Jewish communities

Faye Ginsburg, Rayna Rapp*

Department of Anthropology and Center for Disability Studies, New York University, New York, USA

Corresponding author.



Rayna Rapp is Professor of Anthropology, New York University (USA), where she teaches both undergraduate and graduate courses on medical anthropology, disability studies, science studies and gender intersectionality. Her publications focus in these areas; she is currently writing a book on ‘Disability Worlds: the Public Presence of Disability in American Culture since the Passage of the Americans with Disabilities Act’ with Faye Ginsburg.

Abstract How are we to understand the complexities of prenatal genetic testing across social and cultural worlds? Availability and uptake of this biotechnology is variable, deeply influenced not only by national frameworks but also by local regimes of value. We argue that these intersections of genetic testing and local cultural worlds must be understood as part of broader ‘reproductive imaginaries’, including everything from kinship, pregnancy and gender norms to children’s links to specific community norms of national and cultural futures. In the USA, preconceptual/prenatal genetic testing is widely available, driven by a neoliberal market-based model of consumer choice. In contrast, such tests are far more restricted by bioethical laws and medical regulations in France. This article will examine how particular cultural and religious communities – primarily American orthodox Jewish communities – shape prenatal genetic testing in their own distinct ways.

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Grounded in the Talmudic morality of the Jewish obligation to the next generation, Jewish genetic testing uniquely complicates contemporary debates exploring eugenics in the DNA age

[(Porter, 2015, p. 47).]

Whatever Jewish families do, they are in the business of inclusion and exclusion – and the exclusions, more often than not, are done silently

[(Boyarin, 2013, p. 3).]

E-mail address: rayna.rapp@nyu.edu (R. Rapp).

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The question arises, when do you stop? There are close to 90 genes you wouldn't want to have. Will this lead to people showing each other computer print-outs of their genetic conditions? We'll never get married

[(Tendler, quoted in [Porter, 2015, p. 46](#).)]

How are we to understand the complexities of prenatal genetic testing across social and cultural worlds? At first glance, these tests appear to offer universal benefits; genetic counsellors are, in general, trained to express neutrality about the choices a pregnant woman and her partner may make around genetic testing. Yet the very existence of such rapidly proliferating technologies and the use of such tests under the terms of 'patient autonomy' is premised on a valorization of normalcy, fear of unknown abnormalities and the possibility of abortion. As a result, the availability and uptake of this biotechnology is variable, deeply influenced not only by national frameworks but also by local regimes of value. This article will examine how a particular cultural and religious community – American Ashkenazi Jews – shapes prenatal genetic testing in distinct ways.

We argue that these intersections of genetic testing and local cultural communities must be understood as part of broader 'reproductive imaginaries'. These include everything from kinship, pregnancy and gender to the way that children are linked to specific ideas of national and cultural futures. Writing about imaginaries in general, STS scholars Sheila Jasanoff and Sang-Hyun Kim highlight that such frameworks are:

...instrumental and futuristic: they project visions of what is good, desirable and worth attaining for a political community; they articulate feasible futures. Conversely, imaginaries also warn against risks or hazards that might accompany innovation if it is pushed too hard or too fast. In activating collective consciousness, imaginaries help create the political will or public resolve to attain them

[([Jasanoff and Kim, 2015, p. 123](#)).]

Our use of reproductive imaginaries is consonant with this understanding, calling attention to how the cultural work of reproduction is always both practical and future-oriented, underscoring both aspiration and risk. Moreover, this construct reminds us that sociotechnical imaginaries are always already grounded in specific locations, as research on genetic testing makes clear.

In the USA and France, the reproductive imaginaries shaping genetic testing practices have had radically different trajectories. In the USA, preconceptual/prenatal genetic testing is widely available, driven by a neoliberal market-based model of consumer choice. In contrast, such tests are far more restricted by bioethical laws and medical regulations in France. This French reproductive imaginary, some scholars have suggested, is haunted by World War II's murderous use of eugenics in Europe, making the identification of racialized communities for specific testing taboo in France ([Gaille, 2016](#)). As historian of science Dorothy Porter argues:

