Apnalaya Studies, Series – I

Disability and consanguineous marriages
Shivaji Nagar, Mumbai

Series (eds.): Arun Kumar and Annabel Mehta

APNALAYA

Building self-sustaining communities since 1973

About us

Apnalaya is an NGO founded in 1973. Our main goal is to empower underserved men and women to believe in themselves and in their abilities to change their lives for the better. At present we work in 31 clusters of M-East Ward of Mumbai.

We employ an integrated community development approach, which is informed by interconnectedness of basic issues, like Health, Education and Livelihood, especially in areas as marginalized and disenfranchised as those around Deonar dumping ground. We seek to achieve our goal through the empowerment of the people concerned.

Our Mission

Working with individuals, groups and communities, Apnalaya's aim is to empower the disadvantaged to overcome the many social, political and economic barriers they face, and to help them access opportunities that lead to a better quality of life.

Our Vision

To enable underserved people to improve health, livelihood and gender relations.

Registered under

The Societies Registration Act No.75/73 G.B.B.S.D. dated 28/02/1973
The Bombay Public Trust Act No.F-2830 dated 18/04/1973
The Foreign Contribution Regulation Act No. 083780332 dated 01.11.2016 TO 31.10.2021
Section 80G of the Income Tax Act No.DIT(E)MC/80G/1869/2008/2008-09

Foreword

I am proud and happy to present the second Apnalaya publication based on research carried out in Shivaji Nagar in Govandi, Mumbai. Our first publication in the series 'Life on the Margin' was called 'Charting Realities' and that is just what it did, revealing the stark facts regarding the living conditions of the 6,00,000 people for whom Shivaji Nagar is home.

This publication, 'Disability and Consanguineous Marriages', delves deep into the lives of just one small group of these residents, those struggling to cope with disability in one or more members of their family.

Apnalaya became involved with disability in Shivaji Nagar in 1998 when the Principal of a local Municipal School requested us to help the children with disabilities who were dropping out of school. We extended our fledgling sponsorship programme to cover 24 such children, and over the years the number steadily grew. Through our interaction with these families we became increasingly aware of the complete lack of public facilities available within a reasonable radius, in addition to the lack of understanding and care within family and community.

The programme has adopted a community based approach, whereby Apnalaya staff spread knowledge and awareness about disability, possible causes and available treatments, in order to dispel the myths and superstitions that abound. They are backed up by local volunteers who are trained to work towards this end, and to give support in their communities to families struggling to cope with the problem. Engaging with other NGOs and with Government to extend their programmes into Shivaji Nagar is a major element in the programme.

Since decision making rests largely with the male members of the family, and is subject to the influence of religious beliefs and traditional practices, the report highlights the need to focus on socio-cultural issues, including gender relations, in order to reduce the number of consanguineous marriages. We hope that the findings will go some way towards reducing the incidence of disability in the population at large.

Annabel Mehta

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I. Introduction

Seher wakes up at 6 am every morning and leaves her home to complete her first assigned task of the day. She carries two cans and walks for about a kilometre to buy water from the vendor who will exhaust his supply soon. At 13, her forehead is wrinkled with the familiar lines that harden with worries.

She waits in the queue that has formed, all the while thinking of the unpleasant conversation that took place at home last night, which has deeply disturbed her. Last evening her parents sprung upon her their decision to get Seher married. A proposal had been received and they had agreed to the match!

'And, of course, no one needs to ask Seher what she wants!' she mutters to herself.

'What about my dreams of becoming a teacher? And what about my brother? He is older than me, get him married first!' To her anguish her parents rebuked her for comparing herself to her brother, reiterating that he will be continuing his education and getting married when he starts earning. Further, her parents reminded her, were she like normal women her dreams could have been considered. She should be grateful that someone is willing to marry her at all.

Trying to swallow her anger, Seher filled the cans and paid the vendor. She looked at the brimming cans and took a deep breath.

Carrying water cans with a pronounced congenital limp is never easy.

Social discourses on Disability are often about turning physical inability into stigma, shame, lack, and/or ridicule which are then used as everyday 'tools' of power, of discrimination and deprivation. At Apnalaya we believe that it is the society, government and administration included, that turns physical inability into Disability. Perhaps nothing else compares to Disability when it comes to reducing our entire being to just the way our body is.

For the residents of Shivaji Nagar these mechanics of power play out every day. They reside in utmost poverty, labouring away in the dumping ground to earn a meagre living, exposing themselves to continual health risks, subjected to a disenfranchised life by the very forces and agencies that are duty bound to care and provide for them.

As noted above, invariably people with Disability are brought into focus by reducing them to mere bodies. The 'helpless' bodies are created and, thereafter, condemned to the margins of dignity and rights. Medicalization, or the processes which transform social problems into medical conditions to be diagnosed and treated, symbolizes strategies to preserve, manage, optimize, and normalize life in the form of bodies and populations. Thus through both the subjugation of bodies and the subjection of populations to regulation, medicalization produces the categories of 'normal' and 'abnormal,' able-bodied and disabled. These processes are structured by power and thus insinuate themselves into individual agency. Power, to be sure, qualifies, measures, appraises, and hierarchizes around a 'norm.' The normal and the abnormal are already embedded in a way that the normal is legible only in relation to the abnormal. Informed by this understanding, Apnalaya does not believe it is productive to medicalize Disability, which rather is a social construction.

Social construction theory has offered a strong critique of this paradigm that reduces an individual to a mere 'body' (Reddy 2011). This critique proposes that discrimination against impaired individuals is socially constituted from within established power-knowledge relations. The advocates of this argument focus on the social rather than physical barriers that disable individuals. To start with, Apnalaya's Disability program aims to prevent the incidence of Disability. Further, its aims extend to the identification and integration of individuals with Disability within the community. The former aspect demands well rounded care at the level of pregnancy, entailing regular ante-natal check-ups to improve the health and well-being of the mother and the baby. For the realization of the latter, more complex objective, Apnalaya adopts the model of social construction wherein the focus is to integrate individuals with Disability within the community as well as address their issues through a collective effort in collaboration with the community. The idea is to dismantle the social barriers that prevent individuals from living independently and with dignity.

It is estimated that over 15% of the global population has a Disability (World Health Organization 2011). According to the Census 2011, there are 26.8 million Persons with Disabilities in India, who constitute 2.21% of the total population. Out of the total population of Persons with Disabilities, about 15 million are male and 11.8 million are female. These include persons with visual, hearing, speech and loco-motor disabilities, mental illness, mental retardation, multiple disabilities and other disabilities.
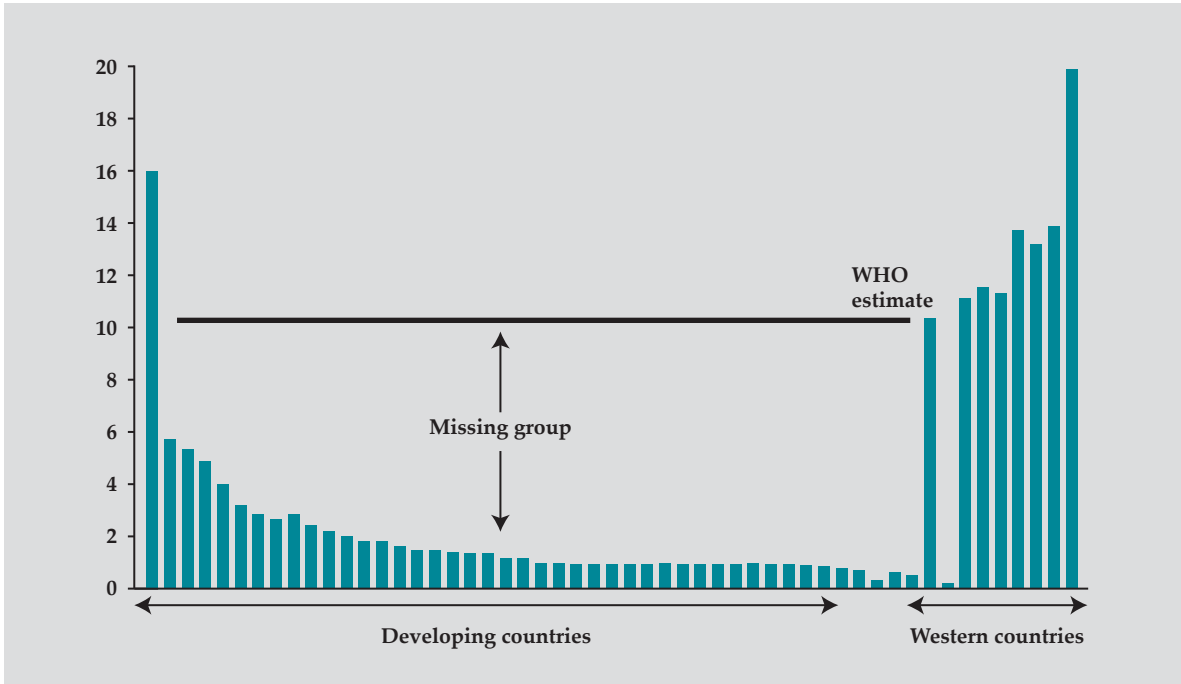
Figure 1: Missing group of persons with disability in developing countries (% of total population)

