THE HUMAN IMMUNODEFICIENCY VIRUS AND ACQUIRED IMMUNE DEFICIENCY SYNDROME (PREVENTION AND CONTROL) BILL, 2014 AND CAPABILITY APPROACH

*Kritika Vohra & Srivats Shankar**

Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome ('HIV/AIDS'), apart from being a life threatening disease, has acquired a significant place in countries across the world due to the kind of stigma and discrimination, seropositive persons and those associated with such persons, suffer. Human rights implications of marginalisation faced by HIV/AIDS affected persons have resulted in many countries taking cognisance of the same, by adopting legislations to protect these persons and prevent the spread of HIV/AIDS. With India following suit and the HIV/AIDS (Prevention and Control) Bill, 2014 having been introduced in the Rajya Sabha, this paper seeks to evaluate significant provisions of this Bill in light of the capability theory laid down by Amartya Sen. Viewing hardships faced by HIV/AIDS affected persons as forms of capability deprivation, we attempt to assess how far the Bill bridges the gap between affected persons and central human capabilities.

I. INTRODUCTION

United Nations Programme on HIV/AIDS ('UNAIDS') research reveals alarming statistics to show that India has the world's third largest HIV/AIDS affected population, second only to South Africa and Nigeria.[1] While the global commitment towards fighting the epidemic has certainly yielded results in the form of declining number of new infections annually[2] and India has not been far behind in this regard;[3] several concerns of HIV/AIDS affected

* 4th and 1st year students of the W.B. National University of Juridical Sciences, Kolkata.

1 United Nations Programme on HIV and AIDS (UNAIDS), *The Gap Report*, 17 (2014), available at http://www.unaids.org/sites/default/files/media_asset/UNAIDS_Gap_report_en.pdf (Last visited on December 14, 2014).

2 United Nations Programme on HIV and AIDS (UNAIDS), *World AIDS Day 2014 Report-Fact Sheet*, 5, available at http://www.unaids.org/sites/default/files/documents/20141118_FS_WADreport_en.pdf (Last visited on December 14, 2014).

3 National AIDS Control Organisation (NACO), *Annual Report 2014-2015*, 403 (Discusses how overall, India's HIV epidemic has slowed down, with a 57 percent decline in new HIV infections between 2000 and 2011).

persons,[4] particularly those pertaining to discrimination on grounds related to HIV/AIDS, continue to be central focus areas for policy initiatives.[5] This is largely explained by the fact that, for long, HIV/AIDS promotion and control strategies in India aimed, primarily, at awareness and knowledge of the infection.[6] In the nineties, however, it was realised that the exclusion faced by HIV/AIDS affected persons, social as well as legal, had reached the last phase of the three phases in which the HIV/AIDS epidemic manifests itself globally, i.e. the one characterised by discrimination, stigma and collective denial ('DSD'), and begged for a comprehensive and nuanced strategy.[7] DSD of this kind is often followed by a kind of coerced withdrawal by these persons from different social interactions, depriving them of a whole range of abilities (or what will later be termed as capabilities).[8]

The referred developments in understanding the layered nature of HIV/AIDS related issues is also an acknowledgement of the crucial link between DSD faced by such persons and continued spread of the infection. There is, indeed, basis to argue that stigma and discrimination on HIV/AIDS related grounds results in an increase in the risk of transmission and reduction in the uptake of HIV testing and treatment.[9] This results in an exponentially higher risk of transmission of the virus, which is fundamentally problematic if the larger goal is to combat the life threatening epidemic on a global level.[10]

Despite such realisation, for years, owing to the lack of a coherent and concrete legislative framework aimed at addressing HIV/AIDS issues, discrimination against this group of individuals at work place, health care, education and other settings continued. After several years of efforts and lobbying by Lawyers Collective, the National AIDS Control Organisation (NACO)

---

4 The Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Bill, 2014 (This phrase has been used in the paper in a broad sense to reflect a large number of people who are affected by HIV/AIDS, though not necessarily due to being HIV positive. The definition of 'protected person' in Clause 2(s) of the Bill may be of help in this regard. Clause 2(s) defines 'protected person' to

"a person who is— (i) HIV-positive; or (ii) actually, or perceived to be, associated with an HIV-positive person; or (iii) actually, or perceived to be, at risk of exposure to HIV infection; or (iv) actually or perceived to be, a member of a group actually or perceived to be, vulnerable to HIV/AIDS").

5 NACO Report, *supra* note 3, 403 (The five cross-cutting themes that are being focused under NACP-IV are quality, innovation, integration, leveraging partnerships and stigma and discrimination).

6 *See* Nita Mawar et al., *The Third Phase of HIV Pandemic: Social Consequences of HIV/AIDS Stigma & Discrimination & Future Needs*, 122 Indian J. Med. Res. 471-484 (2005).

7 *Id*., 471.

8 Sen, *infra* note 16.

9 *See* Anish Mahajan et al., *Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward*, 22 (Suppl 2) AIDS S67-S79 (2008); Avert, *HIV and AIDS Stigma and Discrimination*, available at http://www.avert.org/hiv-aids-stigma-and-discrimination.htm (Last visited on December 14, 2014).

10 *Id*.

and other interest groups; and after several drafts having travelled between the Ministry of Law and Justice and Ministry of Health and Family Welfare,[11] the Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Bill, 2014[12] ('Bill') has finally been tabled in the Rajya Sabha. Moreover, the Standing Committee report was presented to the Rajya Sabha and laid before the Lok Sabha in April, 2015.[13]

Promising as this Bill is, given the overwhelming legal vacuum that precedes it, this paper seeks to analyse some of its key provisions in light of the Capability Approach ('Approach'), as formulated by Amartya Sen ('Sen')[14] by looking at HIV/AIDS related DSD as a form of capability deprivation rather than deprivation of material benefits or legal claims. To this end, the paper is divided into five parts. The first part of the paper gives a brief overview of the Approach, its theoretical basis, contributions to the theory made by Martha Nussbaum ('Nussbaum') and the merits of its application in assessing legal policy in order to equip the readers with a deeper insight into its philosophical underpinnings. It is also pertinent to note, at this point, that the scope of this paper does not go so far as to offer a theoretical critique of the Approach by itself. While some criticisms levelled against it and issues raised with respect to its application, will be addressed for the limited purpose of our application of the Approach to the Bill; it must be noted that this paper, by no means, attempts to generally theorise further on the Approach or its utility. In the second part, we will examine HIV/AIDS in light of the Approach, followed by the third part, wherein we highlight instances of DSD faced by HIV/AIDS affected persons as forms of capability deprivations, in light of the ten central human capabilities enlisted by Nussbaum. In the fourth part, we will attempt to analyse certain specific provisions of the Bill in order to theoretically assess how far the Bill bridges the gap between HIV/AIDS affected persons and capabilities that they have hitherto been deprived of. In the process, we will also delve into concerns and issues, implementation related and other, of the said provisions, in order to make the exercise more fruitful. We will end the paper with concluding comments in the fifth part and attempt to tie the various conceptual threads of the paper together.

---

[11] *See* Lawyers Collective, *HIV and Law-Draft HIV/AIDS Bill*, available at http://www.lawyerscollective.org/hiv-and-law/draft-law.html (Last visited on 14 December, 2014).

[12] *See* The Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Bill, 2014.

[13] *See* Lawyers Collective, *HIV/AIDS Bill Tabled in the Rajya Sabha*, available at http://www.lawyerscollective.org/updates/hivaids-bill-tabled-rajya-sabha.html (Last visited on December 14, 2014).

[14] *See* Stanford Encyclopedia of Philosophy, *The Capability Approach*, (2011), available at http://plato.stanford.edu/archives/sum2011/entries/capability-approach/ (Last visited on December 14, 2014).

II. THE CAPABILITY APPROACH- A THEORETICAL OVERVIEW

This part seeks to give the readers a brief overview of the theoretical basis of the Approach. To this end, contributions of two authors, Sen and Nussbaum will be discussed in detail, while significant contributions made by other scholars will also be drawn upon in order to provide a holistic view of the trajectory that the Approach has followed since its inception in terms of its varied applications.