A hegemonic revulsion against eugenicism...followed the revelation of its murderous potential when the results of the Nazi

policy of the Final Solution were discovered after Germany's defeat in the Second World War. Social planning philosophies subsequently sought to expunge biological explanations from their discourses. Equally the biological sciences of inheritance sought to detach themselves from eugenic racial and social planning ([Porter, 2012, 435](#)).¹

This was certainly the case in France. Although the USA has its own legacy of eugenics ([Stern, 2005](#)), that history has not shaped the US reproductive imaginary in the same way, perhaps because it did not lead to the Nazi's 'Final Solution' and the controversial French participation in it. In the shadow of this history, such tests are not offered in contemporary France unless a known member of the family has a specific condition for which prenatal testing is available. Despite the lack of specific ethno-racial testing, French abortion rates following positive prenatal diagnoses are high, similar to rates in the rest of Europe, and focused primarily on Down syndrome ([Boyd et al., 2008](#); [Vassy, 2005](#); [Vassy et al., 2014](#); [Ville, 2019](#)). In contrast, in the USA, there are no restrictions on the embrace of prenatal genetic testing by certain ethno-racialized and ethno-religious groups known to be at elevated risk for particular genetic conditions.

This context shapes the questions we ask in this article. What happens when some American Jewish communities refashion assisted reproductive technology (ART) to meet the concerns and aspirations of their particular cultural worlds within the US national context? How do their distinctive practices and imaginaries enter into specific cultural circuits that reframe key terms of their reproductive imaginary? Our ethnographic research on the intersections of disability, ART and religion – in this case, among American Ashkenazi Jews – offers complex and revelatory answers to these questions.

Our work reveals two sometimes contradictory frameworks. The first is the enthusiastic uptake of genetic testing by and for American Ashkenazi Jews to prevent the birth of babies with hereditary disorders. This practice has been increasing across all sectors of the Jewish community where genetic diseases run at a relatively elevated rate [[Ferreira et al., 2014](#); [Hoffman et al., 2014](#); [Scott et al., 2010](#); [Ivry, 2010](#) (c.f. [Birenbaum-Carmeli and Carmeli, 2014](#)); [Prainsack and Sigal, 2010](#)].

The second framework engages a growing movement in Jewish life for greater inclusion of disability, whatever its origins. These two approaches are in tension. As ethicist Ronald Green has argued:

Jews of all denominational backgrounds have been early adopters of prenatal testing as a way of avoiding the birth of children with serious genetic defects...Jews everywhere, by virtue of their historic commitment to the avoidance of the evils associated with disease, have eagerly accepted the information and tools of genetic medicine. This has been true despite the bitter experience of modern Jewry with the abuses of genetic medicine in the Nazi period. And it has been true despite the

¹ In making this argument, Porter cites the work of Nils Roll-Hansen ([Roll-Hansen, 2010](#)).

growing number of disability rights activists, feminists, and others who have criticized prenatal testing as unjust and discriminatory. Ordinarily, we might expect that their historic opposition to injustice and discrimination would lead Jews to give these criticisms a hearing...

[(Green, 2015, pp. 268–269).]

Thus, these two powerful orientations index the gap between religious and biomedical understandings of ART, on the one hand, and the emerging presence of disability awareness in Jewish communities, on the other, discussed below.

The circumstance of elevated risk is faced by American Jews of known Ashkenazi descent, whether secular or religious. The relatively high incidence of genetic disorders in this population is due to several factors, including centuries of endogamous and preferred first cousin marriage and isolation in ghettos. Additionally, sudden catastrophic mortality in epidemics reduces diversity in the remaining gene pool, thus concentrating specific genetic differences, including disease, in subsequent generations; these are known as ‘population bottlenecks’. As a result, American Ashkenazi Jews are strongly encouraged to have carrier or fetal screening for the many genetic conditions for which they are considered to be at risk, colloquially called the ‘kosher kit’. This testing is widely accepted and welcomed by North American Jews (Levin, 1999; Scott et al., 2010). However, some bioethicists have raised concerns about the ‘stigmatizing effect of identifying the Jewish people as a whole through the use of genetic disease susceptibilities’ given the long history of negative stereotypes of Jews as sickly and unworthy of life (Wolpe, 2015, p. 205). Historian of science Dorothy Porter notes similar critiques. She quotes Jewish ethicist Laurie Zoloth’s concern that ‘the eugenic imperative of Jewish genetic testing... addresses [not only] disease prevention [but also] scientifically reified racialism and biologicistic normalization’ (Porter, 2015, p. 46). As Porter further observes, ‘Jewish genetic testing dramatically intersects with the hotly disputed legitimacy of using self-identified racial evaluations as ancestry information makers for disease analysis, prevention and therapeutic targeting’. The scientific value of racial self-identification reporting is unreliable, yet ancestry testing is enormously popular, reinforcing ‘biologization of the historically constructed categories of race and stereotypes of biological ability and disability’ (Porter, 2015, p. 46). These historical and bioethical discussions of the benefits and burdens of Jewish ancestry testing take on added significance at this moment give the rise of anti-Semitism in the USA, France and many other countries (Weitzmann, 2019).

