4. PND in Israel: Public Health Services and Uptake in Cultural Context

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This chapter provides a backdrop for the analysis that follows by taking a broad look at public health genetics services for prenatal diagnosis (PND) in Israel as a network situated within relevant political, cultural and professional contexts, highlighting the social factors that make them possible, indeed desirable, and the dynamics that shape their design and prioritisation.

When PND becomes part of public health, although it is a very personal matter it also follows the logic of control and prevention that is characteristic of public health, which is not necessarily attentive to individual needs and preferences (Stewart et al. 2007; Khoury et al. 2000). Prenatal screening for Down syndrome (DS) provides a striking example of this. Prenatal screening for DS has been viewed for most of its history as a public health problem, with public (sometimes mandated) prenatal screening aimed at reducing DS incidence (Raffle 2001). As Bryant et al. (2008) show, only relatively recently have there been efforts to promote reproductive choice rather than test uptake as the preferred measure of public health DS screening success. While the public health goal is to reduce the prevalence of disease, genetic counselling of the parents of a foetus with DS should ideally be non-directive and conducted in a manner that respects the parents' norms and values. This conundrum of self-determination vs. social pressures is embedded in additional axes of influence, including inequality (of access and funding), healthcare professionals' interests, disability and patient advocacy, family relations and health governance, and so on.

In Israel, the confluence of these factors can be seen in the construction of the "Jewish gene pool" by health professionals as especially prone to inherited disorders (beyond DS), boosting "genetic anxiety" (or "responsibility", depending on one's perspective) and creating a collective sense of risk in which the uptake of PND is exceptionally high – at least among those Israelis who are

secular, have a higher income and fewer children, and are of Ashkenazi origin. Furthermore, previous studies of public outlooks on PND in Israel stressed that it is seen by many Israelis as a moral *duty* (Remennick 2006; Raz/Schicktanz 2009a,b). This perception of "collective responsibility" applies not only to doing PND but also to sharing genetic information with relatives. This is also indicated by Israel's Genetic Information Law (2000) which, quite uniquely compared to international regulation, enables healthcare providers to disclose actionable genetic results to family members where consent has not been given for their disclosure (Branum/Wolf 2015).

The chapter begins with an overview of public health services for PND in Israel. Notably, I am not addressing the topic of non-invasive prenatal testing (NIPT) itself as it receives detailed introduction and analysis in other chapters of the book. I am also avoiding the very intriguing topics of in vitro fertilisation (IVF) and prenatal genetic diagnosis (PGD). My focus is on PND that is squarely located as part of the pregnancy and that is furthermore related to genetic testing (therefore omitting the topic of prenatal ultrasound testing, for example). I focus on three contexts that highlight major aspects of the cultural embedding of genetically related PND in Israel: PND and "community genetics", illustrating the unique Israeli social mosaic of ethno-religious communities and their utilisation of PND; PND and the social construction of disability, for example in the context of prenatal screening for DS; and finally, the issue of public/economic pressures concerning PND and the so-called "genetic panel".

PND in Israel: An Overview

The *National Programme for the Detection and Prevention of Birth Defects* was established by the Israeli Ministry of Health (MoH) in 1980. It recommends the following tests, paid for under Israel's universal health insurance: First-trimester screening at 10–13 weeks of pregnancy includes ultrasound to determine nuchal translucency and a blood test for free beta-HCG and PAPP-A; second-trimester tests include maternal serum screening (the "triple test") at 16–18 weeks to identify the probability of DS and neural tube defects for all women. All women older than 35 years are recommended for amniocentesis (paid for by the state). Additional routinely offered prenatal tests include three ultrasound scans. If first- or second-trimester screening tests indicate a chance of more than 1:380 of having a child with DS, neural tube defect, chromosomal abnormality, or a molecularly defined genetic disease, invasive

diagnostic tests (chorionic villus sampling or amniocentesis) are offered free of charge. Invasive diagnostic testing is also provided by the state to women with a high chance of an affected foetus as determined in genetic counselling (for example due to family history). The Israeli Law of Abortion (1977) enables pregnancy termination on the basis of foetal abnormalities, with no legal guidelines concerning the severity of the condition or the probability of its expression (Amir/Binyamini 1992a, b). Up to 22 weeks of pregnancy, termination is allowed for relatively mild medical conditions, but after this period a designated committee approval is needed, based on the risk of severe disease and the predicted functional impairment in the foetus (Singer/Sagi-Dain 2020).