A. SEN AND THE CAPABILITY APPROACH

The Approach was first articulated by Sen in the 1980s as a theoretical framework in the context of welfare and development economics.[15] While the Approach itself is extremely layered, its focus lies in judging individual welfare or well-being by the individual's ability to realise the functionings he or she values.[16] Rejecting utilitarian and resource-based approaches to evaluating individual well-being, Sen attached value to 'freedom' of an individual in determining what may be of value to them.[17] In this manner, acknowledging that every substantive theory must choose an informational focus, Sen, in his theory, shifted this focus to capabilities, i.e. the ability to do or be things that one has reason to value.[18] Arguing that policy framing necessitated the determination of an appropriate informational focus, Sen provided for an alternative informational focus for evaluating individual welfare through the Approach, though at the same time not postulating any formula for its measurement.[19]

Applying the Approach, for instance, in the context of schooling, entails not merely arriving at statistics regarding enrolment ratio, etc., but to ascertain whether those who were desirous of going to school had the real opportunity to do so or were constrained in some manner for reasons such as inadequate infrastructure and unavailability of transport. This manner of appreciating capabilities over functionings, Sen argued, enables better policy formulation as it acknowledges the distinction between those whose lack of schooling was a result of choosing not to attend school (similar to fasting, in the context of food) as opposed to not having the opportunity to do so (similar to starvation).

---

15 *Id*.

16 Amartya Sen, Idea of Justice 231 (2009).

17 *Id*.; Ingrid Robeyns, *An Unworkable Idea or a Promising Alternative? Sen's Capability Approach Re-examined* 7 (Katholieke Universiteit Leuven, Center for Economic Studies, Paper No.00.30, 2000) (The capability to do or be something has been described by Amartya Sen as the real ability and opportunity an individual may have to do or be that which is of value to an individual. Functionings, on the other hand, are the capabilities that are realised and the states of being that are, in fact, achieved).

18 Sen, *supra* note 16, 231-232.

19 *Id*., 232.

Although Sen argues for focus on capabilities, the crucial link between functionings and capabilities is not ignored in its entirety. To truly appreciate the superiority of Approach as an evaluative tool, it is important to recognise that capabilities are defined derivatively on functionings and any cluster of functionings that may be chosen will be a subset of the particular individual's capabilities.[20]

Another benefit of the Approach lies in the fact that it recognises the relativity of value attached to various functionings and accounts for heterogeneous factors that affect the realisation of capabilities.[21] Sen acknowledges some of the most important sources of diversity as the following:[22]

i) personal heterogeneities (e.g., levels of education, age, health status, etc.);

ii) environmental diversities (e.g., political, related to the physical environment, etc.);

iii) variations in the social climate (e.g., local culture, norms, social capital, etc.

iv) differences in relational perspectives (e.g., hierarchies, job relations, etc.);

v) distribution within the family (e.g., concerning the equality of distribution of resources, fairness, prioritisation, etc.).

For instance, capabilities required by a pregnant woman in order to achieve the same functionings as any other woman will be markedly different. Such differences, Sen argues, are to be taken into account while measuring well-being or formulating distributive and other policies. This is because due to the diversity inherent amongst individuals, their capabilities cannot be measured only in terms of the resources they happen to possess.[23]

It is evident from the nature of human diversity and the insistence of Approach on accounting for them that applying it to facts and formulation of policies leaves more questions unanswered than would be desirable. Though concerns relating to operationalising of the Approach will be addressed in the paper at a later point, it is crucial to note that Sen explicitly declined to lay

[20] *Id*., 236.
[21] *Supra* note 14, 6.
[22] *See* Flavio Comim, *Measuring Capabilities* in The Capability Approach: Concepts, Measures and Applications 166 (2008).
[23] *Id*.

down a list of capabilities that should be used while applying it to policy discourses.[24] While he admitted the need for lists that may be needed for different purposes, he refused to contribute to any universal, pre-determined, canonical list.[25] Apart from stating in general terms that a list of capabilities for a particular purpose should be arrived at through a democratic process of discussion and public reason, Sen did not delineate the means for operationalising this path breaking normative approach.

B. NUSSBAUM AND THE CAPABILITY APPROACH

Eminent feminist philosopher, Nussbaum, who endorsed the Approach as a normatively superior approach in the context of gender welfare studies, succinctly responded to the most commonly held criticism of the Approach, namely, underspecification.[26] Starting from a premise that the only way that the Approach could supply useful guidance in gender equality studies would be if a definite list of the most central capabilities was formulated, Nussbaum went on to delineate, what she called, ten central human capabilities.[27] These capabilities, Nussbaum claims, are abstract, in order to allow some room for specification and deliberation by citizens, and are subject to ongoing revision.[28] She also claims that these central human capabilities represent years of cross-cultural discussion and command a kind of 'overlapping consensus', in that all persons will, despite their different views on human life, subscribe to this list.[29] Her list of capabilities includes life, bodily health and bodily integrity, amongst others.[30]

Nussbaum's work on the Approach has strong Aristotelian and Marxian underpinnings in that she views the aforementioned capabilities as not just freedoms and opportunities to achieve any functionings but as capabilities

---

[24] *Supra* note 14, 14.

[25] *Id*.

[26] *See* Sabina Alkire, *Using the Capability Approach: Prospective and Evaluative Analyses* in The Capability Approach: Concepts, Measures and Applications 42, 45 (2008).

[27] Martha Nussbaum, *Introduction* in Women and Human Development 5 (2000).

[28] Martha Nussbaum, *In Defence of Universal Values* in Women and Human Development 77 (2000).

[29] *Id*., 76.

[30] *Id*., 78-80; The complete list of central human capabilities, as listed by Nussbaum, is as follows:

i. life;
ii. bodily health;
iii. bodily integrity;
iv. senses, imagination and thought;
v. emotions;
vi. practical reason;
vii. affiliation;
viii. other species;
ix. play;
x. control over one's environment.

that lead to a 'truly human life', one that is worth living.[31] In furtherance of this view, she speaks of two thresholds within her list of capabilities. The first threshold concerns itself with those functioning which are viewed as central to human life and whose absence or presence marks the absence or presence of human life itself. The second threshold pertains to those functions that characterise a flourishing human life, one that is 'worthy of human being'.[32] In the first category lie the capabilities of life, bodily health, integrity, senses-imagination-thought, which extend into the remaining capabilities which form the second threshold of the ten central human capabilities.[33] Apart from these two thresholds, she also contributed a 'minimum core content' parallel to the jurisprudence on the Approach by stating that she viewed the ten central human capabilities as crucially important, and none of them could be traded off for achieving any other capability.[34] She proposed that every State must fulfil a certain minimum threshold of each capability or all individuals for it to be a fully just society, regardless of the level of opulence.[35]

C. OPERATIONALISING THE APPROACH

As was mentioned earlier, one of the biggest criticisms of the Approach has continued to be the difficulty in applying the Approach when it comes to formulating policies or analysing data, due to theoretical under-specification.[36] Rawls, for instance, called it an 'unworkable idea.'[37] Robert Sugden has also questioned whether, in light of the theoretical richness of the Approach and the likelihood of disagreement between people about the nature of good life, the Approach is a realistic proposition and one that is better than alternative methods relied on by economists.[38] In this manner, the Approach, while advocating for a broader informational space, fails to shed light on what must occupy this space.[39] Thus, even those sympathetic of the Approach have acknowledged the challenges posed by operationalising of such an approach

---

31 Nussbaum, *supra* note 28, 70.

32 *Id*.; David Bilchitz, Poverty and Fundamental Rights: The Justification and Enforcement of Socio-economic Rights (2008); Kasongo Lubo, *Corporate Obligations Towards the Realization of the Right to Development*, 37 (2012) (unpublished LL.M. Dissertation, University of Johannesburg).

33 Lubo, *id*., 31, 37-38.

34 Comim, *supra* note 22.

35 Martha Nussbaum, *Capabilities as Fundamental Entitlements*: *Sen and Social Justice* in Capabilities, Freedom and Equality: Amartya Sen's work from a Gender Perspective 41 (2007).

36 The under-specification that the Capability Approach is often criticised for is with respect to several aspects, such as which capabilities and functionings ought to be taken into account, what weight is to be attached to each of the capabilities, what weight is to be attached to different people in arriving at moral judgments; *See* Mozaffar Qilibash, *Amartya Sen's Capability View: Insightful Sketch or Distorted Picture?* in The Capability Approach: Concepts, Measures and Applications 62 (2008); *Supra* note 14, 21.

37 *Supra* note 14, 2.

38 *Id*., 21.