Despite these critiques, diverse possibilities for action based on genetic knowledge have taken root in many parts of the American Ashkenazi world – from ultra-Orthodox Haredi² to modern Orthodox to Conservative, Reconstructionist and Reform adherents, to secular Jews – motivating innovations in the self-management of such information. This is particularly

the case in parts of the Haredi Jewish community where arranged marriages remain common. For example, ‘Dor Yeshorim’ (trans: ‘Upright Generations’) was founded in 1983 to provide genetic testing in a way that respects such community norms regarding both arranged marriage and stringent restrictions on abortion. Young adults in ultra-Orthodox high schools are tested before potential matches are proposed by third party matchmakers, operating outside both families, who have permission to access their genetic data. This assures that ‘genetically incompatible’ couples are not likely to marry or reproduce together. A match would thus not be proposed without checking ‘The Test’ as it is widely known in the community. Additionally, extreme confidentiality ensures that no information about an individual’s genetic status is circulating, given the stigma attached to being a carrier of any genetic condition; otherwise, a person’s marriageability as well as that of other family members is at risk. These practices that have emerged around genetic testing are widely accepted and communally enforced.

The enthusiasm in US Jewish communities for embracing genetic testing over the last half-century cannot be overemphasized (Levin, 1999; Scott et al., 2010). In fact, the test for Tay-Sachs disease, a devastating fatal neurological recessive disorder carried by Ashkenazi Jews (among others), could not have been developed without their active participation. In 1971, members of a Maryland Conservative synagogue, some of whom had lost young children to Tay-Sachs disease, responded vigorously to pioneering efforts to test for this disease. They volunteered to work with geneticists and doctors at nearby Johns Hopkins University who were developing the first prenatal screening for Tay-Sachs disease. One of those doctors, Dr Michael Kaback, a Johns Hopkins pediatrician-geneticist, later recalled the sense of team effort:

With the help of 40 trained lay volunteers and 15 physicians, more than 1500 people volunteered for testing and were processed through the ‘system’ in about 5 h...For me, it was like having written a symphony and hearing it for the first time – and it went beautifully, without glitches

[(Stoll, 2017).]

Temple bazaars and cake sales funded the first machine – which cost \$15,000 – to process the tests (Stoll, 2017). Subsequent mass screenings quickly followed among Conservative Jewish communities in the Boston and Philadelphia areas, referred to by some as ‘genetics for the community’ (Cowan, 2008; Stoll, 2017).³ In this period, carrier couples faced harrowing choices and medical-legal gauntlets should they wish to terminate a Tay-Sachs pregnancy; this circumstance changed after the 1973 Roe v. Wade Supreme Court ruling legalizing abortion throughout the USA

Over the next decade, the embrace of prenatal testing, and later adult-onset disease testing, spread to other parts of

² Haredi (adjective) or Haredim (collective noun.) This is a word taken from the biblical book of Isaiah meaning ‘one who trembles before God’. It is a self-description of strictly observant Jews who reject many aspects of modern life. They are often termed ‘ultra-Orthodox’, but many of them consider that phrase offensive. They started using the word ‘Haredim’ instead in the 1950s, first in Israel. It is still used more widely there, but has spread to the USA and elsewhere. Virtually all Hasidic Jews would identify as Haredi (Davidly, 2018).