*Source- Bonnel 2004

The gap between the percentage of Disability quoted globally and that in India or other developing countries is huge. This has been attributed to the fact that Disability is narrowly defined in the developing countries, limited only to severe physical, sensory and mental impairments, which leads to a lower estimation of Disability rates, ranging from 0.3 to 3% (refer to figure 1). However, when the definition or concept of what constitutes a Disability is broadened, the rates turn out to be higher, as evident in developed countries (Bonnel 2004).

Even though linkages have been drawn between Disability and poverty, people with disabilities have often been excluded from the development agenda. Poverty is a cause as well as a consequence of Disability (Sonpal 2012), as it is said to increase the likelihood of Disability: chronically poor people are at risk of ill-health and injuries, which may be a cause of Disability (Groce et al 2011; Mitra et al 2013). Poverty is associated with malnutrition, inadequate access to public health services (e.g. immunisation), poor living conditions (e.g. lack of safe drinking water), and environmental exposures (e.g. unsafe work environments) which can lead to health conditions that result in Disability (Mitra et al 2013).

Shivaji Nagar, the site of this study, situated in M-East ward, is the perfect example of the kind of situation mentioned above that links the incidence of Disability to poor living conditions. M-East ward, with the lowest average age at death (proxy indicator for Life Expectancy) at 39 years, is ranked at the bottom of all the 24 wards in Mumbai (Mumbai Human Development Report 2009). The infant mortality rate in the ward is 66 (of 1000 live births) (Mumbai Human Development Report 2009) while

the national average is 38 (World Bank 2015). M-East ward with a population of 8,07,720 has only one government hospital (Praja 2016), while Shivaji Nagar, with a population of 6,00,000, has just one government dispensary and four health posts and no tertiary hospital (Apnalaya data).

Shivaji Nagar comprises of slum clusters marked by abysmal basic amenities. Located adjacent to one of the world's largest waste dumping sites and abattoirs, the slum clusters lack the most basic civic amenities in terms of proper drainage, potable water, public health facilities, government secondary schools and access to decent housing. The average household income in the area is INR 7,802 per month. One in two households with a family size of five subsists on a meagre income of up to INR 6,000 (Apnalaya 2017). Nearly half (44%, according to Apnalaya's growth monitoring data) of the children in Shivaji Nagar are underweight in comparison with the other Mumbai slums where it averages 36% (Maharashtra Human Development Report 2012). More than half of the children are stunted.

Of the multiple factors such as genetic factors, disease and illness during pregnancy that may be linked to disabilities, scholars have suggested a causal link between consanguineous marriages and disabilities in offspring. Marriage among blood relatives or within the kin group is not uncommon across societies the world over. Consanguineous marriages attract attention as a causative factor in the prevalence of genetic disorders. A considerable amount of literature demonstrates that early postnatal mortality is higher in the progeny of consanguineous marriages as a result of the expression of the deleterious recessive genes. While this study focuses on the link between consanguineous marriages and Disability, it does not claim that other factors such as those mentioned above do not contribute to the incidence of Disability.

Consanguineous marriages are prevalent in Shivaji Nagar. Bearing in mind the medically established link between consanguineous marriages and possibility of Disability, this research study focuses on identifying factors – social, economic and cultural – that contribute to the incidence of consanguineous marriages within the Shivaji Nagar community. This information is crucial for Apnalaya to inform awareness programs that highlight the relationship between the two.

Arun Kumar
Sonya Ochaney

II. Review of literature

A. Consanguineous marriages as a cause of Disability

This research study has a specific focus on consanguineous marriages as a cause of Disability and the factors that contribute to its prevalence. It is estimated that globally over 20% of the human population live in communities with a preference for consanguineous marriage, and over 8.5% of all children have consanguineous parents (Shawky et al 2013). Many anthropological studies suggest that a primary prohibition with respect to who can marry whom is the basis of any social formation. Marriage in which individuals share at least one common ancestor, is defined as consanguineous or endogamous marriage (Padmadas 2001), for instance, the marriage of a man with his father's sister's daughter or marriage with mother's brother's daughter, and uncle-niece marriages. Where they are prevalent, consanguineous marriages are usually between first and second cousins with a rate of 20-55% (Rabia 2005). Sustained genetic studies conducted globally on consanguineous relationships suggest there is an increased risk that they will both carry the same faulty gene variation. The offspring of consanguineous unions may be at increased risk of genetic disorders because of the expression of autosomal recessive gene mutations inherited from a common ancestor. In other words, the closer the biological relationship between the parents, the greater the probability that their offspring will inherit genes that could lead to disabilities (Shawky et al 2013). This causal link between consanguineous marriages and a predisposition to Disability has been established through various medical studies. If parents are unrelated, the risk of their having a child with a birth defect or Disability is between 2% and 3%. If parents are first cousins, the risk is a little higher at 5% to 6% (Centre for Genetics Education).

Parallel first cousin marriages are prevalent in Muslim societies, most commonly between the son and his father's brother's daughter. This type of marriage results in a coefficient of inbreeding in their children of 0.0625, that is, they are predicted to inherit identical gene copies from each parent at 6.2% of all gene loci, over and above the baseline of homozygosity in the general population (Bittles 1994). In India consanguineous marriages also exist in the form of cousin-cousin marriages or uncle-niece marriages, mostly among south Indians or among Dravidian descendants (Padmadas 2001). On an average 20-45% of marriages in the primarily Hindu states of South India are between close relatives, the most popular being those between uncle and niece (with a coefficient of inbreeding at 0.125), and cross first cousin marriages with mother's brother's daughter (Bittles et al 1991).

Several studies conducted in India have documented the incidence and impact of inbreeding on reproductive outcomes and genetic factors. However most of these studies were biological in nature. Nevertheless,
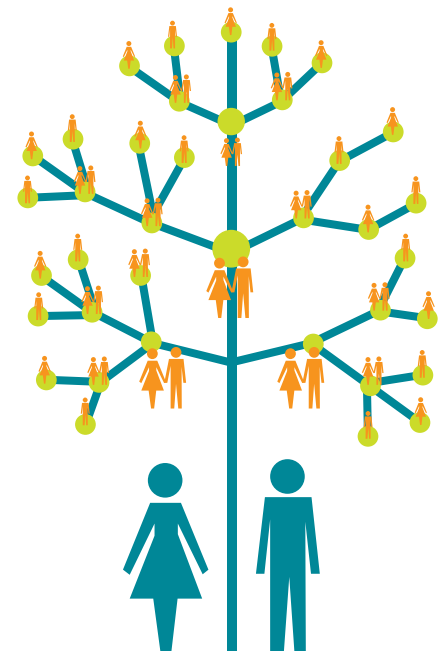
some of the researchers argued that demographic, socio-economic, cultural and environmental factors determined consanguinity and inbreeding (Padmadas 2001).

We used such research studies as the foundation of our own research. Our study examines in depth the reasons and attitudes surrounding consanguineous marriages and Disability in order to strengthen and localize our awareness programs. The study estimates the extent of the problem, on the basis of which specific community-based awareness programs will be initiated.