39 Qilibash, *supra* note 36.

with respect to either its value judgments, demanding informational requirements or its multidimensional nature.[40] This, indeed, is also the criticism most necessary to be addressed for the purpose of this paper as it attempts to apply the Approach in evaluating the Bill and prescribing changes thereto. Is this really a flaw in the Approach? Many have argued otherwise.[41]

Before delving deeper into the issues pertaining to operationalising of the Approach and justifying it in the context of this study, it is crucial to understand what exactly one means by 'operationalisation' to begin with. Within the capability literature itself, there have been many approaches to answering this question.[42] Some have defined it as the process of transforming a theory into an object of practical value, not limited to mere quantification but extending to using the theory for different purposes in a wider sense. Some others have argued that it entails adding enough particulars to the hypothesis so that it can be put to work in real time and space.[43] The one common feature of operationalising that can be culled out from the diverse opinions is that operationalisation of the Approach often involves 'filing in the gaps' left in the theoretical framework by Sen's incompleteness.[44]

It appears, thus, that the framework for operationalising this Approach defies formulaic predictability.[45] Indeed, Sen's writings, wherein he stated that the methodology to be adopted in any application of the Approach should be guided by the purpose that the inquiry seeks to serve, would support such a position.[46] That explains why most capability scholars have adopted a proactive and constructive approach to the under-specification by viewing it as a work in progress and agreeing that answers to questions like which capabilities must be sought, who should determine these capabilities, etc. will vary depending on different normative exercises.[47] The under-specification, in fact, is in light with prescriptive relativism[48] and provides for an opportunity for determining a suitable level specification, given the diversity and ever expanding

---

40 Comim, *supra* note 22, 162.

41 *Id*., 161.

42 Enrica Chiappero-Martinetti & Jose Manuel Roche, *Operationalization of the Capability Approach, from Theory to Practice: A Review of Techniques and Empirical Applications* in Debating Global society: Reach and Limits of the Capability Approach 157 (2009).

43 *Id*., 157-158.

44 Qilibash, *supra* note 36.

45 Chiappero-Martinetti & Roche, *supra* note 42.

46 Alkire, *supra* note 26, 42.

47 Ingrid Robeyns, *Capability Ethics* in The Blackwell Guide to Ethical Theory, 412-432 (2013); *Supra* note 14, 27.

48 James Nickel, Making Sense of Human Rights 74-75 (1987) (The philosophy of prescriptive relativism believes that universal norms should be few and broad so that modest local standards and practices can be compatible with them. This approach, in the context of international human rights, suggests that the strict language of rights be modified by abstract language and exceptions to make them more flexible and allow for a reasonable amount of diversity. It is for this reason that formulation of international human rights are often broad or abstract enough to allow for sufficient latitude to local interpretation).

nature of functioning one may value.[49] Indeed, empirical applications of the capability literature have been growing fast and across a wide range of disciplines with diverse aims, multiplicity of data and techniques used.[50] This is, however, not true of empirical research alone. Nussbaum's account of the well-being and welfare of women in India has shown to many a critic how the Approach can be put to work even qualitatively.[51]

1. Prospective and Evaluative Frameworks

The number and varying kinds of analyses and applications that the Approach has given rise to, is an indicator of the value addition the Approach has made to the general jurisprudence on evaluation of welfare.[52] The plethora of studies conducted in the application of the Approach and the varied methodologies adopted by different scholars, therefore, lead us to two conclusions about operationalising of the Approach. One, that there is no precise formula for the application of the Approach, since the methodology to be adapted depends on the focus of the exercise; and two, that this implementational challenge does not render the Approach redundant. Indeed, it can be argued that the fact of such diverse approaches being adopted is in tune with the spirit of the Approach which was postulated as a broad informational tool rather than as a mechanism for empirical studies.

Having established that under-specification of the Approach does not *per se* obliterate the utility of the Approach, one can now appreciate the different ends that the Approach has been used to arrive at: evaluative framework and the prospective framework.[53] The Approach as an evaluative framework concerns itself with assessments of certain states of affairs by utilising capabilities as the metric.[54] Utilising the Approach in this manner entails evaluating which state of affairs serves capabilities better or whether capabilities examined have expanded or contracted over time, by utilising information collected through primary or secondary sources.[55] This approach is a consequentialist one in which the focus remains on the end result rather than the process

---

[49] *See* Amartya Sen, Development as Freedom 70-71 (1999) (Nussbaum's argument on multiple realisability of her list of central human capabilities also makes a strong case in favour of such under-specification and the broadly worded and inclusive nature of the approach allows, in the second stage, for specification based on the particular historical contexts of the societies or individuals concerned); *See* Nussbaum, *supra* note 28, 77.

[50] Chiappero-Martinetti & Roche, *supra* note 42, 159 (The areas of study wherein the capability approach has been utilised include poverty, inequality, social justice, well-being, child poverty and health); *See* David. A. Clark, *The Capability Approach: Its Development, Critiques and Recent Advances*, 10-11, available at http://www.gprg.org/pubs/workingpapers/pdfs/gprg-wps-032.pdf (Last visited on December 14, 2014); Alkire, *supra* note 26, 27, 41.

[51] *Supra* note 14, 26.

[52] Alkire, *supra* note 26, 27.

[53] *Id*., 30, 32.

[54] *Id*.

[55] *Id*.

which was used to arrive at the result.[56] This manner of utilising the Approach utilises the broader and more reflective informational focus provided by the capability approach, thus yielding better evaluations of states of affairs in question. The prospective framework, on the other hand, concerns itself with policy recommendations and suggests activities that are aimed at enhancing capabilities of the concerned individuals.[57] The focus, in achieving this end, is on causality and consequently recommending steps and changes to the political, social, cultural, institutional and economic structures in order to best enhance and advance a greater stream of capabilities of those concerned.[58] Indeed, one could argue that this is the essence of what Sen proposed in his initial writings when he pioneered the Approach as the way forward for welfare policy making. Prospective analyses using the Approach is inherently heterogeneous and while in the evaluative framework one can list the questions that one may answer (like which capabilities to evaluate, how to measure them, etc.), in a prospective framework, more attention needs to be paid to the discipline, level of analysis, policy audience, region and context.[59]

III. HIV/AIDS AND THE CAPABILITY APPROACH

In the sections above, we delved, in some detail, into the theoretical basis of the Approach, the superiority of the Approach in terms of its broad informational focus and some issues surrounding it that were pertinent in light of the scope of this paper. This section will offer to the readers a better insight into why this Approach is well suited for a study of this nature, how it will be applied and which capabilities will guide this study.

A. WHY CAPABILITY APPROACH?

There are primarily two reasons for opting for the Approach as the evaluative tool in the context of HIV/AIDS related DSD. Since there is no legislation that specifically excludes HIV/AIDS affected persons, it is difficult to articulate this kind of exclusion in terms of deprivation of resources or of right to equality. Instead, the DSD faced by these individuals can be better viewed as an issue of lack of ability to 'substantively' fulfil certain functionings that they may have reason to value, an informational subset that the Approach effectively caters to. For instance, it is not that the government policy on provision of free health care in government hospitals or on provision of free education in government schools *per se* disallows HIV/AIDS affected persons from availing these benefits. However, these policies, as they play out, reveal barriers in the form

[56] *Id*.
[57] *Id*.
[58] *Id*.
[59] *Id*., 41.

of DSD that prevent HIV/AIDS affected persons from, in fact, utilising these benefits and, as we will see in the next part, from achieving the desired functionings. Simple examples, as are detailed below, reveal the complexity of the exclusion and marginalisation faced by these persons. Viewing this exclusion as a deprivation merely of resources or primary goods, like income or food, therefore, will tantamount to grossly understating the complexity of issues surrounding HIV/AIDS related exclusion.

Flowing from this line of thought is the second reason for opting for the Approach, which is its layered nature and its ability to accommodate the diverse cultural, social and institutional structures when evaluating the substantive realisation of functionings.[60] HIV/AIDS related DSD, like DSD based on many other grounds, is also a result of institutional and systemic societal issues. Although the detailed analysis in the next part will expose the readers to a better understanding of the nuances of HIV/AIDS related DSD, it will suffice to mention at this stage that it is a consequence of not just association with the infection, but of several sociological structures and beliefs that surround the disease and individuals at the highest risk of acquiring the infection. Add to that the interaction of this DSD with demographics like gender and age and it becomes evident that a single algorithm offered by any other approach is ill suited for analysing these issues in light of the Bill and prescribing changes thereto. A theoretical approach as normatively rich as the Approach, on the other hand, allows one to best understand the nature of deprivations faced by these persons and to determine, in a more holistic manner, the legal and policy recourse best suited to address the said deprivations.

B. PERTINENT CAPABILITIES AND METHODOLOGY

As has been discussed above, the capabilities considered and methodology used for any operationalisation of the Approach is best determined on the context and purpose of such an application.[61] It is on this premise that we propose to base the list of capabilities that will be utilised and the methodology that will be followed in analysing HIV/AIDS related DSD as capability deprivations.