³ Conservative Judaism (known as ‘Masorti Judaism’ outside North America) is a Jewish religious movement which regards the authority of Jewish law and tradition as emanating primarily from the assent of the people and the community through the generations, more than from divine revelation. It therefore views Jewish law, or ‘Halakha’, as both binding and subject to historical development (Conservative Judaism, 2019).

the American Jewish community, underscoring the ambiguous status of Jewish identity as based on both religion and biology. Indeed, Judaism as a faith draws on particular theological traditions and practices, yet the category of 'the Jew' also indexes a kin-based cultural world – a 'Gemeinschaft'. 'Being Jewish' systematically braids together longstanding customs and theology, ranging from bagels to the 'bima' (synagogue pulpit or platform), with a shared genetic heritage. This intersection has produced a cultural discourse around 'Jewish genes' that is continually reshaped by ongoing transformations in genetic technologies, reframing contemporary personhood and family formation and even popular culture. Thus, in the Haredi Jewish community and elsewhere, the impact of new knowledge at the molecular and genetic level is increasingly experienced through the routinization of prenatal genetic testing on their own cultural terms.

In 1983, Rabbi Josef Ekstein founded 'Dor Yeshorim' in Brooklyn, NY to promote premarital genetic testing. He had lost four of his 10 children to Tay-Sachs disease; he 'believed the methods of Tay-Sachs prevention that involved abortion, artificial insemination or screening of preimplantations outside the womb were incongruous with Halakhic law and thus founded a confidential screening system with the goal of eliminating the disease within the community' (Porter, 2015, p. 44). Concerned that others in his community should know about and use genetic testing to avoid the grief that he and his family had experienced, he also worried that his healthy children would suffer relentless shame and never find partners in a community where arranged marriages were and remain the norm. The group's objective, to minimize and eventually eliminate the birth of children with Jewish hereditary disorders, succeeds through an ironclad policy of complete anonymity; individual results are not even disclosed to those being tested.

We believe, and the system's resounding global success supports, that in keeping all testing results confidential, any potential stigmatization of individuals and families is eliminated. Furthermore, statistics show that the knowledge that one is carrying a deleterious gene can be psychologically difficult. In the case of genetic carrier status, the freedom to not know can be more liberating than the right to know (Dor Yeshorim, n.d.).

Thus, no one is marked as a carrier of a highly stigmatized condition that would render them less marriageable. Instead, the genetic profiles of prospective couples are checked for 'genetic compatibility' before a match is proposed. As a result, young adults who use 'Dor Yeshorim' can enter marriage with the assurance that they are very unlikely to produce babies with Jewish genetic diseases.

Of course, non-disclosure has its limits. Critics point out that "when a match is proposed and nothing happens, people naturally ask, why didn't this happen? They submitted to 'Dor Yeshorim' and then decided not to get married. This reveals immediately to their entire Jewish community that there are two people who are blemished" (Tendler, quoted in Porter, 2012). One well-respected NYC neurologist credits the near-total disappearance of Tay-Sachs disease from the Haredi community to 'Dor Yeshorim'. Additionally, "Ekstein has been accused of 'playing God' by the founder of the Jewish Genetic Disease Consortium...for withholding information from individuals who have tested positive" for diseases other than Tay-Sachs for which medical interventions may be available (Porter, 2015, p. 45).

Despite these concerns, the success of this approach has been remarkable. An article in an online Jewish magazine described 'Dor Yeshorim' as 'Tinder for Tay Sachs', remarking that 'In the age of digital dating and compatibility algorithms, dialing a hotline to determine [genetic] compatibility [before going out] isn't so far-fetched' (Stiles, 2014). The 'Dor Yeshorim' website explains:

We screen an astounding 20,000 young adults plus individuals annually... 'Dor Yeshorim' is a household name, operating in 11 countries including the United States, Canada, Europe, and Israel; supported and endorsed by leading rabbinical authorities and medical experts the world over (Dor Yeshorim, n.d.). More than three decades after its founding, the organization continues to offer affordable genetic testing, 'subsidized' as they say, 'by donors around the globe who share our passion for the health and wellbeing of future generations'

[(Dor Yeshorim, n.d.).]