B. Social factors contributing to consanguineous marriages

The rate of consanguineous marriage in different countries depends on religion, ethnicity, socio-cultural factors, and isolation of populations (Abdulkareem and Seifeddin, 1998; Bener, Abdullah, & Murdoch 1993). Scholars who have reviewed work on the global prevalence of consanguineous marriages have argued that socio-economic and cultural factors need to be controlled in order to assess the effects of inbreeding (Bittles 1994, Padmadas 2001). Controlling for socio-economic factors, a prevalence of high rates of consanguineous marriages has been observed in poor communities in rural areas where levels of education are low (Rao et al 1977; Reddy 1988; Bittles 1990). Among landowning families, the preservation of estates and landholdings is probably the critical factor in choosing to marry close kin. Consanguineous marriages ensure property rights remain enclosed with the family instead of being distributed and dispersed outside (Khlat 1986). The maintenance of family property is a major consideration, with only token or significantly reduced dowry or bride-wealth payments required when marriages between close biological relatives are contracted (Barth 1954, Reddy 1988).

In most parts of India, the dowry system or bride price inevitably influences the timing of marriage, especially of females (Rao 1993; Bittles 1994; Bhat et al 1999). Parents are often under pressure to find a suitable husband for their marriageable daughters, allocating a major proportion of household assets and other landholdings as dowry. In such situations, the tendency to arrange marriage within the kin, especially among blood relatives, would not only be economically feasible but would also ensure more affinity among relatives, further easing other pre-nuptial negotiations and contracts (Reddy 1988). Furthermore, marriages among blood relatives are expected to render comparatively more freedom and status to the new bride, thus narrowing the possibility of conflict between the bride and her mother-in law (Bittles et al 1993).

Studies focusing on the social, economic and cultural causes for the prevalence of consanguineous marriages are few. This has compelled us to draw conclusions from the findings and base them, within a localized context, on the limited literature that is available.

III. Locale of the study

Figure 2: M-East ward - Location
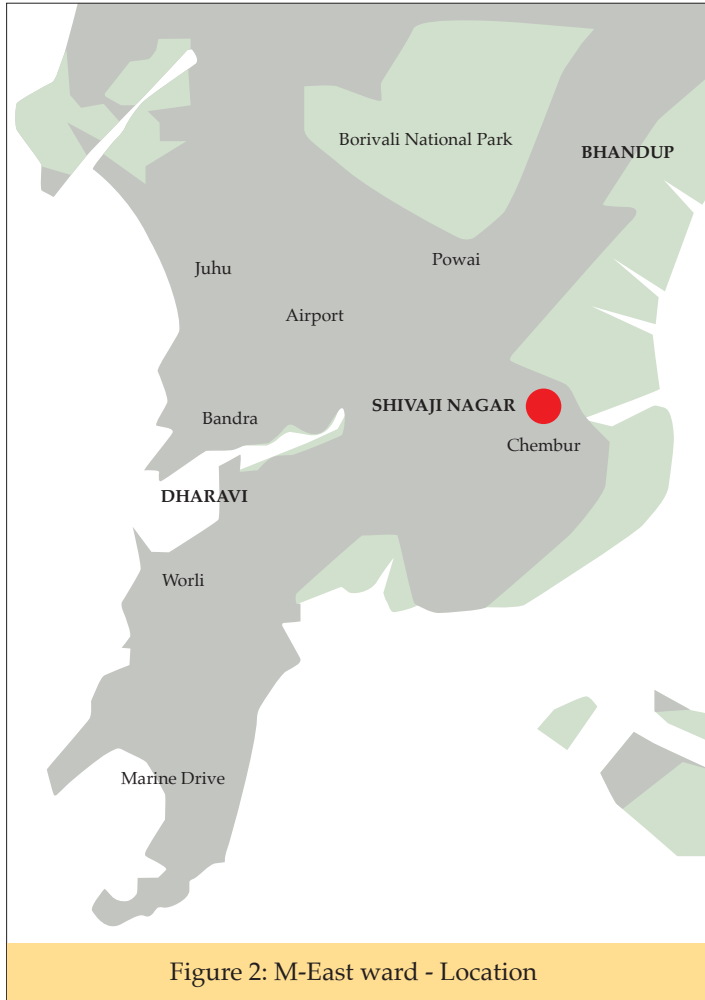
Since the 1960s, M-East ward has been home to migrant populations that immigrate to the city from different parts of India, as well as those that have been resettled from slums in the city's centre (TISS 2015). The ward has the lowest human development index in Mumbai (24th out of 24 wards in Human Development Indices) (MCGM 2010), emphasising the acuteness and multiplicity of problems in the region that have amassed as a result of years of neglect and deprivation. The average age at death here is 39 years. The infant mortality rate is 66 (of 1,000 live births) while the national average is 41. Shivaji Nagar was one of the first settlements of M-East ward, adjacent to one of Asia's largest waste dump and India's largest abattoir. The city's municipal corporation, under the Site and Services resettlement scheme of the Slum Act, developed the neighbourhood for slum communities that had been displaced from other areas of the city. Under this scheme, relocated households were allotted 10'x15' plots for self-development (TISS 2015).

Although slums in M-East ward share some common hardships, Shivaji Nagar has its unique set of problems amidst changing population dynamics, environmental vulnerabilities, legal status, industrial proliferation, security of housing, availability of infrastructure, accessibility to education and health services and urban developmental plans.

Figure 3: Shivaji Nagar in a glimpse

The abattoir and dumping ground provide a means of informal livelihood for a large number of individuals in the region. Contractual and temporary casual labour in the industries in adjoining areas is another major source of employment. The area is diverse and includes migrant communities from Maharashtra, Uttar Pradesh, Bihar, Bengal and Gujarat. However, the proportion of Muslims is significantly high in the region.

Both the physical and the population densities of the area are very high. Life in Shivaji Nagar is extremely challenging owing to numerous factors, poverty and unemployment being the chief ones. Its identity is unique and its spatiality is the product of several socio-economic factors which have been governing it. The vulnerable groups - women, children, the elderly and people with Disability - are prone to additional health hazards and socio-economic marginalization.

For this study the target population consisted of couples who have had consanguineous marriages and are associated with the Disability program of Apnalaya. This population was chosen since the objective of the study was primarily to identify factors -- social, cultural, religious and economic - that contribute to the prevalence of consanguineous marriages in the community.

IV. Research methodology

An empirical-analytical approach was used to determine the underlying factors for consanguineous marriages in Shivaji Nagar. An interpretative methodology informed this study. Mixed methods were used for collection of data and analysis.

85 children of the total 580, registered with our Disability program are born out of consanguineous marriages. Since some have more than one affected child there were 75 rather than 85 couples. Out of these 75 couples, we aimed to reach out to 30 couples, and could cover 29 couples plus two women. A survey was conducted with this group (questionnaire attached in Annexure), which represents 40% of the program people with Apnalaya. The tool was based upon two focus group discussions conducted with a group of males and females separately. This discussion helped us gain insight into the social, economic and cultural factors which needed to be probed in the survey.

In an attempt to record, analyse and uncover the significance of human behaviour and experience, including contradictory beliefs driven by religion and culture, and emotions associated with close kin marriages, a qualitative method of collecting information was adopted. An in-depth, structured interview with a selected sample group of five couples was conducted with male and female separately to gather contextual evidence. A bottom-up approach was adopted for qualitative research. The data collected helped in deducing a theory elucidating a pattern of meaning. Of necessity the methods used on this relatively small population were more open-ended, less narrow and more exploratory.

A focus group discussion was also conducted with a group of adolescents aged from 15 to 19 with some form of Disability in order to interact with the youth and explore their experiences within the family, school and surroundings. A further aim was to give us an insight into the perceptions that other people have regarding disabilities.

The sampling method was purposive for all the methods of data collection.

V. Socio-economic profile of the study population

In total, 60 participants were chosen for the interviews that contained a combination of quantitative and qualitative information. Of these 60, in-depth interviews, which were mainly qualitative in nature, were conducted with 10 participants in an attempt to explore in detail the factors which determine the occurrence of consanguineous marriages.

A. Age composition

The study population comprised of 31 (51.7%) females and 29 (48.3 %) males. The average age of the women interviewed was 36.7 years and of the males 40.7 years.

B. Family size and income

The average family size of the sample population was 6.6. Average family income of the households interviewed was INR 7,650.