The capabilities that will be used for this exercise will be those listed by Nussbaum in her work on women and development in India as the ten central human capabilities. These capabilities have been selected primarily for two reasons. *First*, although this list was framed in the context of gender equality studies, it provides for an overall holistic account of the basic capabilities that every State must endeavour to assure to all. While Nussbaum's theory by no means offers a complete picture of a State's obligations towards its citizens,

[60] Comim, *supra* note 22.
[61] Alkire, s*upra* note 26, 42.

the broadly worded capabilities do command an overlapping consensus[62] and serve as a suitable starting point towards the identification of the capabilities that a liberal democracy like India should attempt to advance for the part of its population affected by HIV/AIDS. This is primarily because a basic level of these ten capabilities, as Nussbaum points out, is indeed necessary for any individual to acquire the autonomy and freedom that one must have to be or do things that one has reason to value. *Second*, a review of different accounts of HIV/AIDS related DSD reveals that the ten capabilities listed by Nussbaum capture, fairly and satisfactorily, the kinds of capability deprivations such individuals face on a daily basis. Although, this Approach might appear to be circular, in that observed capability deprivations guide what capabilities ought to be examined, such an understanding, in our opinion, will be erroneous. As was noted before, the capabilities that ought to be selected for a study depends deeply on what would best serve the purpose of the study with the least amount of bias.[63] Nussbaum's list, when seen in light of the instances of HIV related DSD offers the best means of meaningfully evaluating this phenomenon.

The methodology, just as the list of capabilities one seeks to rely on, is a function of the nature, purpose and context of the study. It is for this reason that the approach adopted in this paper will not rely on empirical data but instead base capability related evaluations on factual accounts elucidated in different studies conducted by scholars on HIV/AIDS related exclusion and discrimination. We will use these overwhelmingly similar accounts to determine which of the ten capabilities they deprive this vulnerable group of individuals of. Given that DSD experienced by most HIV/AIDS affected persons is not on account of the seropositive status alone but is also a function of their gender, age, class, sexual orientation, profession, etc., using the list of ten fairly intertwined capabilities will enable us to unravel the complexities of these instances. In this manner, the study will be a qualitative account based on secondary sources as opposed to a quantitative account.

Moreover, no attempt will be made to measure any capability, in the strict sense, during the course of this paper. It is our opinion that operationalising the Approach need not necessarily entail using a unit of measurement for each capability, measuring the extent of deprivation and, thereafter, measuring the extent to which the capabilities may be enhanced. Instead, an application of the Approach in qualitatively seeing what the capabilities are, what amounts to deprivation of their capabilities i.e. lessening of the capabilities, and what will contribute to their advancement i.e. enhancement of the capabilities would also amount to successful operationalising. Thus, with the starting point as the capabilities that HIV/AIDS affected persons must have, we will undertake a qualitative exercise to evaluate how DSD on HIV/AIDS related grounds deprives them of these capabilities, how the Bill helps in enhancing

[62] *Supra* note 14, 415.

[63] Alkire, s*upra* note 26, 42.

them and bridging the gap between these individuals and these capabilities and what must be done to enhance these capabilities further.

IV. HIV/AIDS RELATED DSD AND CAPABILITY DEPRIVATION

This part of the paper will seek to examine several of the capabilities listed by Nussbaum in light of instances of DSD faced by HIV/AIDS affected persons. For this exercise, it may also be pertinent to bear in mind that these capabilities are not rigidly defined and easily distinguishable but are often fluid and interconnected with other capabilities.[64] Therefore, many instances may evidence deprivation of not one but several capabilities at the same time. This adds to the fact that HIV/AIDS related DSD cannot be compartmentalised into rigid categories and reinforces the choice of utilising the Approach as the normative framework for the purposes of this study.

A. LIFE

This first capability on Nussbaum's list and one of the few that qualify as part of the first threshold is one's ability to live a life of normal length and not live a life that is not worth living.[65] Broadly worded as this capability is, it is possible to conceive several instances of HIV/AIDS related DSD as a deprivation of this capability. The easiest to view, in this manner, would be the obvious fact that having the HIV infection, and it later progressing to AIDS, most often results in considerable shortening of patients' life span and would be far from what Nussbaum would describe as a 'life of normal length'. Having said that, let us not forget that a State's responsibility cannot go so far as to ensure that a life threatening disease does not affect the patient in a manner it is pathologically bound do. However, having HIV infection and not being able to address it with treatment at the appropriate stage[66] certainly renders this capability impossible to achieve for many. With treatment to HIV not being made universally available to all[67] and discrimination in the numerous spheres of life discouraging individuals from getting tested for HIV, it is conceivable that seropositive individuals are deprived of the capability of 'human life' as postulated by Nussbaum.

---

[64] Bina Agarwal et al., Capabilities, Freedom and Equality: Amartya Sen's work from a Gender Perspective 47 (2007).

[65] Nussbaum, *supra* note 35, 47.

[66] Avert, *HIV and AIDS Treatment & Care*, available at http://www.avert.org/hiv-and-aids-treatment-care.htm (Last visited on December 14, 2014) (Discussing how appropriate treatment can enable HIV positive persons to live long and healthy lives).

[67] Avert, *HIV & AIDS in India*, available at http://www.avert.org/hiv-aids-india.htm (Last visited on December 14, 2014).

So far as having the ability to live a life that in not a life not worth living is concerned, it is even easier to demonstrate that many HIV/AIDS infected persons are deprived of this capability. This capability implies that not only must one have the ability to lead a life of normal length but must also be living a life that is worth living. The fact that HIV/AIDS and related DSD prevents individuals from leading a life worth living may be implied from cross-country studies which document an alarmingly high suicidal ideation in seropositive persons.[68] While such suicidal tendencies, at best, give an account of a state of being (i.e. the result), what leads HIV positive person to form such an opinion of their life's worth (i.e. causality) is a combination of a myriad of factors, which will be discussed in detail at a later stage as they are more directly related to deprivation of certain other capabilities.

B. BODILY HEALTH

This capability entails being able to have good health, including reproductive health. The prerequisite to being able to have good health is access to healthcare at par with others. Monetary factors aside, it has been proven time and again that some of the most conspicuous forms of DSD are faced by HIV affected individuals in the access to healthcare services.[69] Several studies evidence the existence of misconceptions leading to DSD at the hands of health care providers.[70] Patients are often denied treatment, and where they are not, they are shunted between wards and openly tagged as HIV/AIDS patients, leading to isolation by non- HIV/AIDS patients and the staff alike.[71]

Apart from instances of such DSD in health care settings, what also becomes extremely pertinent in this context is the importance of timely treatment of HIV infection for a seropositive person. People with HIV can live for decades after diagnosis if antiretroviral treatment ('ART') is availed of in a timely and effective manner.[72] Although free ART has been available in India since 2004, in 2012, only about half of those eligible to receive the treatment were actually able to receive it due to insufficient accessibility to clinics.[73] Since focus on this capability would essentially entail making available the real opportunity to be able to achieve bodily health, access to ART for HIV

---

[68] *See* Nina Cooperman & Jane Simoni, *Suicidal Ideation and Attempted Suicide Among Women Living with HIV/AIDS*, 28(2) Journal of Behavioural Medicine 149-156 (2005); *See* A. Komiti et al., *Suicidal behaviour in people with HIV/AIDS: A Review*, 35 Aust. N. Z. J. of Psychiatry 747–757 (2001).

[69] *See generally* United Nations Programme on HIV and AIDS (UNAIDS), *India: HIV and AIDS related Discrimination, Stigmatization and Denial*, available at http://data.unaids.org/publications/irc-pub02/jc587-india_en.pdf (Last visited on December 14, 2014).

[70] M. Kurien et al., *Screening for HIV infection by health professionals in India,* 20(2) Nat. Med. J. of India (2007).

[71] S*upra* note 69, 18 &19.

[72] *Supra* note 66.

[73] *Supra* note 67.

positive patients is one of the essential components to fulfil this capability. It can, therefore, be seen that bodily health, one of the most crucial first threshold capabilities, in Nussbaum's list, is one that HIV/AIDS affected persons are deprived of in different ways.

The issue of reproductive health of seropositive persons acquires significant importance in light of the fact that HIV is one of the leading causes of death in pregnant women across the world.[74] Reproductive health for HIV positive women would include not only health care services for themselves but also avenues to prevent transmission of the virus to the unborn child. It has been proven that obtaining treatment during pregnancy can reduce the risk of transmission to the unborn child significantly.[75] Unfortunately, several women, across the world, are unable to receive this treatment for reason of affordability and access.[76] Moreover, several women face extreme cases of discrimination in health care settings during labour as the risk of transmission to the health care staff is high due to exposure.[77] Being, thus, deprived of reproductive health in their most vulnerable state, women with HIV/AIDS suffer an even more severe form of capability deprivation than others.