It is not only rabbis and donors who are passionate about 'Dor Yeshorim' testing. In 2016, this group received unanticipated media attention when a rap video went viral on YouTube. The short and hilarious do-it-yourself video was made by two teenaged schoolgirls attending the well-known 'Bais Yaakov Yeshiva', thanking 'Dor Yeshorim' for their imagined betrothals and resulting healthy children and grandchildren as they sang and beat-boxed a song they wrote combining Yiddish, Hebrew and English, a community-acknowledged Jewish language variety known as 'Yeshivish' that even has its own dictionary (Weiser, 1995).

A writer for The Jewish Daily Forward's 'Schmooze' column summed it up:

Weirdly talented rapping Orthodox Yeshiva girls in long dark skirts in front of a row of school lockers star in their illicit viral hit about their own and their future daughters' marriage prospects, as it bubbled up through the dark net of Orthodox WhatsApp groups

[(Nathan-Kazis, 2016).]

'Dor Yeshorim' representatives claimed to be 'very disturbed', stating that '...it is below our dignity as an organization to promote such a thing', distancing itself from the video. While the girls offered an apology, the thousands of views on YouTube suggest that this lively commentary on the virtues of premarital genetic testing has a fan base.⁴

⁴ Ayala Fader, an anthropologist known for her longstanding research with Hasidic and Haredi women and their media and language practices, suggested that the video should be seen in the context of the rumoured 'shidduch' (arranged marriage) crisis. There is a lot of anxiety that there are not enough boys for 'good girls' because boys wait a little bit, going to Israel to learn and then want younger girls. Then 'older girls' have no one to marry. No one seems to know if there is a real 'shidduch' crisis or if it is fake. There has been some press from inside communities in books and magazines advising that 'frum' (Orthodox) older girls should learn to use make-up, or pleading with boys to take an older girl. There is no 'shidduch' crisis among Hasidim as young men and women get married at around the same time (Fader, personal communication, April 2018).

In addition to the offbeat charm and ethnographic glimpse into the world of Yeshiva girls that this video offers, we also highlight how 'Dor Yeshorim' has been taken up creatively by two young women who are their desired consumers. While individual results always remain confidential, the group's reputation for enabling 'healthy marriages' is widespread as is evident in this cultural artifact. Their performance and especially their lyrics project a disability-free future full of able-bodied Jewish progeny for over 120 years, the life span of Moses that ends their rap. In short, this 90-s amateur production that spread rapidly across the Jewish community, creating some controversy, was also a compelling window into the reproductive imaginary of young Haredi single women, their target audience (Ghert-Zand, 2016; Nathan-Kazis, 2016).

Here are the lyrics (Anonymous, n.d.).⁵

Dor Yeshorim rap (2016)

Doing this test to see if we're a match
 And if it's a yes, well I'm a really good catch
 Going on a date to look for a connection
 And under the 'chuppah' [wedding canopy], we'll express
 our affection
 Got a diamond ring, tennis bracelet, rubies and pearls
 But this is expected for all the 'frum' [Orthodox] girls
 Walkin' down the street with the face that's glowing
 'Excuse me young miss, but can you tell that I'm
 showing?'
 Got my first of 7, we'll see that they're 'tsnuos shtark'
 [strictly modest]
 Immersed in yeshiva, I've dealt with the 'hock'
 [annoyance].
 Now my girls will have great personality and looks
 We'll be getting resumes [for arranged marriages] by the
 books
 Hold up (Uh)
 Wait. Rewind
 Let's go back to 'kollel' [religious school for married men]
 when we're living on dimes
 Got a 2 bedroom 'partment for us and 3 kids
 The kitchen's so spacious, two people almost fit
 And then all of our money on tuition, rent and food
 That a-hundred-a-week is really pulling us through
 Now I got my kids, raise 'em up with 'chinuch' [education]
 and 'pahtches' [discipline]
 All 'mensches' [good people], love G-d, who frequently
 'daven' [pray at synagogue]
 Now they do 'Dor Yeshorim', go out, get wed
 Then they have their own kids and we start again

Now I'm 'Bubbe' [grandmother] he's 'Zayde'
 [grandfather]
 With a room full of toys
 Wait for our grandchildren to come make noise
 Give 'em 20 for Chanukah
 50 dollars for their birthday birthday, birthday, birthday
 (birthday)
 Now I'm lying in bed
 Hooked up to IV's
 Wow, 120 did pass in a breeze [the number of years that
 Moses lived]
 Lived a full full life dedicated to 'Hashem' [God]
 Thanks 'Dor Yeshorim' – this is the end
 CHORUS
 Did 'Dor Yeshorim'
 Cause I got 'Dor Yeshorim'
 Cause I got 'Dor Yeshorim'
 Cause I did 'Dor Yeshorim'
 Hey! Hey! My 'chosson' [groom] did it too
 Hey! Hey! Cause he's a good Jew.