The *National Programme for the Detection and Prevention of Birth Defects* also covers adult carrier screening. This screening was originally recommended "pre-conceptionally" but in many cases the test is conducted on prospective parents during pregnancy and thus leads directly to PND. The screening is targeted to couples, usually with the woman tested first and if she is found to be a carrier, her partner is also tested (Zlotogora et al. 2015). The tests are performed either in medical genetic units or in community clinics, and patients with a positive result receive genetic counselling. More extensive prenatal genetic testing can be offered, with coverage shared between the individual and their supplementary health insurance – a point I return to in the section below on public/economic pressures concerning the "genetic panel" in PND. Today, the main diseases included in the national carrier screening programme are Tay-Sachs, CF, fragile X syndrome (FXS), familial dysautonomia and spinal muscular atrophy (SMA). Additional diseases are dynamically added to this panel based on criteria of severity, reliability and prevalence (Singer/Sagi-Dain 2020; Rosner/Rosner/Orr-Urtreger 2009).

PND and "Community Genetics"

The Department of Community Genetics in the Israeli Ministry of Health is responsible for a variety of public health genetics services including prenatal diagnosis. Importantly, the title of the major Israeli public health body overseeing genetics services is the Department of "Community Genetics". This is not a standard title. But what does "community genetics" mean in the Israeli context? This question provides a point of departure for the next section.

Israel has very high fertility rates: 3.1 children per woman on average, with even higher rates in the ultra-orthodox religious Jewish community (6.9), South Bedouins (5.7) and Muslim Arabs (3.37) (Singer/Sagi-Dain 2020). In conjunction with the high tendency for endogamy in various communities (25 per cent among the north Israeli Arab population, see Na'amnih et al. 2015), the result is increased prevalence of specific autosomal recessive genetic disorders in each of these communities. Since the establishment of the national carrier screening programme, its activities have gradually increased, in terms of both additional diseases and varied implementation within different communities. Some of these activities provide an alternative to PND while others lead directly to it. The ultra-orthodox Ashkenazi Jewish (Haredi) community (compromising about 12 per cent of the Israeli population), in which selective abortion is banned by many rabbis, has developed and is operating a special programme ("Dor Yeshorim"), which prevents the marriage of two carriers of recessive genetic diseases (Ekstein/Katzenstein 2001). The Israeli branch of the Haredi carrier screening and matching programme is organisationally and financially supported by the State of Israel and served by Israeli genetics labs (Broide et al. 1993). Among modern-religious Jews in Israel, where marriage is not pre-arranged as in the Haredi community, carrier testing by Dor Yeshorim often leads to PND or PGD (Frumkin et al. 2011). A national carrier screening programme for the prevention of β-thalassemia was implemented in Israel for the Arab-Israeli population and some Jewish communities in which the disease is relatively frequent. Since 2002, targeted carrier screening has also been offered free of charge to other, smaller ethnic communities in which well-established, severe genetic diseases are present at a frequency higher than 1/1000 live births, namely Arab, Druze and Bedouin populations who mostly live in villages and have a high rate of consanguinity. Multiple founder mutations have been documented by Israeli geneticists in these various ethnic populations, often down to the level of specific villages or tribes.

Being secular, having a higher income, fewer children, and being of Ashkenazi origin remain significant factors predicting the uptake of prenatal testing. Out of 377 Jewish Israeli women who were surveyed in hospital maternity departments in 2002 (Sher et al. 2003), 94 per cent of the secular women older than 35 years performed amniocentesis, in contrast to 36 per cent of the religious, and none of the ultra-orthodox (Haredi) women. Indeed, the "35 years" policy has led to a prevailing belief among many Israeli women that age is a sufficient risk factor in and of itself and that women over 35 must have amniocentesis, even with normal triple serum screening results

(Grinshpun-Cohen/Miron-Shatz/Ries-Levavi/Pras 2014; Grinshpun-Cohen/Miron-Shatz/Berkenstet/Pras 2015). This 94 per cent uptake is often cited as indicative of the widespread uptake of PND in Israel, but we should remember that this uptake differs significantly by religiosity and ethnicity. Israel is a land of contrasts, in this sense as well. On the one hand, a very high number of non-recommended/elective amniocenteses including CMA are performed by Israelis who are secular, have a higher income, fewer children, and are of Ashkenazi origin. On the other hand, Israelis who are very religious and have a lower income and more children are more likely to reject PND. Most babies with Down syndrome in Israel are born in religious communities, both Jewish and Muslim. In religious/traditional Jewish communities, 95 per cent of the pregnancies diagnosed with Down syndrome are born alive, compared to 25 per cent in largely secular communities (Zlotogora et al. 2007).