C. Age at marriage

The mean age at marriage for the women in the sample population was 17.03 years. 35.4% of the women were married before or at the age of 16 years, and 77.4% before the age of 18 years. The mean age at marriage for men in the sample population was 21.1 years. 48.3% of the men were married before the legal age of 21 years.

D. Education levels

42.4% of the sample population fall in the bracket of 5th to 8th standard level of education, while 27.1% is illiterate. 50% of the males interviewed are within the 5th to 8th standard bracket and 35.5% of the women fall into the same bracket. 17.8% of the males are illiterate whereas 35.5% of the women interviewed are illiterate.

E. Religion

95% of those interviewed belong to the Muslim community, which is similar to the trends observed in Shivaji Nagar at large where majority of the population i.e. 82% belong to the Muslim community. Of the total Disability cases registered with Apnalaya, 83% are Muslim and the balance 17% Hindu.

F. Migration

86% of the sample population are migrants from other parts of India, of whom 82.7% migrated from Northern India, including Uttar Pradesh and Bihar. The study population comes predominantly from a rural background.

As per the Human Development Report (2009), previously Mumbai witnessed migration mainly from Gujarat, Uttar Pradesh and Karnataka. This trend has changed over the years with Uttar Pradesh and Bihar forming a larger percentage (28% cumulatively) of the migrants, many of whom settled in Shivaji Nagar as a result of the 'pull factors' of the city.

G. Children with Disability

Of the 30 families interviewed, six i.e. 20% have two children with disabilities.

Figure 4: Percentage distribution according to type of disability in children
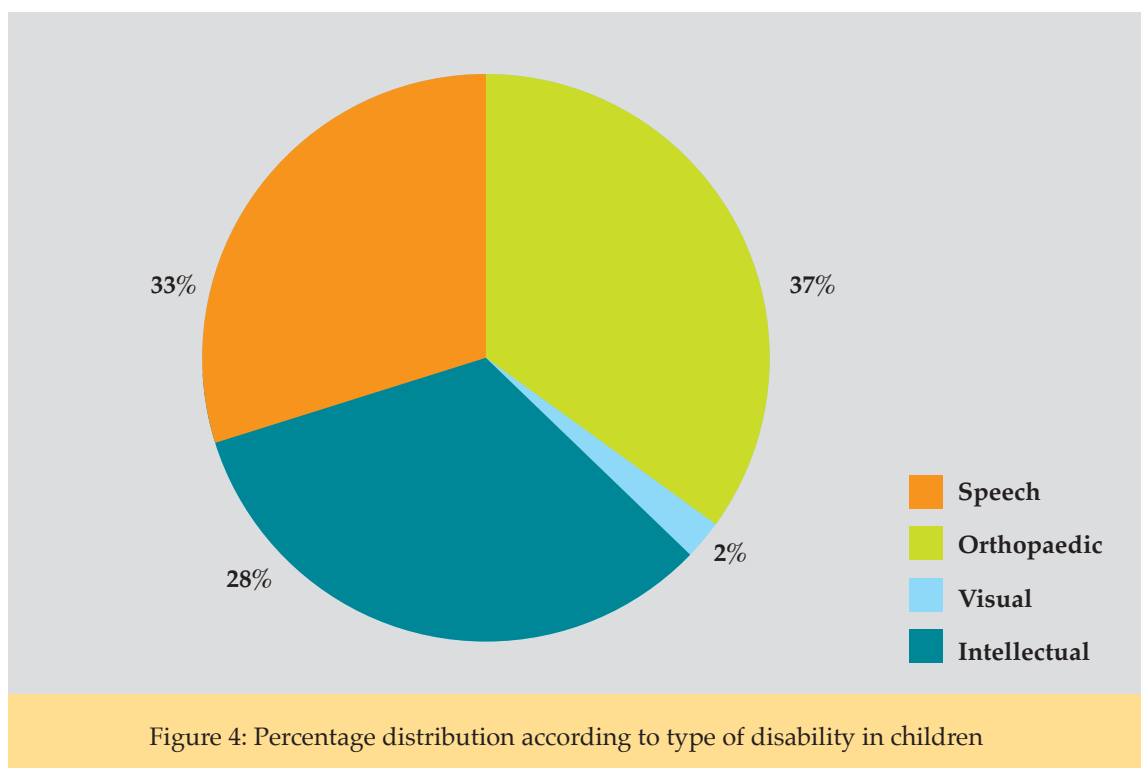
Orthopaedic disabilities at 37% were the most prevalent, followed by Speech Impairment at 33%, with Visual Impairment afflicting only 2% of the children of the sample population under consideration.

Table 1. Comparison of important variables between study population and population at large of Shivaji Nagar (Apnalaya 2017)		
Indicators	**Sample population**	**Shivaji Nagar**
Average family size	**6.58**	**5.01**
Average income (INR)	**7,650**	**7,802**
Mean age at marriage (in years) — Female	17.03	18.0
Mean age at marriage (in years) — Male	21.1	21.0
Literate population — Female	64.5%	69.1%
Literate population — Male	82.7%	76.9%

This table draws a comparison between various important indices between the study population and the population of Shivaji Nagar at large. Stark differences are visible in the average family size, which stands at 6.58 for the sample. This is higher than the rest of the population whose average stands at 5.01.

The average family income of families interviewed is INR 7,650, which is less than the average income of the rest of Shivaji Nagar at INR 7,802. Sustaining large families on low average monthly incomes coupled with expenses related to disability further add to the economic woes of the families.

Disabled and invisibalized

Systemic, recurrent, undercounting disables the people on the margin. Not recognising population living on an unauthorized landmass and not issuing them voter's identity card, for instance, disenfranchises people already enduring severe deprivation. Likewise, undercounting people with Disability prevents them from accessing whatever government facilities may exist.

According to the WHO 's estimate, about 15% of the global population has some form of Disability. In contrast, throughout the developing world this percentage is surprisingly low. India in general and M-East ward, Mumbai, in particular, is no exception.

Disability in India, Maharashtra, Mumbai and M-East Ward

- Total persons with Disabilities: 2.68 crore (26.8 million) (2%)

- Maharashtra: 29.6 lakh (2.96 million) (3%)

- Mumbai: 5 lakh (0.5 million) (4%)

- Persons with Disabilities in Mumbai slums: 3 lakh (0.3 million) (5.6%)

In response to an RTI filed withthe Department of Health, M Ward, in October 2016 regarding the number of people with Disability, the number provided was a shocker. With a Disability rate of 5.6% in Mumbai slums (Padhyeguriar 2011) for the total population of 8.09 lakhs in M-East ward, the estimated number should be around 31,000. The Department of Health, however, claims that there are merely 1,596 people with Disability!

VI. Findings and analysis

Given that the context of the demographic profile of the study population has been set, the next section highlights in detail the factors impacting and contributing to consanguineous marriages within the study location.