Unlike the commitment of 'Dor Yeshorim' to anonymity about individual carrier status in the service of arranged marriage, those who are less Orthodox as well as secular Jews use genetic testing in a more standard biomedical frame, in which people are informed of their screening results. Groups such as the Jewish Genetic Disease Consortium mentioned above, for example, encourage public awareness and genetic testing for anyone of known Jewish descent, premised on a collective recognition of a community at risk. This is also the case for Chicago's Center for Jewish Genetics, a cooperative of Jewish and children's hospital's associations founded in 1997 (Porter, 2015, p. 46).

Most recently, in 2013, Caroline and Randy Gold established a new model called 'JScreen' which also offers individual testing. As a modern Orthodox Jewish family, the Golds became vocal advocates for standardized preconceptual Jewish genetic testing after their daughter was diagnosed at 18 months with mucopolidiosis type 4, an incurable genetic neurological disease more likely to occur among Ashkenazim than in the general population. JScreen is now a national public health initiative that provides at-home education and carrier screening for 40 diseases, including the 16 for which Ashkenazim are at increased risk. In contrast to 'Dor Yeshorim', which promises non-disclosure of carrier status, JScreen informs individual participants of any results indicating a potential anomaly; genetic counsellors then connect via Skype or telephone to explain results, risks and options. It is up to the consumer to decide when and to whom to disclose genetic information. As JScreen's outreach coordinator explained, 'Our goal is for everyone to do this as a life-cycle event. Just like you buy a ring and plan a wedding, we want it to be a step that everyone knows about'. As one satisfied customer opined, 'If someone doesn't want to date me because I'm a carrier for a disease, then maybe I don't want to be with that person. I'd rather skip the free dinner' (Stiles, 2014).

The rhetoric of normalizing, medicalizing and individualizing this intervention into Jewish genetic futures stands in contrast to the kind of secrecy that is central to 'Dor Yeshorim'. However, both are testimony to Jewish women's desire to control the genetic fate – and health – of their anticipated children within communal structures initiated

⁵ As one anonymous commentator remarked about the whole phenomenon: While the exact origins of the song have yet to be reported/substantiated, rumour is that the video of two female students rapping and beat-boxing about 'Dor Yeshorim', a relatively well-known Jewish genetic screening programme among Haredi American Jews, was recorded in a 'Bais Yaakov' school and shared via social media (e.g. WhatsApp and Facebook), against the wishes of those in the video. Regardless of ethical questions surrounding the sharing of the video, the rhymes in the poem are dope, and merit a wider audience. And/or a Nobel Prize for Poetry.

and sustained by men. The use of preconceptual genetic testing reveals a contemporary Jewish reproductive imaginary in which disability appears to be unproblematically controlled and erased. (For disability activists, we note that genetic disorders such as Tay-Sachs disease, involving inevitable suffering and early childhood death, are not considered disabilities, unlike some genetic disorders with which people can successfully live with appropriate support.) However, of course, most disabilities are not the result of genetic disorders, and mutated genes do not disappear from a population, as they are transmitted continually by silent carriers. What are the consequences of this potential desire to erase potential genetically based disability in Jewish life? Disability, we argue, haunts the embrace of genetic testing in this community and others. How does disability, genetic and otherwise, figure in the ongoing destabilizations and reimaginings of reproduction in the Jewish Orthodox communities under examination?

Some responses to these questions were offered by Jewish women activists whose experiences as mothers of disabled children led them to build culturally innovative awareness and inclusion of disability into different sectors of Jewish life. Shelley Cohen, for example, founded the Jewish Inclusion Project in 2013. Stunned at the lack of knowledge on the part of many modern Orthodox rabbis whom she encountered as a mother of a son with muscular dystrophy, she established vital training for Rabbinical students across all Jewish denominations. Her goal is 'to educate future religious leaders about the roles they need to play in integrating the communal and personal lives of people with disabilities and their families' (Cohen, n.d.).