C. BODILY INTEGRITY

This capability, according to Nussbaum, includes the ability of an individual to have one's body to be treated as sovereign, i.e. to be secure from different kinds of assault.[78] Inherent to this capability is the ability of an individual to not have one's self medically tested without one's consent. Several instances in the case of HIV positive persons involve the deprivation of this capability. For instance, in a study conducted by UNAIDS, it was revealed that in hospitals across India, the practice of testing of blood without consent in cases wherein the patient did not respond to treatment for 'marker diseases' was not uncommon.[79] In many cases, non-consensual HIV testing would be conducted for patients suspected of being HIV positive, pregnant women and surgical patients.[80] Apart from health care settings, mandatory testing is also practiced in educational institutions and workplaces wherein the HIV positive

---

[74] United Nations Programme on HIV and AIDS (UNAIDS), *The Gap Report- Children and Pregnant Women Living with HIV, 2014*, 4 (2014), available at http://www.unaids.org/sites/default/files/media_asset/09_ChildrenandpregnantwomenlivingwithHIV.pdf (Last visited on December 14, 2014).

[75] Avert, *Preventing Mother-to-child Transmission of HIV*, available at http://www.avert.org/preventing-mother-child-transmission-hiv.htm (Last visited on December 14, 2014).

[76] UNAIDS Report, *supra* note 74, 7 (An analysis by the United Nations Children's Fund (UNICEF) shows pronounced inequities in coverage for many essential health services, whereby pregnant women from wealthier households are more likely to receive care than those from poorer households).

[77] *Supra* note 69, 19.

[78] Nussbaum, *supra* note 28.

[79] *Supra* note 69, 22.

[80] *Id*.

status of a person results in the individual being denied education or job opportunities.[81] Indeed, the administration of such tests without prior informed consent deprives these persons of the ability to have their body treated as sovereign and protected from assault.

Apart from HIV testing without consent, many studies across the world have revealed increased instances of violence against women subsequent to being tested HIV- positive.[82] While instance of domestic violence are extremely common amongst HIV-positive women, violence is also faced by many other high risk groups, such as commercial sex workers and men who have sex with men ('MSMs').[83] It is, therefore, evident that in different spheres of life, HIV/AIDS affected persons are deprived of the inviolable capability of one's bodily integrity being respected.

D. SENSES, IMAGINATION AND THOUGHT

Since Nussbaum describes this capability broadly, the aspect that is most crucial in the context of HIV/AIDS, i.e. education will be delved into in order to demonstrate the deprivation of this capability amongst HIV/AIDS affected persons. Nussbaum states that this capability entails having one's senses and thoughts being informed by adequate education in the form of literacy and basic scientific and mathematical training.[84] It is in this regard that schooling becomes extremely crucial (although often not sufficient by itself) in enabling individuals to achieve this capability. By implication, any hindrance to one's educational training would be sufficient to deprive one of this capability. This, we believe is what happens in cases of HIV/AIDS affected children. Also given the broad definition of HIV/AIDS affected persons adopted in the analysis, this term includes not only children who are HIV positive but also children who have HIV positive parents. The deprivation of this capability then manifests in two ways.

---

[81] *See* Lawyers Collective, *Mandatory HIV Testing of Foreign Students*, available at http://www.lawyerscollective.org/updates/mandatory-hiv-testing-foreign-students.html (Last visited on 14 December, 2014); Debanjani Aich, *HIV testing at BPOs may be Illegal,* Economic Times, June 5, 2007.

[82] *See* Karen Rothenberg et al., *The Risk of Domestic Violence and women with HIV Infection: Implications for Partner Notification, Public Policy, and the Law,* 85(11) Am. J. Public Health. 1569–1576 (1995); *See* Karen Rothenberg et al., *Domestic Violence and Partner Notification: Implications for Treatment and Counselling of Women with HIV,* 50(3-4) J. Am. Med Womens Assoc. 87-93 (1995); *See* Suzanne Maman et al., *The Intersections of HIV and Violence: Directions for Future Research and Interventions,* 50(4) Social Science and Medicine 459-478 (2000); *See* Suzanna Maman et al., *HIV Positive Women Report More Lifetime Partner Violence: Finding from a Voluntary Counselling and Testing Clinic in Dar es Salaam, Tanzania*, 92(8) American Journal of Public Health 1331-1337 (2002).

[83] *Supra* note 69, 57.

[84] Nussbaum, *supra* note 28, 6.

First, deprivation can be in terms of discrimination and denial[85] in provision of education at schools, which has been documented by several studies.[86] A study conducted by UNAIDS revealed instances of school authorities compelling parents to withdraw their HIV positive children from their school without offering any reasons and other instances of institutions mandatorily testing their students before admission,[87] only to segregate[88] them or transfer them to a different institution on receiving positive results.[89] There have also been instances of insistence by some institutions of withdrawal of HIV negative children of HIV positive persons on the purported grounds of negative effects on other students.[90] In fact, as recently as March 2014, the Apex Court took cognisance of rampant discrimination against such persons in the school setting and initiated actions for guidelines to be formulated by the Government to address the issue of discrimination at the time of admission in schools.[91]

Another manner in which HIV/AIDS affected children are deprived of education and, therefore, of this capability, is in cases wherein the parents' HIV positive status and consequent ill health compels their children to drop out of school in order to look after their parents or to make ends meet.[92] Several such instances have been recorded over the years and indeed, this issue persists even today in not just India but in several countries across the world.[93]

E. EMOTION

This capability, as per Nussbaum's articulation, includes not having one's emotional development blighted by fear and anxiety or by traumatic, abusive and neglecting events.[94] Achievement of this capability in light of HIV/AIDS affected persons would entail such individuals leading their lives free from fear or threat of abuse. Studies have however shown otherwise. A survey conducted amongst 801 HIV/AIDS persons in Maharashtra over a period of two

---

85 Times of India, *School may face action for HIV discrimination*, December 24, 2010, available at http://timesofindia.indiatimes.com/city/gurgaon/School-may-face-action-for-HIV-discrimination/articleshow/7153650.cms (Last visited on December 14, 2014).

86 *See* Human Rights Watch, *Discrimination Against Children Affected by HIV/AIDS*, available at http://www.hrw.org/reports/2004/india0704/5.htm (Last visited on December 14, 2014).

87 *Supra* note 81.

88 *Supra* note 86.

89 *Supra* note 69, 47.

90 *Id*.

91 IANS, *SC Notice on Discrimination Against HIV+ve Children*, The Hindu (New Delhi) March 4, 2014; PTI, *Supreme Court directs Centre, states to stop discrimination against HIV + kids*, Indian Express (New Delhi) March 3, 2014.

92 *Supra* note 86.

93 *Id*.

94 Nussbaum, *supra* note 28.

years revealed that the most common reactions to being diagnosed seropositive were fear, followed by depression and suicidal thoughts.[95]

Adding to this the complex dimension of gender issues, it becomes evident that HIV positive women are often at the receiving end of constant physical and mental abuse.[96] Not only are these women often blamed for transmitting infection to the husband, especially if the seropositive status is detected after marriage,[97] they are also made to live in a constant state of anxiety and fear of exclusion from household or share in the family property.[98] This is precisely why spousal notification laws across the world have invited criticisms for being 'gender blind'[99] in their approach. In the aforementioned survey, as well, the reaction of fear and depression were more common in women than in men who were surveyed, highlighting how skewed gender relations affect the perception of their seropositive status amongst women.[100] Thus, it can be argued that an HIV/AIDS affected person is compelled, by societal reactions, to constantly live under fear and anxiety of abuse or neglect, and is therefore deprived of this capability in this regard.

F. PRACTICAL REASON

Having this capability fulfilled, according to Nussbaum, would entail one being able to form a conception of good and also being able to critically reflect on, and plan, one's life.[101] When examined in the context of HIV/AIDS affected persons, one comes across several instances of HIV/AIDS positive persons internalising the DSD that is meted out to them in different spheres of life. Accounts of many HIV positive persons reveal that the discriminatory behaviour and the stigma attached to their seropositive status results in their believing that they are paying for their 'sins', and that they 'deserve' the ill-treatment.[102] Certainly, one cannot argue that such opinions are formulated based on practical reason and with the ability to conceive good or bad through critical reflection.[103]

---

[95] Umesh S. Joge et al., *"Human Immunodeficiency Virus serostatus disclosure-Rate, reactions, and discrimination": a cross-sectional study at a rural tertiary care hospital*, 79(1) Indian J Dermatol Venereol Leprol. 135 (2013).

[96] United Nations Programme on HIV and AIDS (UNAIDS), *Unite with Women, Unite Against Violence, 2014*, available at http://www.unaids.org/sites/default/files/media_asset/JC2602_UniteWithWomen_en_0.pdf (Last visited at May 31, 2015).

[97] *Supra* note 69, 9.

[98] *Id*.

[99] United Nations Programme on HIV and AIDS (UNAIDS), *Gender Assessment Tool: Towards a gender-transformative HIV response*, 4, available at http://www.unaids.org/sites/default/files/media_asset/JC2543_gender-assessment_en.pdf (Last visited on December 14, 2014).