A. Types of consanguineous marriages

Figure 5: Percentage distribution according to types of consanguineous marriages
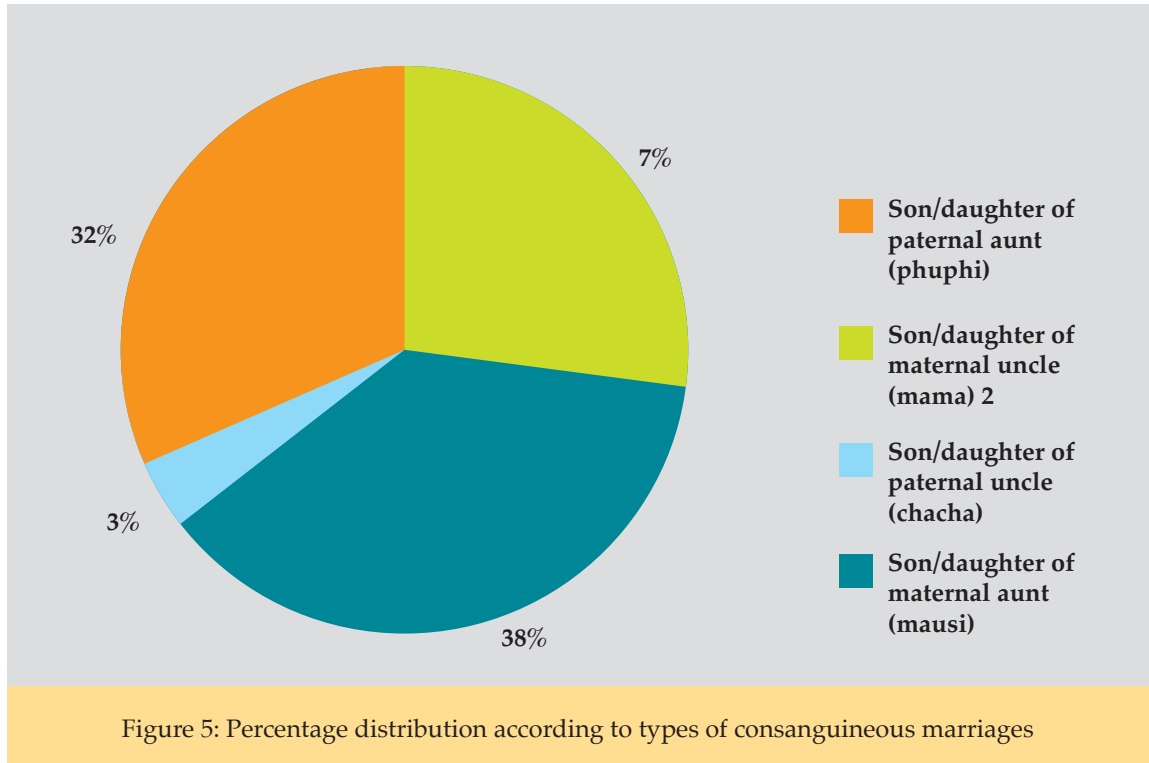
Three kinds of marriages are termed as consanguineous marriages - marriages between cross cousins, between parallel cousins, and uncle-niece marriages. The third kind of marriage is prevalent among some Hindu communities especially in South India (Padmadas 1991). Cross-cousin marriages are those that take place between the children of siblings of the opposite sex. Parallel cousin marriages are those that take place between the children of siblings of the same sex (V. Subramnayam 1999). As stated by V. Subramnayam (1999), among Indian Muslims the incidence of parallel cousin marriages is reported to be less in number. Within the sample population cross-cousin marriages are 58.3%, including marriage with children of maternal uncle and paternal aunt, while parallel cousin marriages are 41.7% including marriage with the children of paternal uncle and maternal aunt.

> *'As long as two children have not been breastfed by the same women, they can get married to each other' - A female respondent*

B. Decisions makers in consanguineous marriages

Figure 6: Percentage distribution of decision makers regarding marital partners
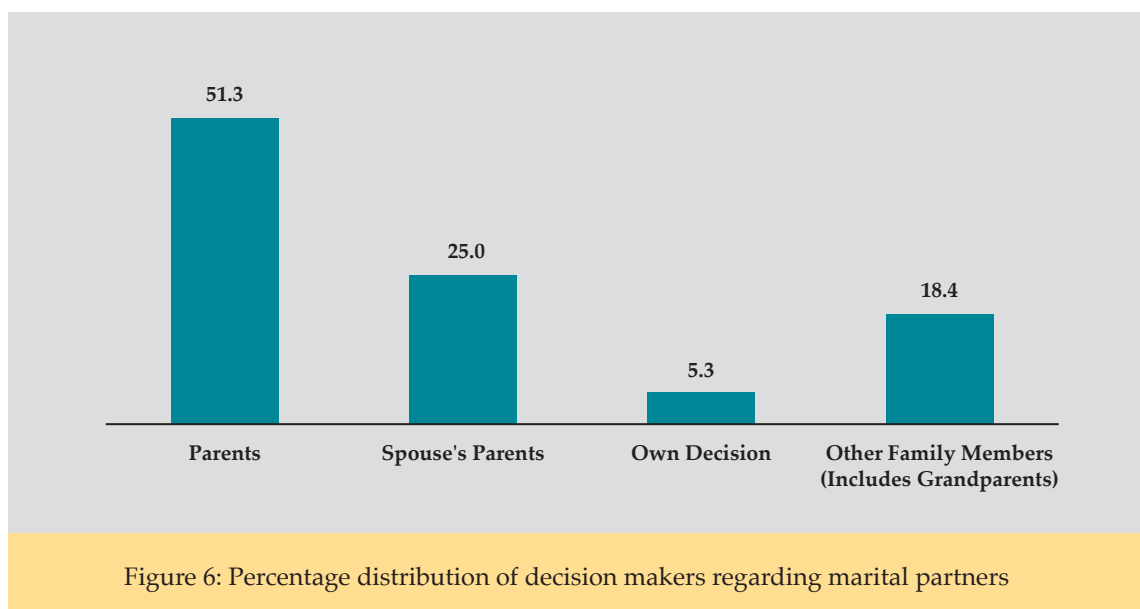
Nearly all the marriages, 95%, were decided by the parents (76.3%) or other family members (18.5%). Though a small proportion, 5%, of the respondents took independent decisions for their own marriage. The early initiation of marriage among consanguineous groups, with mean age at marriage of females being 17.03 years (refer to page 11), could be ascribed to the fact that marital partners could be more easily identified and accessed within kinship than elsewhere (Padmadas 2001). In the in-depth interviews, some respondents recounted that their marriages had been decided when they were very young. One of them said that when she was barely four months old her spouse's father made her father promise her hand in marriage to his son. And they were married when she came of age despite the fact that her father in law, who had promised the alliance, had passed away.

In the in-depth interviews all the respondents, except two, said that their opinion was not asked, and they were informed that they were to be married to a person chosen by their parents. This is not to say that they were all unhappy with the situation, many agreeing to the arrangement rather than upset or disappoint their parents.

'Parents did not ask for my opinion when they decided who I should marry, but they are our elders and they know what's best for us so we cannot disobey them' – A male respondent
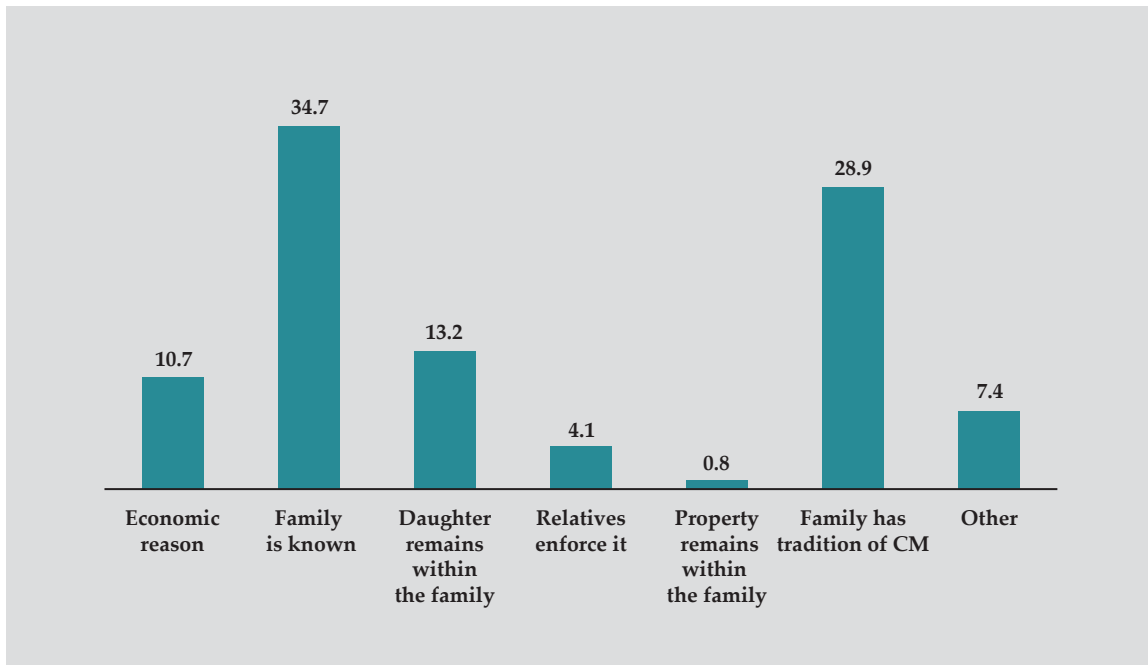
C. Reasons for consanguineous marriages

Figure 7: Percentage distribution of reasons for consanguineous marriages

A number of reasons came to light when we explored the factors that are prevalent for consanguineous marriages. One reason that resonated among majority respondents, 34.7%, was that known families provide the security of familiarity. Perhaps of greatest importance is the underlying conviction that by marrying within the extended family, hidden uncertainties regarding health or other unfavourable family characteristics will not arise (Bittles et al 1991). The fact that the family was known and there was already an established relationship made many respondents feel comfortable, as compared to the uncertainty they would face in new families. This was shared by the respondents during the in-depth interviews.