Previous studies have indicated that the Arab minority ethnic group, accounting for approximately 25 per cent of Israel's entire population, tends to underutilise genetic testing, even though the rates of birth defects are considerably higher in the Arab (and especially the Bedouin) population than in the Israeli Jewish community (Cohen-Kfir et al. 2020). Reasons for this underutilisation include religiosity (the Muslim ban on abortion) but also genetic illiteracy and lack of access to services. An ethnographic study of genetic testing in a Bedouin tribe conducted by the author (Raz 2005a) showed that Bedouin women were interested in using prenatal tests. They utilised prenatal ultrasound since it could be performed free of charge at local clinics in Bedouin towns, which many women can often visit on their own. However, in contrast to the high uptake of ultrasound, the uptake of amniocentesis was very low, often because the latter required the husband's approval and active participation. Bedouin men objected to prenatal genetic counselling that was critical of the high rates of consanguinity in the community, which most community members saw as normative and socially functional. They also objected to amniocentesis for various reasons including religiosity, genetic illiteracy, or cost (many of the women were younger than 35 so amniocentesis was not automatically covered). Some also perceived genetic counselling as curtailing their autonomy and representing a Jewish conspiracy to limit their reproduction (Raz 2005a; Lewando-Hundt 2001).

PND and the Construction of Disability

The majority of disability activists in Israel support the use of PND and carrier screening to prevent life with disability (Raz 2004). In contrast, in the USA and Europe, and especially in Germany, some in the disability community have voiced strong opposition to PND and carrier screening as sending a discriminatory message that "responsible parenting" means using prenatal tests to terminate an affected foetus (Parens/Asch 2000). Disability scholars around the Western, industrialised world have criticised genetic screening programmes, claiming that: (a) prenatal testing is morally problematic because it expresses negative or discriminatory attitudes about impairments and those who carry them; and (b) prenatal genetic counselling is driven by misinformation because it propagates misconceptions about disability and does not include information on community-based services for children with disabilities and their families as well as on financial assistance programmes and laws protecting the civil rights of persons with disabilities. Perhaps because of such criticism, disability advocacy organisations in the USA and Europe (including Germany) emphasise care and treatment over prevention, lobbying for additional research on treatments and newborn screening, rather than for PND or carrier screening. The latter are framed as individual choices.

Why has no public debate emerged in Israel concerning disability rights and prenatal testing, despite the wide usage of prenatal genetic diagnosis that often leads to selective termination of pregnancy? To answer this question, I conducted interviews with high-ranking officials of support groups "of" and "for" people with genetic conditions and physical disabilities in Israel (Raz 2004; 2005b). Only organisations involved with genetically based disabilities in which a genetic test for the condition was available were contacted. The common attitude that emerged from interviews with most respondents (14/17, 82 per cent) can be described as a two-fold view of disability: support for genetic testing during pregnancy, and support of the disabled person after birth. Support for prenatal diagnosis and selective abortion was also voiced by officials of organisations of disabled people with conditions that are not life-threatening and are characterised by a wide spectrum of clinical symptoms, from severe to mild. Genetic counselling and prenatal diagnosis were seen by these respondents as ways to reduce suffering. While some respondents were aware of the ethical problems inherent in the two-fold view of disability, they still argued for its consistency. On the one hand, for example, selective abortion following prenatal diagnosis of Down syndrome was for encouraged

because of the perceived severity of the condition. On the other hand, Israeli DS advocates insisted that DS is labelled a "syndrome" and not a "disease" in the context of supporting those already born with DS.