In our interview with Shelley about what motivated her to begin this important educational campaign, she immediately turned to the story of the struggles she had locating Orthodox educational and camp experiences for her son Nathaniel:

You know Nathaniel was the pebble in the pool. Now, [due to my efforts], no Orthodox camp is without support for kids with disabilities. 'Yachad' [the longstanding Jewish organization supporting people with disabilities, founded in 1983] is now involved in helping with that as well. ... Lincoln Square synagogue (in NYC) was the only modern Orthodox synagogue that is wheelchair accessible and we were able to have his Bar Mitzvah there. For his funeral in April 2007, there were over 800 people... Nathaniel would have loved it. Lincoln Square really learned a lot from Nathaniel. The main sanctuary is named after him. You need to keep throwing those pebbles.

In September 2019, a much broader initiative, LifeTown, was launched by a Hasidic Lubavitcher Rabbi Zalman Grossbaum and his wife Toba Grossbaum, who had been struck by the needs of people she was seeing in her special education work. They wanted to address this clear need in their community. As Rabbi Grossbaum explained, 'We really felt that these families were lost, they had so many needs, both social, educational and therapeutic, but also they felt very left out of the community'. Through donations, investments, community support and the Chabad Lubavitch community, they created a \$19 million complex in Livingston, NJ. LifeTown is a kosher facility and respects Jewish

rituals, but is nonetheless non-denominational; it caters to the needs of people with intellectual disabilities, especially autism, who can be hypersensitive to various stimulations. This enterprise offers a myriad of opportunities for recreation, education and therapeutic play aimed at providing a comprehensive slate of programming for individuals with disabilities and their families, with an eye to integration into the broader community and possible employment (Nir, 2020).

Such initiatives have grown from deep roots. The late Rabbi Lynne Landsberg, who was disabled by a car crash, was one of the American Jewish community's best-known advocates for disability rights. She lobbied for passage of the Americans with Disabilities Act, for reproductive rights, and co-founded 'Hineinu: Jewish Community for People of All Abilities', a historic collaboration of the Chabad, Haredi, Reform, Orthodox, Conservative and Reconstructionist Jewish Movements dedicated to furthering the inclusion of disability – whatever its source, whether genetic or otherwise – as part of a near-future imaginary (JTA, 2018). Their work has become the touchstone for inclusion across many faith communities, advancing the idea that we are all made in the image of God, drawn from Genesis 1:27.

Despite this emerging commitment to inclusion as spiritually ordained, the question of arranged marriage in Haredi and other Orthodox communities and subsequent reproduction remains a daunting barrier to people with disabilities in everyday life. Ariella Barker, for example, a modern Orthodox Jewish wheelchair-using disability activist, discussed this in an interview in February 2019. She describes her religious community as:

truly incomparable in terms of being supportive and caring... However, where I've experienced difficulty in being accepted... in the context of love and marriage. The Jewish community tends to view disability as a defect when approaching 'shidduchim' [matchmaking]. As a result, despite being a young, intelligent and highly educated attorney, I have been set up with a grandfather of six, a convicted paedophile and fugitive from justice... or, most common, others with disabilities, with whom I have nothing in common other than a disability. Often this mind frame comes from the intention of ensuring genetically pure non-disabled children. Obviously, no one wishes to have a child with disabilities. But breaking off a relationship or refusing to date someone because of perceptions of an 'impure' genetic line or disability sends an ableist message that people with disabilities are better off dead or a burden to their loved ones
[(Barker, 2018).]

As Ariella's concerns make clear, disability has not yet escaped the shadow of deviance; the stigma attached to her disability is evident in the proposed and inappropriate matches presented to her. Her situation represents the intersections of two expanding if contradictory imaginaries – genetic testing to prevent the birth of babies with hereditary disorders and the growing movement for greater disability inclusion in Jewish life – that are increasingly intersecting in ways not anticipated when 'Dor Yeshorim' first emerged more than 40 years ago. As scholars dedicated to understanding the local implications of these

transforming technologies, we underscore the foundational yet too-often-silenced presence of disability that haunts these neo-eugenic projects. Genetic testing in the American Orthodox and other Jewish communities is accelerating at a dizzying pace, even as growing disability awareness is transforming the social landscape that shapes everyday decisions about marriage, reproduction and social acceptance of people with disabilities.