When women were probed for their reasons for a consanguineous marriage, the responses were largely that the daughter remains within the same family. When asked whether women gain any advantage from consanguineous marriages, female respondents felt that they face fewer conflicts at home. Moreover, when conflicts did arise they were easily resolved, since they were part of the same family. Researchers, Dyson and Moore (1983) as well as Bittles et al (1994) have mentioned that relationships within consanguineous marriages are believed to be relatively conflict-free thereby elevating the status of women. In contrast to this finding, female respondents in the focus group discussion shared that there are times when they feel doubly burdened as a consequence of consanguineous marriage, since they are unable to argue during conflicts. They feel that marriage outside the family gives women the liberty to express themselves in case of dissent.

It is important to note that there are gendered differences in the explanations underlying the reasons for consanguineous marriages. Some males expressed the belief that a girl from within the family would respect and take care of his parents, whereas someone from outside would not be as easy to deal with in terms of conflicts and demanding certain rights. Further, they were of the opinion that their spouses, being accustomed to the family and its ways, would adjust easily thus reducing the possibility of conflict. This reflects the kind of expectations that men have from the women they marry.

A secondary reason highlighted was the predisposition within the family for consanguineous marriages. Respondents attributed its prevalence to tradition. Their families have a history of consanguineous marriages, and they believed that they were continuing the tradition and did not choose to question it.

Economic reasons were also cited in many instances, 10.7%, as the factor that leads to consanguineous marriages. Meher and dowry is what is under consideration in economic reasons. As researcher Vijayendra Rao (1993) has noted, not only have dowries increased but in communities in which traditionally bride prices have been paid, there has been a switch to paying dowries. Parents living in poverty are under a lot of pressure to find a suitable groom who will not demand large sums of dowry. Thus, searching for a suitable spouse within the family is a better option as they are aware of the financial conditions.

Although, some of the respondents from the focus group discussions said that it did not make much difference economically whether marriage was within or outside the family as even within the family dowry is demanded.

That property will be retained within the family is a factor that has been mentioned in a number of research studies; but it is not relevant to this sample population as they belong largely to the lowest socio-economic groups, and therefore inheritance of land or any other immovable property is rarely a consideration.
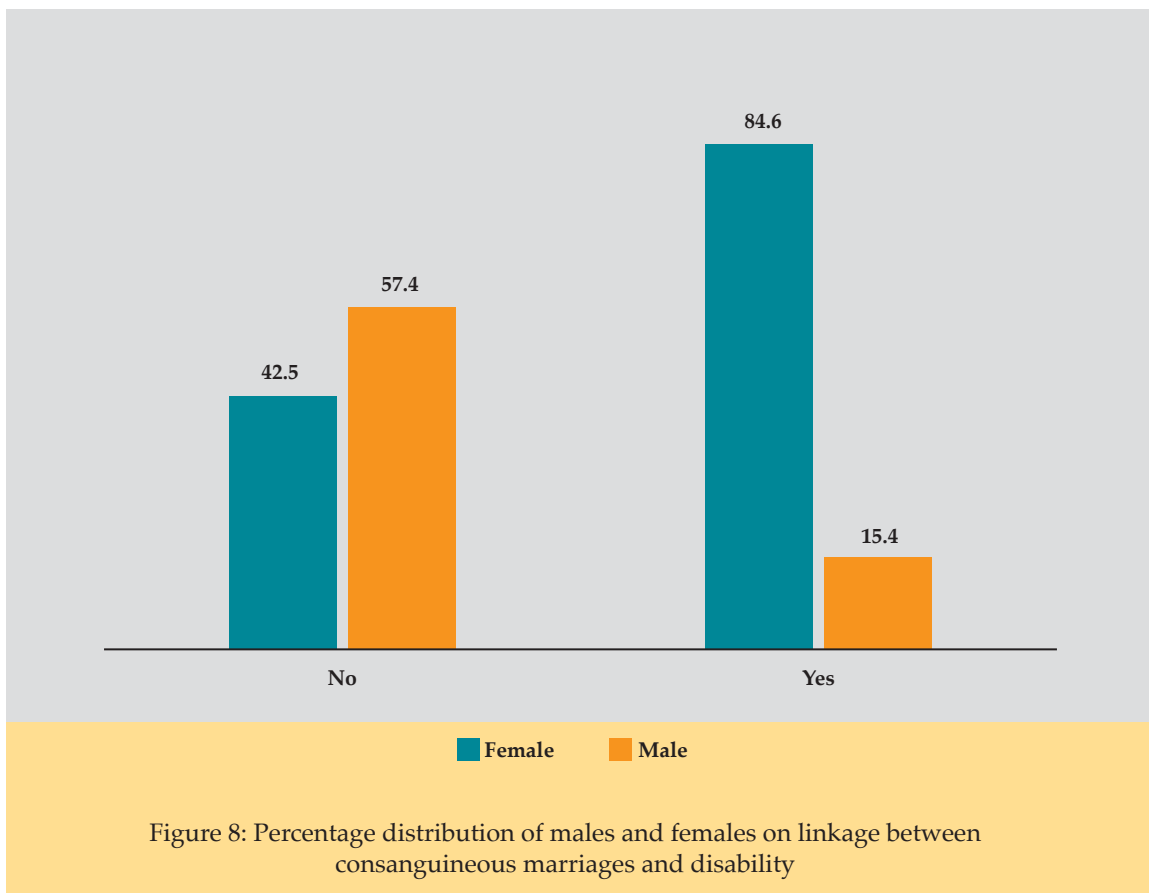
The other reasons included less conflicts within the family and an exchange of sons and daughters between two families.

When asked to establish the relationship between sanction by Islam and prevalence of consanguineous marriages, nine out of ten people said they would not have had this type of marriage if there was no sanction. Upon probing the source of their information, many of them shared that they had not read it anywhere but had heard it from the clerics. The clerics or maulanas, it was recounted, ask to search for a suitable bride or groom within the family, before seeking a match outside.

There were a few individuals who dissented from this opinion. According to them religious sanction had nothing to do with it, and they had a consanguineous marriage since it was a family tradition.

D. Consanguineous marriages and the likelihood of Disability

Figure 8: Percentage distribution of males and females on linkage between consanguineous marriages and disability

When asked whether consanguineous marriages are a contributing factor in Disability among children, 78.3% (48) respondents of the sample population said that there are no linkages between the two.

Of the 21.7% (13) respondents who answered that there may be a link, the majority (84.6%) are women, compared to only 15.4% males. It is important to note that even after experiencing Disability personally, a large population of males is not willing to accept or admit to the possibility of a link.

Majority of the respondents not willing to support consanguineous marriages for their children are women (77.4%). This could be attributed to the fact that women are the primary care-givers, and the burden of work increases if a child is suffering from a Disability, also coupled with reasons such as inability to voice their opinions which have been established earlier. The in-depth interview probed the care-giving activities performed by the parents for the disabled child. The responses elucidated by the sample gave a clear indication that the mothers spend a larger amount of time with the child in different capacities. They are the ones tending to their daily needs, hence are well versed with the child's needs as well as likes and dislikes. They also take the child to school. Apart from taking the child to doctors, the father is almost absent, as he is the primary bread-winner. The time spent in taking care of the child, the increase in the burden of work and in dealing with the difficulties at close quarters, as well as the possibility of losing out on opportunities to work and be economically independent - these factors could be said to influence the women's refusal to support consanguineous marriages for their children. This conclusion though is not free from assumptions about the degree and type of Disability that the child has, which is not in the scope of this study.

The respondents who admitted to the possibility of a link realized it only after their child was born with a Disability. All these respondents said that the doctors apprised them only when they visited various hospitals to seek treatment for their children.