For many of the above-mentioned respondents, prenatal genetic testing was eugenic and was indeed supported precisely for that reason, since "eugenic" for them meant the improvement of the health of progeny and carried positive rather than negative connotations. The two-fold view of disability – based on the separation of prenatal (preventive testing) and post-natal (supporting disability) – cannot be logically rooted in Orthodox Judaism. The Jewish religion forbids selective abortion. Indeed, Orthodox Jewish women refrain from doing amniocentesis because of this religious restriction. The two-fold view is therefore a secular construction which is furthermore situated in legal, economic and cultural contexts. Rather than having a single, parsimonious cause, it is probably the result of a complex interplay of several inter-connected factors. First, legally speaking, it is enabled by the flexibility of the Israeli Law of Abortion, which does not define the degree of severity of the condition or the probability of its expression (Amir/Binyamini 1992a, 1992b). Second, the preference for preventive genetic testing should be considered against the backdrop of the economic and social hardships of raising a child with congenital disability in Israel. Although Israeli society has adopted a generous restorative approach towards disabled war veterans, this is not so in the case of individuals born with disabling genetic conditions, who – unless covered by other programmes – are provided only a minimum income. As Gal (2001: 239) claims, "despite the overtly inequitable nature of the system of benefits for disabled people in Israel, this issue has not achieved any significant visibility on the public agenda [. . .] The few calls for reforming this system and granting equal rights to all the disabled, regardless of cause of disability, have generally been limited to academic or professional circles." Third, the cultural construction of normality versus disability in Israel should be considered. Congenital disability has been stigmatised in Israeli society as part of the Zionist quest for "Jews with muscles" that will replace diasporic weakness with masculine vigour and militarism (Weiss 2002). Finally, many Israeli healthcare professionals advocate prenatal tests in a directive manner (Wertz 1998).

More is Better? Public/Economic Pressures in PND

In addition to the genetic tests for diseases that are included free of charge in the national carrier screening programme, there are many prenatal genetic tests that users may choose to pay for. About 10 years ago, before advanced DNA new generation sequencing became cost-efficient, Israeli users could choose how many genetic tests (for specific diseases) they wish to add to the so-called "panel" of prenatal genetic testing. Gaucher disease (GD) provides an intriguing example in this context.

In GD, deficiency of the enzyme glucocerebrosidase results in the accumulation of harmful quantities of certain fats, especially within the bone marrow, spleen and liver. Some individuals will develop few or no symptoms while others may have serious complications unless medically treated. Although GD is one of the most prevalent Ashkenazi Jewish genetic diseases, with a carrier frequency of 1 in 15 (Kannai/Chertok 2006), there are strong arguments against providing carrier screening for this disorder. Firstly, the most common GD mutation in Ashkenazi Jews leads to a highly variable but usually mild or symptomless phenotype. In addition, enzyme replacement pills allow patients to lead a near normal life, although treatment is life-long and very expensive. Annual costs can reach USD 400,000 per patient. As Borry et al. (2008) argue, it is ethically questionable to set out systematically to identify carrier couples and offer them prenatal diagnosis and the termination of pregnancy for a condition that will usually not be severe and is treatable. For these reasons, GD was not recommended to be included in the national screening programme by the Israeli Geneticists Association. However, individuals could still pay for it out-of-pocket.

Zuckerman et al. (2007) reported that 10 Israeli genetic centres screened an estimated 28,893 individuals for Gaucher disease between 1995 and 2003, identifying 82 carrier couples at risk for offspring affected by GD type 1. In subsequent pregnancies of these couples, there was a 76 per cent uptake of prenatal diagnosis, leading to a termination of pregnancy for 15 per cent (2 of 13) of the foetuses predicted to be no more than mildly affected and 67 per cent (2 of 3) of the foetuses with predicted moderate disease.

Indeed, when I interviewed the chairperson of The Israeli Association of Patients with Gaucher disease (Raz 2004: 1862), he was (in contrast to his colleagues) very critical of the way GD screening was being conducted at that time in Israel and explained it in terms of economic interests:

> Patients and their families should be given the knowledge that enables them to cope with the disease […]. Genetic counselling for Gaucher should provide, in addition to the genetic results, all the information concerning the medical treatment. Today, genetic counselling does not do that, and the result is unnecessary abortions […]. It's easy to sell the genetic test to people. If geneticists didn't do Gaucher, they would lose clients. This is purely business.