[100] *See* Joge, *supra* note 95.

[101] Nussbaum, *supra* note 28.

[102] *Supra* note 69, 53.

[103] *See* Amartya Sen, Inequality Reexamined 9-10 (1992) (Interestingly, one can relate this sort of capability deprivation to what Sen called the problem of 'adaptive preferences' and it is

Moreover, being able to plan one's life through critical reflection would inherently entail not living under constant fear and anxiety that leads one to abusive and suicidal tendencies. It is not difficult to see how these represent a state of being deprived of the capability of critical reflection. It is pertinent to mention, at this juncture, that the regressive impact of HIV/AIDS related DSD affects the core content of this capability as well as the capability of 'Emotions'. One must constantly bear in mind the interconnectedness and interdependent nature of the ten capabilities and the fluid state of their boundaries that Nussbaum also emphasised on. It is due to this quality of the ten capabilities that one often runs into the other and one must attempt to understand them in a fluid and interconnected way rather than attempting to demarcate and view them in a straight jacketed sense.

G. AFFILIATION

This widely phrased capability is one that HIV/AIDS affected persons are deprived of in an overarching manner. All kinds of DSD faced by such persons can be construed as affecting their ability to engage in various forms of social interactions, to live with and in connection with others, to have a social basis of self-respect and to be treated with dignity.[104]

Instances of DSD, as is evident from several accounts that have been quoted above, inherently entail a social evaluation of the affected person, one that results in the individual being treated unequally and being made to feel less worthy than others. For reasons of indulging in morally reproachable behaviour that leads one to contract the infection, as also for the reason of belonging to high risk groups, persons affected by HIV/AIDS in India suffer from multiple levels of capability deprivation and are shunned to the margins of the society.[105] Systemic DSD of the kind mentioned above ensures that these persons are not left in a position wherein they could possibly interact with members of the mainstream society. It is, therefore, not very difficult to envisage that these persons are deprived of the capability of affiliation.

H. CONTROL OVER ONE'S ENVIRONMENT

This capability includes one's ability to hold property, in terms of the real opportunity, and one's ability to seek employment on an equal basis with others.[106] In the context of HIV/AIDS affected persons, deprivation of this capability is not uncommon as a seropositive diagnosis often culminates into

evident why Nussbaum's list accounts for the same by making this capability one of the ten central human capabilities).

[104] Nussbaum, *supra* note 28.

[105] *Supra* note 69, 54.

[106] *Id*.

the exclusion of such persons from the household, family property etc.[107] Apart from adults, children are often deprived of the rightful interest in family property, more so in cases where both parents die due to prolonged AIDS induced illnesses.[108]

In the context of employment, as well, extreme DSD is faced by these persons. This starts at the level of job interviews, wherein many employers consider it unproblematic to conduct HIV tests as pre-employment procedures and to factor that into the assessment of one's suitability for the job.[109] Ignorance about modes of transmission and stigma attached to the infection lends credence to discriminatory practices at workplaces for HIV/AIDS affected persons across the world in different fields of work.[110] Instances of loss of employment on revealing one's seropositive status are not uncommon and causes many seropositive persons to conceal their status until declining health conditions leave them with no option, but to reveal it.[111] In deed every HIV/AIDS affected person is at an inherent disadvantage in terms of not being at par with her or his peers at work. What is crucial to note is that often this DSD does not stem from factual disadvantages like the need to take excess leaves for addressing health concerns, etc. but stems from ignorance about and the stigma surrounding the infection *per se*.[112]

V. THE BILL - HELPING ENHANCE CAPABILITIES?

Having given a brief overview of the Approach and demonstrated HIV/AIDS related DSD as forms of capability deprivation we will now proceed to examine the Bill in light of the same. Seeing the manner in which HIV/AIDS affected are deprived of their essential capabilities, there clearly exists a gap between these individuals and their desired capabilities. Whether and to what extent the Bill helps bridge this gap, is the question that this part seeks to address. Given the wide ambit of the Bill, we will focus our attention on certain central provisions and examine them in the aforesaid context to determine their expected impact on capabilities of HIV/AIDS affected persons. The provisions that will be examined, will be those pertaining to informed consent for testing and disclosure, children affected by HIV/AIDS and preventive strategies in the context of high risk groups. We will also attempt to elucidate on the issues

---

[107] *Id*., 9.

[108] Sarah Flicker et al., *Falling Through the Cracks of the Big Cities*, 96(4) Canadian Journal of Public Health 308 (2005).

[109] *See* Aich, *supra* note 81.

[110] *Supra* note 69, 35.

[111] *Id*., 40.

[112] The disease develops slowly and decades can pass without one having to reveal their seropositive status due to health reasons.

surrounding these provisions of the Bill and make certain recommendations to remedy their shortcomings.

A. INFORMED CONSENT

The process of obtaining informed consent before a medical procedure or treatment has long been an essential component of the internationally accepted code of conduct for medical practitioners.[113] The peculiarity of HIV/AIDS has given rise to a global consensus on the need for prior informed consent before HIV testing.[114] Despite this, the practice in India has been far behind other countries with even lesser prevalence of HIV/AIDS, as is evident from several examples of mandatory testing as cited above.[115] It is in this light that informed consent provisions contained in the Bill assume special significance.

Clause 2(n) of the Bill defines 'informed consent' for specific interventions. It entails not only the consent of the individual (or her/his representative) free from coercion, undue influence, fraud, mistake or misrepresentation, but also requires that the consent is obtained after informing the concerned person(s) of the risks, benefits, alternatives to the said intervention in a language and manner that is understood by them.

1. Informed Consent and HIV Testing

Chapter III of the Bill pertains specifically to informed consent in the context of HIV testing and treatment. Clause 5(1) necessitates the obtaining of informed consent of the individual or their representative before HIV testing, treatment, research or intervention. Clause 5(2) provides that informed consent 'shall' include pre-test and post-test counselling to the person consenting. It is, therefore, clear that counselling, both pre-test and post-test, is an essential component for the consent to be an informed one. It is however notable that the provisions leave the manner of testing, treatment, research, intervention and counselling to the guidelines to be framed in this regard. Clause 6 proceeds to lay down certain cases where informed consent is not necessary. These cases are limited to first, when a court, by order, determines that such testing or examination is necessary for determination of a question before it; second, for the use of a human body or its part(s), including blood, semen, etc., for medical research or therapy; third, for surveillance or epidemiological purposes where

[113] *See* Zulfiqar A. Bhutta, *Beyond Informed Consent,* 82(10) Bull. World Health Organ. 771-777 (2004).

[114] *See* World Health Organization, *Statement on HIV Testing and Counselling: WHO, UNAIDS re-affirm opposition to mandatory HIV testing*, (November 28, 2012), available at http://www.who.int/hiv/events/2012/world_aids_day/hiv_testing_counselling/en/ (Last visited on December 14, 2014); *See* British HIV Association, *UK National Guidelines for HIV Testing 2008*, September 2008, available at http://www.health.ny.gov/diseases/aids/providers/forms/informedconsent.htm (Last visited on December 14, 2014).

[115] *See supra* note 81.

the testing is anonymous and not for the purpose of determination of the HIV status of the concerned persons; and fourth, for the purposes of screening in a licensed blood bank.

Examining the impact of these provisions on the capabilities of HIV/AIDS affected persons is straightforward. In one sense, this provision eliminates the possibility of mandatory testing altogether. In this manner, the capability of 'bodily integrity' stands considerably enhanced. With prior informed consent being mandatory, testing without consent which seems to be prevalent in health care settings in India, is now outlawed. In many cases, discriminatory treatment in the form of denial of treatment, pre-mature discharge, etc. was not meted out at the first instance but was resorted to once surgical patients and pregnant women were tested for HIV.[116] With mandatory testing being thus prohibited, such instances will certainly reduce.

Moreover, with pre-testing and post-testing counselling being made an essential aspect of informed consent, the capability of 'emotions' stands significantly enhanced. This is so because lack of correct information regarding HIV, the consequences of acquiring the infection, the modes of transmission, etc. coupled with the stigma surrounding HIV/AIDS severely restricts one's ability to process the implications of both getting tested for HIV and being diagnosed with it.[117] Although the impact of prospective abuse and ridicule faced in the family as a result of one's seropositive status cannot be belittled, there is certainly reason to believe that the aforementioned factors result in ignorance amongst these individuals, leading to their initial feelings of fear and depression. The pre-test and post-test counselling will certainly enable these persons to deicide to test for HIV from a position of knowledge rather than ignorance. Also, it will also better enable these individuals to assess the effects and implications of their seropositive status in a manner that is less likely to yield fear and anxiety. In the same manner, the gap between HIV positive persons and their capability of 'practical reason' will also be bridged by this provision since counselling would address psychosocial and psychological fears[118] regarding future progression and management of the infection and, thereby, enable the concerned person to form a better and more informed conception of her life.