'The doctor told us that our child may be disabled due to a consanguineous marriage, but I do not believe him. I take my child to him for treatment because he is educated, but I do not agree with him on the link between these two' – A male respondent

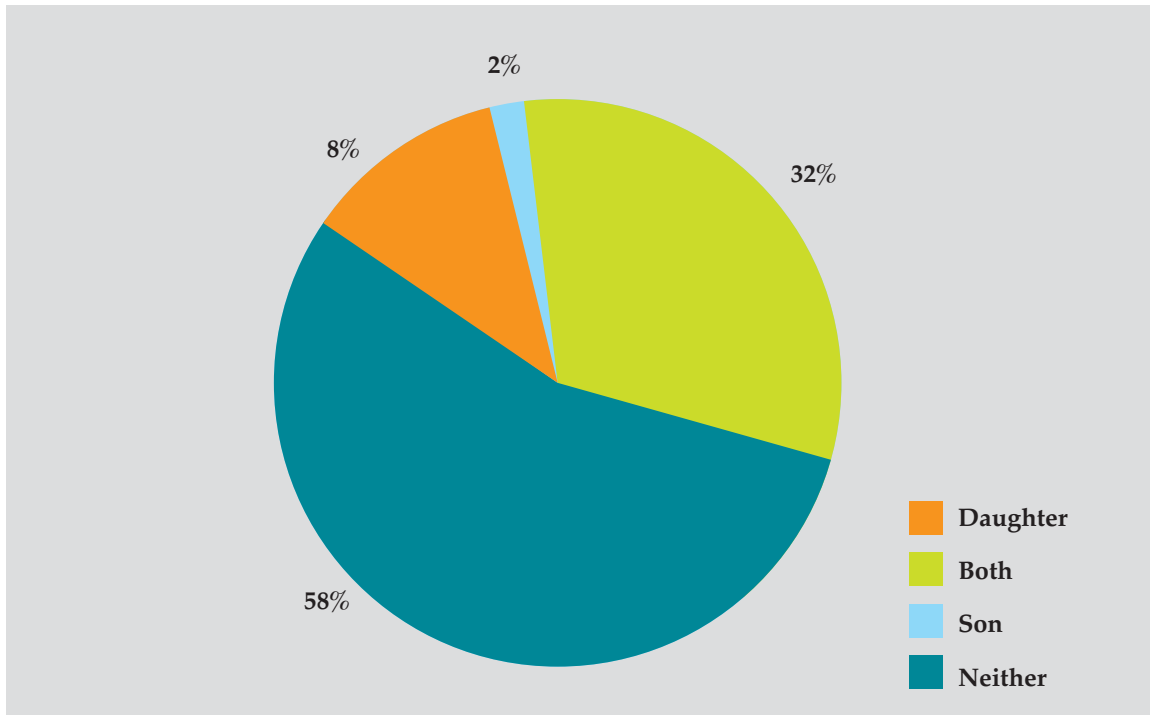# E. Support for consanguineous marriages

Figure 9: Support for consanguineous marriages

More than half (58%) of the sample population responded that they will not support consanguineous marriages for their children, whereas 32% were willing to support it for both, sons and daughters.
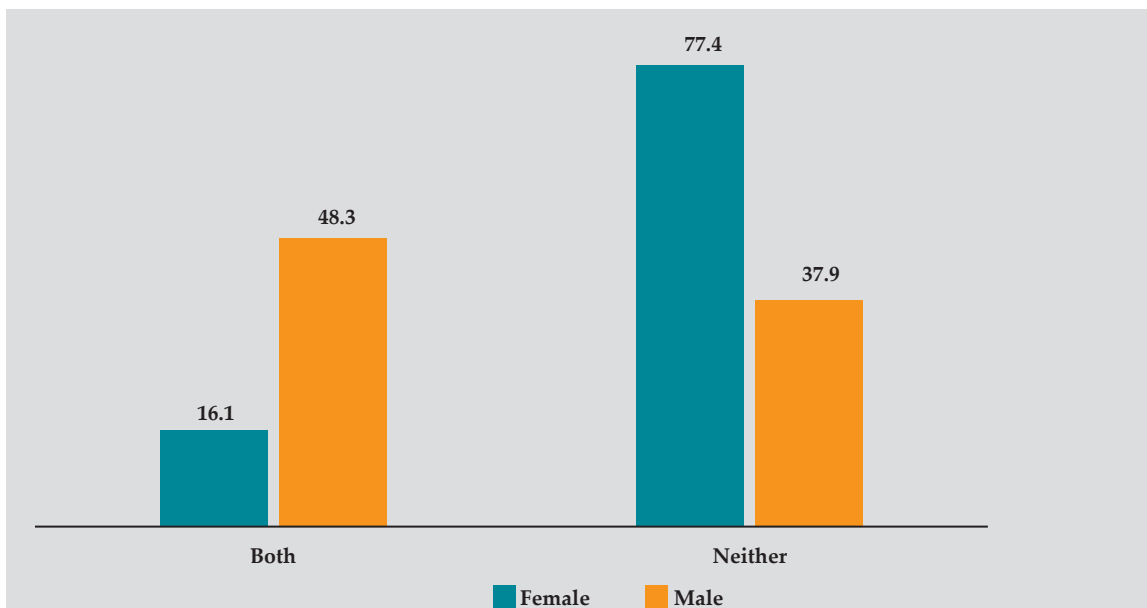

Figure 10: Sex-wise percentage distribution of support for consanguineous marriages

Of the respondents, 77.4% females did not support consanguineous marriage for their sons and daughters against 37.9% males. While 16.1% females and 48.3% males support consanguineous marriage for their sons and daughters.

For the respondents who are willing to continue to support consanguineous marriages, the rationale is the same as the reasons that were highlighted earlier, such as familiarity with the family and less chances of conflict within the family.

'After listening to what the doctor said about consanguineous marriages as a possible cause of Disability, I do not want to support it for my children. But does my opinion matter? My husband tells me to stay out of these decisions and let him handle them' – A female respondent

F. Difference in experiences of disabled girls and boys

To have a Disability is not only a physical or mental condition; it is also a social and stigmatized one (Goffman 1963). This became abundantly clear in the focus group interaction with adolescents who were disabled. Almost all the children we interacted with had faced experiences of stigmatization and bullying within school and/or the neighbourhood. Some of the children recounted instances of stigmatization even within the family.

The experiences of women with disabilities differ from those of men with disabilities.

The boys in the group were all confident and pursuing higher education. They had given a thought to and shared their future plans with their parents, and were receiving complete support from their families.

The girls on the other hand seemed to lack confidence. They had given some thought to their future plans, but were unsure of support from their family. All girls shared with us that they had been discriminated against within their family spheres. When one of them failed in her 10th grade, her extended family discouraged her from studying, saying that as she is disabled she will not be able to achieve anything. However, she fought against her family and joined a nursing course, which she is currently pursuing. Another respondent also narrated instances of her mother discouraging her.

When asked about their marriages, all the girls had experienced talk of marriage, even one girl of 14 years. It is important to note that all the girls had received proposals, more importantly, from within the family. The marriage of one of the girls was already arranged to a member of her family.

During the research, when the respondents were asked who, according to them, will face greater difficulty finding a suitable match, 89.3% of the males as compared to 39.3% of the females said disabled

girls will face more difficulty. The social stigma associated with disabled girls drives families to pressurise them into consanguineous marriages as the negotiations are easier. Sadly, this in turn contributes to the cycle of deleterious effects of continued inbreeding.

Overall, the boys and girls faced somewhat similar issues; but the girls' experiences of discrimination were exacerbated by the lack of support from home and the pressure for marriage from an early age.

'My mother received a proposal for me from a family member who was also demanding dowry. She refused it saying that she isn't prepared to spend so much money on a disabled girl and would rather spend it on her sons' – A girl with Disability

VII. Conclusion

This study was undertaken to identify the social, cultural and economic causal factors for the prevalence of consanguineous marriages in our area. An analysis of these factors will inform the development of awareness programs highlighting the possible linkage between consanguineous marriages and Disability in the offspring. Through the dissemination of information we aim to reduce the incidence of consanguineous marriages thereby reducing the incidence of disabilities.

The one theme that stands out in the study and runs throughout is the gender aspect. There are notable differences of opinion among men and women in all the components.