Prof. Ari Zimran, head of the Gaucher clinic in a major hospital in Jerusalem, commented in this context that:

> More than 80 per cent of the foetuses diagnosed with Gaucher will not develop any meaningful clinical symptoms […]. This screening is performed because of the money involved. Genetic institutes sell services, and the more they sell the better their financial situation is. The Gaucher test is not in the national Basket of Health Services so patients are paying for it, directly to the provider (cited in Traubman 2003).

The case of GD exposes the challenges of leaving PND in the hands of the free market. As Kannai and Chertok suggest in their review of GD screening in Israel (2006: 348): "Prenatal genetic testing for Gaucher may be a business tactic to attract clients". Individuals who are offered a panel of prenatal genetic tests will usually test for all the disorders in the panel. To summarise, screening for GD among Ashkenazi Jews in Israel was included in the providers' panel because it is one of the most prevalent recessive disorders in this community, for which testing is available, and test sensitivity is high. This may have occurred as a kind of "technological imperative", without careful consideration of the benefits and/or harms of this choice; it may have been assumed that screening for more disorders is always desirable – a variation, as Borry et al. (2008) suggest, on the theme of "bigger is better" or "can do, will do". As Zuckerman et al. (2007) suggest: "availability, rather than utility, of a test could be a major determinant of its introduction." In 2008 the Israeli Ministry of Health issued a formal instruction not to include un-recommended tests as part of the panel of genetic tests offered to consumers in genetic labs at Israeli hospitals.

In Lieu of Conclusion

This chapter has examined the design and uptake of public health genetics services for PND in Israel as embedding several cultural scripts (Bowker/ Star 1999). We have looked at different organisational settings and cultural factors involved in PND. The first example was the design of PND for ethnic and religious communities, both as a national strategy underlying the Programme for the Detection and Prevention of Birth Defects within the Department of Community Genetics, and its planned and unintentional adoption by these communities and members. The second context was the justification of PND that leads to selective abortion within the social construction of disability and "genetic responsibility" with the aim of reducing suffering. The third context was about public/economic pressures concerning the genetic panel in PND and carrier testing. These different contexts provide a collage of "Israeli PND", portraying different variations on the theme of self-determination vs. social pressures. Each context illustrates how this theme is further embedded in additional axes of influence, including inequality of access and funding (e.g. the case of PND within ethnic and religious communities, especially the Bedouin community), healthcare professionals' interests (the case of the expanding genetic panel in PND), and disability and patient advocacy (the case of the "two-fold view" of disability by advocates and the public in Israel). All these contexts portrayed something unique to the local ways in which the global technologies of PND are being implemented and used in Israel, adding an important social component to the technological imperative in health care (McCoyd 2010), suggesting that the technological imperative does not work alone. It is already entangled within social, economic and political "imperatives".

While realising the local adaptations of global health technologies is an important feat (and one that the study of NIPT will build on and expand in the later parts of this book), it should be accompanied by a critical look at the "deep structure" of health governance. The local adaptations of health technologies show us how institutional commitments are often reconciled with the more fundamental social and ethical questions and challenges inherent in PND. Targeting ethnic communities for genetic testing, or providing free-of-charge amniocentesis for women over 35, are technical health matters that also have profound normative premises and repercussions. In considering these arrangements we should ask not only how their instrumental rationality can be accounted for but also (to draw on Max Weber's classical distinction), what is the constructive rationality they embody.

This chapter has shown that Israel is both reckless and pioneering – depending on one's perspective (Raz 2019). There has been criticism of Israel for its recklessness and for not looking before leaping, for example in the context of its expanded prenatal panel of genetic tests (Borry et al. 2008). While this criticism is sometimes true, for some countries and in the context of other genetics services, Israel is leading the way. Some scholars have proposed that "Israeli PND" is by and large a product of its biopolitics of reproduction as survival in the face of demographic and militaristic threats (Prainsack 2006; Prainsack/Firestine 2006; Prainsack/Hashiloni-Dolev 2008; Prainsack/Siegal 2006). The analysis presented here usefully complicates this picture by showing how Israeli PND services have been shaped by the ongoing pragmatic concern of public health policymakers with religious and ethnic distinctions within Israeli society. The framing of "genetic risk and responsibility" is being constructed on several levels, not just in the context of the Jewish-Palestinian conflict but also in the context of prevention vs. care. It is by looking at the production of PND services within relevant political, economic and professional contexts that we can discern more fully the upstream factors that make these services possible, and the downstream dynamics that shape their uses and meanings and make them actionable.

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