The provisions relating to informed consent for HIV testing and intervention therefore do assist in enhancing capabilities of HIV/AIDS affected persons. Having said that, however, one must be mindful of some issues that arise on an examination of these provisions. *First*, although Clause 5 provides for consent to be given by the person being tested or their representative, the

---

[116] *Supra* note 69, 18-19.

[117] *Id*., 22-23.

[118] *See* Sarah Chippindale & Lesley French, *HIV Counselling and the Psychosocial Management of Patients with HIV or AIDS*, 322(7301) BMJ. 1533-1535 (2001).

definition Clause of the Bill does not elaborate on who may constitute as a representative of the person being tested or treated and in what circumstances may personal individual consent give way to consent by a representative. Indeed, there have been instances wherein women, especially those belonging to the lower socio-economic classes of society, have been denied individual autonomy and their husband's or in-laws' consent have been sought instead of their own.[119] If the husband or in-laws were to be construed as 'representatives' of the women in such cases, it would result in hindering the woman's capability of 'bodily integrity'. The definition of who may be a representative and in what circumstances their consent may be sought must be specified in the text of the Bill. The ability to tender consent is central to one's autonomy and in order for the provision pertaining to informed consent to meaningfully enhance capabilities, the provision must expressly delineate the contours of the exceptions in the form of taking a representative's consent.[120] In this regard, we recommend that the circumstances could be limited to cases where the individual being tested or treated lacks the capacity, for reasons of minority, mental or physical disability or death.[121] So far as who may constitute one's representative, a distinction may be made between those lacking capability due to minority and those lacking capacity for other reasons. For the former, a parent or a *de facto* guardian, and if neither is available, a relative[122] may act as a representative, whereas for the latter, any relative may act as a representative. In the absence of any relative, in both these cases, the consent may be given by a medical practitioner of a certain level of seniority, with reasons recorded in writing.

The second crucial issue that will have a significant impact on Chapter III's potential to enhance capabilities of HIV/AIDS affected persons is the content of pre-test and post-test counselling, the qualifications of the counsellors etc. The Act, under Clause 46, provides that the Central government may make guidelines providing for the manner of pre-test and post-test counselling. While the approach of not providing detailed provisions relating to counselling

---

[119] *Supra* note 69, 24-25.

[120] The Bill delineates strictly worded exceptions for several provisions in the Bill. For instance, Clause 6 provides an exhaustive list of instances wherein informed consent may not be a prerequisite for HIV testing and Clause 8(b) of the Bill provides a similar list of exceptions for disclosure of one's HIV status; *See supra* note 12 (A similar approach is advisable so far as resorting to representatives' consent is concerned).

[121] Similar details were provided for in the 2012 Draft of the Bill.

[122] Clause 2(u) of the Bill defines 'relative' as follows: " (*u*) "relative", with reference to the protected person, means:

(*i*) spouse of the protected person;
(*ii*) parents of the protected person;
(*iii*) brother or sister of the protected person;
(*iv*) brother or sister of the spouse of the protected person;
(*v*) brother or sister of either of the parents of the protected person;
(*vi*) in the absence of any of the relatives mentioned at sub-clauses (*i*) to(*v*),any lineal ascendant or descendant of the protected person;
(*vii*) in the absence of any of the relatives mentioned at sub-clauses (*i*) to (*vi*), any lineal ascendant or descendant of the spouse of the protected person;"

in the Bill is understandable,[123] it is imperative that guidelines that may be subsequently framed do not undermine the capability enhancing potential of the Bill. In order for the guidelines to be meaningful, therefore, it is recommended that attention be paid to international practices and recommendations on voluntary counselling and testing. For instances, the World Health Organization provides guidance on HIV counselling and also provides specifically for counselling for adolescents, couples, children, intravenous drug users, etc.[124] Seeing how age, gender, social background, high risk behaviour, etc. are intrinsically linked to the DSD and resultant capability deprivation that an HIV/AIDS affected person faces, taking these factors into account would indeed be critical to the success of these guidelines. It is also crucial to point out that while it may be advisable that the guidelines lay down the broad objectives and the factors to be taken into account, it is certainly necessary to leave sufficient room for the counsellors to adapt to the difference in facts of each case.[125] As has been highlighted before, the infection when combined with other social parameters gives rise to unique issues for HIV/AIDS affected persons and these factors ought to be taken into account by the counsellors. Moreover, the guidelines should also provide for the minimum qualifications of the counsellors to be appointed by centres licensed for HIV testing in order to ensure that the quality of the counselling being provided is not compromised. Yet another factor that should to be taken into account in the guidelines would be the option to an affected individual to avail follow-up counselling. The lack of such follow-up counselling could prove to be detrimental to the capability enhancing potential of the exercise of counselling itself. Lastly, we also recommend that the guidelines provide for a fixed time period within which all such licensed organisations must appoint counsellors.

---

[123] Often arguments are made that details of this nature are better left to delegated legislature as opposed to being provided for in the parent legislation in order to avoid rigidity that accompanies legislative drafting.

[124] World Health Organization, *HIV and Adolescents: Guidance for HIV Testing and Counselling and Care for Adolescents Living with HIV*, 2013, available at http://apps.who.int/iris/bitstream/10665/94334/1/9789241506168_eng.pdf?ua=1 (Last visited on May 31, 2015); World Health Organization, *Guidance on Couples HIV Testing and Counselling Including Antiretroviral Therapy for Treatment and Prevention in Serodiscordant Couples*, April 2012, available at http://apps.who.int/iris/bitstream/10665/44646/1/9789241501972_eng.pdf?ua=1 (Last visited on May 31, 2015); World Health Organization, *Guidelines on HIV Disclosure Counselling for Children up to 123 Years of Age*, 2011, available at http://whqlibdoc.who.int/publications/2011/9789241502863_eng.pdf?ua=1 (Last visited on May 31, 2015); World Health Organization, *Guidance on Testing and Counselling for HIV in Settings Attended by People Who Inject Drugs*, 2009, available at http://www.who.int/hiv/topics/idu/care/GuidanceTC_IDUsettings.pdf?ua=1 (Last visited on May 31, 2015); World Health Organization, *Guidance on Provider- Initiated HIV Testing and Counselling in Health Facilities*, 2007, available at http://whqlibdoc.who.int/publications/2007/9789241595568_eng.pdf?ua=1 (Last visited on May 31, 2015).

[125] United Nations Programme on HIV and AIDS (UNAIDS), *Voluntary Counselling and Testing (VCT)*, May, 2000, available at http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/dataimport/publications/irc-pub01/jc379-vct_en.pdf (Last visited on December 14, 2014).

2. Informed Consent and Disclosure

Clause 8 of the Bill starts with a *non obstante* clause and provides in sub-clause (1) that no person can be compelled to disclose their HIV status, except by an order of the court that states that such disclosure is essential for the purpose of determination of an issue before it. The sub-clause further states that no person can be compelled to disclose the HIV status, or any private information given in confidence, of another person except with the informed consent of the concerned person or their representative, in a manner similar to Clause 5. Sub-clause (2) of Clause 8 provides for further exceptions to the need for informed consent for disclosure of the HIV status of another person. This entails cases wherein disclosure of a person's HIV status is made by one healthcare provider to another when it is necessary for her treatment; when disclosure is deemed necessary by a court order in order to determine an issue before it; in suits of proceedings when disclosure is necessary for filing; when disclosure is made to the individual's partner in accordance with Clause 9; when it pertains to statistical or other information that could not, reasonably, lead to the individual being identified and when it is disclosed to officers of the government, central or state, or the State AIDS Control Society for the purposes of evaluation, monitoring and supervision. Clearly, the exceptions are fairly and rigidly framed and in all other circumstances, there is a prohibition on compelling one to disclose their own or someone else's HIV status.

Clause 9 of the Bill provides that a physician or a counsellor may disclose to the partner of an HIV positive person their seropositive status, subject to certain conditions being fulfilled.[126] The third proviso to this Clause states that the healthcare provider 'shall not' inform the partner of the women of her seropositive status where there is a reasonable apprehension of violence, abandonment or other actions being initiated against her, affecting negatively her mental and physical health or safety, her children or close relatives.