- The underlying rationale for the stated reasons behind consanguineous marriages are coloured with gender bias

- A large proportion of men do not accept the possibility of a linkage between consanguineous marriages and Disability

- A large proportion of men are willing to get their children married in consanguineous relationships.

- The majority of the male respondents also feel it is more difficult to arrange the marriage of a disabled girl, thereby demonstrating increased stigmatization of the disabled girl.

These findings point to the gendered nature of the understanding within the community, and this must be borne in mind while designing awareness programs.

An additional reason to target males in the campaign is that the decision making powers in the family lie almost exclusively in their hands. Some women who did not support consanguineous marriages said that their opinion was of little consequence since the husbands are the decision makers.

Another conclusion that can be drawn from this study, and one that has been mirrored in other research, is that cultural, traditional and religious values rule marriage decisions, especially consanguineous ones, which eventually influence reproductive outcome (Padmadas 1999).

There is an urgent need to target youth in order to make them understand the possible harmful effects of inbreeding on future generations. Dissemination of this kind of information at the right age can have positive effects on the decisions regarding marriage and reproductive choices made by the family.

Consanguineous marriages, as seen and discussed in great detail, is a deeply rooted social trend amongst a proportion of people residing in communities. Such marriages are customary due to an interplay of several factors – religion, culture and socio-economic backgrounds. Questions about

consanguineous marriages are raised in health-care settings by health professionals, apart from this, no efforts have been made to prevent the possibility of an offspring with Disability. Counselling, as another preventive measure, is also yet to be introduced for greater awareness and impact.

A scaled-up awareness program seems imperative here. There is a capacity to provide health education regarding consanguineous marriages at individual, family and community level, delivered by public frontline health care personnel along with premarital and preconception genetic counselling. Ensuring access of the community to such programs seems to be an effective method for preventing consanguineous marriages in collaboration with the government.

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IX. Annexure

The annexure contains the guidelines employed for the Focus Group Discussion, Survey questionnaire and In-depth interviews.

A. Focus Group Discussion with consanguineous married couples with children with Disability

- Are you in any way aware of the linkage between consanguineous marriages and incidence of Disability among offspring? How?

- Do you know of any other family with Disability? Did they have a consanguineous marriage?

- In your opinion, why do people get married within the same family? Is it related to religious sanction and/or cultural acceptance? Does dowry or meher play a role in it? If there was no cultural/religious sanction, would you still do it? Why?

- Have you migrated from elsewhere? If you were living in your village, would you have had a consanguineous marriage? How do people search for life partners?

- Is there a difficulty in finding marriage partners? Are the cultural linkages/ networks not as strong in the city?

- If given a choice now, would you support or encourage a consanguineous marriage? Why?

- In your opinion are consanguineous marriages increasing or waning? Why do you think so?

- Is being disabled worse off for a boy or a girl? Why?

- If you had to spread awareness about the link between Disability and consanguineous marriages, how would you do it?

- What are your aspirations for your children? What do you want them to do?

B. Questions for 60 participants

1.Name:

2. Age:

3. Sex:

4. Education:

o Illiterate

o Non-formal education

o Pre- Primary

o 1st – 4th

o 5th – 8th

o 9th – 10th

o 11th – 12th

o Diploma or certification

o Graduation

o Post- Graduation and above

5. Apnalaya Individual id:

6. Apnalaya Family id:

7. Total Family Members:

8. Total family income:

9. Number of children with Disability:

Name	Disability	Age	Sex	Going to school (Yes/No)

10. Have you migrated from elsewhere?

    o Yes
    o No

11. If yes, where is your hometown?

12. At what age did you marry?

13. How was your spouse related to you before you got married?

    o Son/ daughter of maternal uncle (Mama)
    o Son/ daughter of maternal aunt (mausi, mausa)
    o Son/ daughter of paternal uncle (chacha)
    o Son/ daughter of paternal aunt (phupha)

14. That you two should get married was decided by-

    o Your parents
    o Spouses' parents
    o Your decision
    o Other family members, specify
    o Other, specify

15. Which are the factors for prevalence of consanguineous marriages
    (can tick more than one response)
    o Economic reasons- Dowry / meher
    o Family is known to us
    o Daughter is within the family
    o Property will remain within the family
    o Relatives and family enforce it
    o Family supports consanguineous marriages

16. What is your reason/s for marrying within the family? (can tick more than one response)
    o Lesser Dowry / meher required
    o Family is known to us
    o Daughter remains within the family
    o Property will remain within the family
    o Possibility of inheriting property
    o Relatives and family enforced it
    o Prefer consanguineous marriages in the family
    o Any other? Please specify…

17. If there was no religious sanction, would you have opted for consanguineous marriage?
    o Yes
    o No
    o Not Applicable

18. Who else in your family has had a consanguineous marriage?
    o My parents
    o Spouses' parents
    o My siblings
    o Other family members, specify
    o No one

19. Do any of these couples have children with disabilities?
    o Yes
    o No
    o Not Applicable

20. Do you know any family in Shivaji Nagar or anywhere where couples of consanguineous marriages have children with Disability?
    o Yes
    o No

21. Do you think consanguineous marriages can contribute to the occurrence of Disability in the offspring?
    o Yes
    o No

22. If yes,
    Did you know this:
    o before the marriage
    o after the marriage
    o after your child with Disability was born

23. How did you know this?
- o Have seen it in the family / neighborhood
- o Have heard about it (Source_____)
- o Doctors told us when we went for child's treatment
- o Other, _____

24. If the doctor informs you about the relationship between consanguineous marriage and Disability, will you encourage/suggest consanguineous marriages to anyone
- o Yes
- o No

25. What are the other reasons children are born with Disability, in your opinion?
- o Medicines taken during pregnancy
- o Medical procedure
- o Superstitions, _____
- o Other

26. Do you think it is difficult for people with Disability to get married? If yes, in whose marriage would you face more difficulty?
- o Son
- o Daughter
- o Both

27. Who are you more likely to support a consanguineous marriage for?
- o Your Son
- o Your Daughter
- o Both
- o Neither

28. Why?

C. In-depth Interview guideline

Question 1. Please provide your family details

a. Name:

b. Age:

c. Sex:

d. Education:

e. Total Family members:

f. Family income:

g. Family ID:

h. Apnalaya ID:

i. Cluster

j.   How much time have you been associated with Apnalaya?

Question 2. Details of the marriage

a. What was your age when you got married?

b. Who decided your marriage?

c. Was your opinion asked?

d. Were you happy with the decision?

e. Why did the family choose a consanguineous marriage?

    Ask about economic, social, cultural reasons

    Pointers for discussion

f. Dowry/meher, less expenses, inheritance of property, property within family, protection of women, stronger family ties, tradition, consanguineous marriage preferred, family encourages it, do not look outside for spouse

g. Why do you think Islam/Hinduism encourages consanguineous marriage? What is your source of information?

Question 3. How do you feel consanguineous marriage has benefitted you?
(expecting answers regarding family relations, ease of adjusting in the house for females, burden of work, avoiding premarital relationships, ease of controlling the female in case of males, conflict resolution…etc)

Question 4. What would have been different in a non-consanguineous marriage for you?
(expecting answers regarding family relations, ability to hold their own for females, conflict resolution, lesser control over wife for the males)

Question 5. Why do you believe your child was born with a Disability?
(Medical/ social/ superstitious / religious beliefs)

Question 6. Who takes care of your disabled child? What is the routine of the child?
(expecting different answers from males and females to explore the gendered nature of care-giving)

Question 7. Doctor's attitude- does their behavior discourage you from getting medical help?

Question 8. What is theteacher's behavior towards the child? Is he/she encouraged to attend school?
Expectations from different settings (social, institutional etc)

Question 9. How is the following different for a disabled boy from a disabled girl?
(education, attitude of the family, care-giving, marriage)

Question 10. Would you support a consanguineous marriage? Why?
(Expecting reasons that go beyond Disability)

D. Focus Group Discussion with adolescents with Disability

1. Have you/ are you currently in school/ studying?
2. How do you like the school? Are you enjoying the school?
3. What are your plans for the future?
4. Do you feel discriminated against in any social/family sphere?
5. Have you thought about marriage? What do your parents say about your marriage?
6. Will you be willing to marry within your family? Why?

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