Conclusion

As we have demonstrated in this article, social circumstances, religious beliefs, cultural practices and national contexts all deeply influence the contemporary uptake and impact of Jewish genetic screening. In the American context, genetic testing based on racialized/ethno-religious differences is not controversial.

In contrast, in France, general prenatal screening is widely used, especially for Down syndrome and other trisomies. However, medical practices attached to ethnic/racial identities remain culturally taboo; for example, a French branch of the Israeli-based 'Institut Pouah-France' offers 'halachic' (Jewish religious law) supervision of fertility treatments for Orthodox Jews. The group has flourished in Israel but has had difficulty establishing itself in France due to national restrictions on the presence of religious personnel in laboratories, reinforcing strict adherence to 'laïcité' (secularism) (Benishay, 2019).⁶ Recently, public debates have erupted in France regarding the need to track dramatically disparate health outcomes by racialized/ethnic categories associated with postcolonial migrants. In this context, we note that Franco-African communities carry certain conditions such as sickle cell anaemia at elevated rates (Fassin, 2019; Simon, 2019). Whether this will reframe French attitudes and practices regarding genetic screening for them and other ethno/racial groups is an open question, especially given the increasing public presence of anti-Semitism, and French efforts to counter that by insisting on the integration of Jews into the French nation.

Reproductive imaginaries always bring the past into the present, yet they are also always about an anticipated yet unpredictable future. For example, Counsyl screening, introduced in the USA in 2007, is an inexpensive preconceptual test incorporating over 100 recognized genetic conditions including all known genetic variants for which Ashkenazi Jews are at heightened risk (Gregory, 2018). Will this easily available 'global' genetic preconceptual test render groups such as 'Dor Yeshorim' and JScreen obsolete? This is, of course, an empirical question about the future status of Jewish practices around genetic testing as well as reproductive imaginaries. If we were predictive social scientists rather than inductive fieldworkers, we would expect 'Dor Yeshorim' to persist because of the enduring importance of arranged marriages

and anonymity in the tightly knit Haredi communities that the group targets. JScreen, however, which offers screening at the individual level, may be challenged by the ever-increasing availability of secular inexpensive preconceptual testing such as Counsyl that includes Ashkenazi genetic variants among all the others. In the more distant if fast-approaching future, we anticipate that proposed biotechnologies for prenatal testing (e.g. whole exome analysis and CRISPR-cas9) that offer the promise of removing deleterious genetic traits may raise new ethical issues for religious communities and destabilize existing practices, or be incorporated in innovative and culturally meaningful ways. At the same time, as many Jewish disability activists remind us, using a famous section from Genesis 1:27, "'B'tzelem Elohim': we are all made in the image of God". This provides a theological basis for disability inclusion in Jewish life across many forms of practice. In short, these different attitudes towards human diversity (seen as imperfection by some) continue to be in tension now and for the foreseeable future. Many Jews continue to wrestle with contradictory attitudes espousing either removal of genetic anomalies through biotechnology, or acceptance of disability through inclusive community. Stay tuned.

Our focus here on Ashkenazi genetic testing in the USA, while interesting in its own right, also reveals that reproductive imaginaries have had radically different trajectories in particular national contexts. As we discussed above, such ethno/racialized targeted testing is not available in France, where the too-present history of World War II's genocidal eugenics continues to haunt everyday attitudes as well as state health policy. Despite universal claims, genetic screening, like all biomedical technologies, is inevitably localized in relation to community norms, aspirations and national agendas that together help us to understand the complex and heterodox reproductive imaginaries of contemporary life.

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⁶ We thank Séverine Mathieu for pointing us to the contradictions faced by the Pouah Institute in France. As a recent article explains, the Pouah Institute takes its name from the midwife who refused to comply with Pharaoh's order to throw all male Hebrew newborns into the Nile. This institute was created in 1990 by 'Rav' (Rabbi) Menahem Borstein. He mainly helps and advises couples who encounter fertility problems, and makes the connection between medicine and 'halacha' (Benishay, 2019).

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