A provision like Clause 8 is likely to enhance the capabilities of 'life', 'bodily health', 'emotions', 'practical reason', 'affiliation', 'sense, imagination and thought' and 'control over one's environment'. This is so because with compelled disclosure of one's HIV status prohibited, discriminatory practices that ensue therefrom in spaces like health care setups can be contained. The capabilities of 'life' and 'bodily health' will be enhanced as medical services will become substantively accessible to these persons, without the fear of being transferred to a different ward, or discharged early etc. This provision will also result in lessening of the stigma around HIV positive persons as such

[126] Conditions to be fulfilled are that the healthcare provider must be convinced that the partner is at a significant risk of transmission of HIV, that such person has been counselled to inform their partner, the healthcare provider is satisfied that the person will not inform his or her partner and the health care provider has informed the person of his or her intent to disclose the person's HIV status to their partner.

stigma stems largely from the knowledge of an individual's seropositive status. The effective redressal of the aforesaid concerns would lead to reduction in reactions of fear and anxiety common amongst seropositive persons, thereby enhancing the capability of 'emotions' as well as 'practical reason'. Similarly, humiliation that often stems from forced disclosure of one's HIV positive status will cease to a great extent, thereby enhancing the capability of 'affiliation'. Such a provision (particularly in the field of education) enhances the capabilities of HIV positive persons by prohibiting the denial of admission to HIV positive persons on grounds of their seropositive status, thereby enhancing the capability of 'senses, imagination and thought'. Similar application of the provision in job interviews, and in the work place generally, will enable a significant number of HIV positive persons to attain jobs and continue with their work lives at par with others without the humiliation that often accompanies mandatory disclosure of their HIV status at the workplace.[127] In this manner, this provision has the potential of significantly enhancing the capability of 'control over one's environment'.

Clause 9, it is evident, attempts to strike a balance between capabilities of the HIV positive person and those of their partner, as the partner is likely to be at a significant risk of acquiring the disease. Partner notification has attracted much attention in the global debate on strategies for controlling the spread of HIV/AIDS and balancing of competing interests, given the increased risk of violence that a disproportionately high number of women face on disclosure of their HIV status to their partners.[128] The aforementioned proviso to Clause 9 makes a special provision for women by making it obligatory for healthcare professionals to take threats of violate, etc. into account. In this manner, not only is the provision in consonance with the international view on the subject, it also enhances women's capabilities and reduces the impact that coupling of disadvantages[129] has on HIV positive women.

Although the aforementioned provisions make a significant headway in bringing HIV/AIDS affected persons closer to their central human capabilities, certain issues continue to remain unaddressed. Much like the provisions of Chapter III, Clause 8 also relies on 'informed consent' and thereby attracts the same criticisms of under-specification in terms of definition of 'representative' and content of pre and post-test counselling, that were levelled against Chapter III provisions. Moreover, the exception the proviso to Clause 9 creates, although laudable for taking into account the gender dimension of HIV disclosure, is extremely widely worded. While the capabilities of an HIV positive

[127] The fear of humiliation at the workplace compels many to quit their jobs altogether; *Supra* note 69, 34.

[128] *See* Richard North & Karen Rothenberg, *Partner Notification and the Threat of Domestic Violence against Women with HIV Infection*, 329(16) New England J. of Med., 1194-1196 (1993).

[129] Doessel, *infra* note 134.

woman are certainly enhanced, there seems to be little reason to completely prioritise the woman's capabilities over the significant threat of her partner being deprived of many of his capabilities. It is certainly evident why the Bill, given its aim of protecting HIV positive persons, opts for a broadly worded protectionist provision. However, given the far reaching implications of a woman's HIV status not being disclosed to her partner, there is certainly reason to worry that a balance has not been struck and the HIV woman's capabilities have been prioritised over her partner's. To remedy such blatant prioritising and to make the provision more balanced in its approach, perhaps guidelines could be laid down to monitor how the health care professional concerned exercises his or her discretion in determining whether a case is one in which he should not resort to partner notification. Such guidelines could also provide for mandatory counselling of the partner and/or his family members at the time of notification in cases where, according to the health care professional, it is likely to eliminate the possibility of domestic violence, etc.

B. ANTI-DISCRIMINATION PROVISIONS

Chapter II of the Bill pertains to prohibition of certain acts. Clause 3 therein, prohibits discrimination against 'protected persons'[130] on HIV/AIDS related grounds, and the inclusive list therein prohibits denial, termination of or unfair treatment in several spheres of public life like education, employment, health care services, access to recreational services, occupying property, holding office, etc.

This overarching provision prohibiting varying kinds of discrimination against HIV/AIDS affected persons and addresses several capability deprivations faced by these persons at once. With all kinds of discrimination prohibited, denial of treatment in the health care set up, denial of education, denial of equal opportunities at work, denial and stigmatisation in all social interactions are all prohibited under the Bill. When read in line with provisions of informed consent and disclosure, the Bill certainly brings with it immense potential of mitigating the DSD faced by individuals and, thereby, enhancing different capabilities that HIV/AIDS affected persons are deprived of. Removal of DSD in general enhances the capabilities of 'emotions', 'practical reason' and 'affiliation'. Particularly, access to health care facilities without the associated DSD enhances capabilities of 'human life' and 'bodily integrity' while access to education enhances the capabilities of 'senses, imagination and thought' and 'control over one's environment'. Also, since a real opportunity for employment entails the opportunity to be able to acquire qualifications necessary for employment; removal of DSD in the context of education enhances capabilities of 'control over one's environment'.

[130] Clause 2(s) defines 'protected person' as a person who is "(*i*) HIV-Positive; or (*ii*) ordinarily living, residing or cohabiting with a person who is HIV positive person; or (*iii*) ordinarily lived, resided or cohabited with a person who was HIV positive."

C. HIGH-RISK ACTIVITIES AND HIV

Persons indulging in high-risk activities, including intravenous drug users (IDU), female sex workers (FSW) and MSM, face a greater risk of contracting HIV in comparison to other members of society.[131] Studies conducted in 2011 revealed the average rate of HIV in India is 0.27%[132], as opposed to 7.14% in IDU's, 4.43% in MSM's and 2.67% in FSW's. The highest rates of HIV have been found in Trans-Genders (TG) pegged at 8.82%.[133] These disproportionate rates of infection show that HIV/AIDS exists in higher frequency in certain groups as compared to others. It is, therefore, necessary to prioritise the needs of such groups in order to reduce the overall rates of HIV/AIDS.

Having said that, it is also pertinent to note that the fact of an individual belonging to these groups by itself has a negative effect on their capabilities, both as individuals and as a collective group in the society. The treatment they are meted out, in fact, clearly exemplifies what Sen calls 'coupling of disadvantages'.[134] These groups, due to their indulgence in high risk behaviour, are already pushed to the margins of the society, with ridicule and stigma attached to their activities. Add to this the hardships faced by HIV/AIDS affected persons, and we arrive at the coupled disadvantage and capability deprivation that is faced by HIV positive IDUs, FSWs, MSMs and TGs. It is most crucial that any policy regarding individuals indulging in high risk activities be mindful of this.

Social and legal barriers standing between these high-risk groups from receiving financial and medical assistance impair their capabilities and prevent them from escaping their predicament. Any individual involved in these activities suffers from this impairment. Access to resources like land and medical care[135] is extremely difficult for such groups. Medical staff who lack sufficient medical training often neglect patients who come from such groups and this discrimination prevents these high-risk groups from seeking medical attention.[136] These capabilities can become further impaired, when an individual suffers from HIV. In the sphere of employment, as well, such individuals are excluded and are not deemed fit for any mainstream jobs. They are also

---

[131] National AIDS Control Organisation (NACO), *Department of AIDS Control - Ministry of Health & Family Welfare Government of India: Annual Report*, *2013 – 2014*.

[132] *Id*.

[133] *Id*.

[134] D.P. Doessel, *Applying Concepts from Mill and Sen to the Standard of Living for Disabled People* (University of Queensland, Centre for Mental Health Research, 2004) (In this concept Sen talked about of handicaps that went alongside disability, which are "earning handicaps" and 'conversion handicaps'. He believed that individuals with disability suffered a double disadvantage. He says that individuals with a disability often have higher expenditures then able-bodied people therefore requiring a higher income, along with that they will also other requirements as higher income may not suffice, such as things like wheelchairs, ramps, etc.).

[135] *Supra* note 67.

[136] *Id*.

more susceptible to violence, both at the hands of the police and their families, compelling them to constantly live in fear and anxiety.[137] All this cumulatively deprives these individuals of the capabilities elaborated above,[138] to a much greater extent than other HIV/AIDS affected persons.

1. Risk Reduction Strategies and High Risk Activities

The Bill, in order to facilitate assistance to high risk groups legalises the provision of such assistance persons and organisations. There have been cases in the past, where attempts to assist high risk groups have been deemed illegal and persons providing such assistance have been prosecuted. In one case, a woman was imprisoned overnight as she had helped a woman in a brothel to escape her exploitative situation.[139] Such criminalisation, evidently, hampers and risk reduction strategies that NGOs and other organisations may want to initiate in order to enable members of high risk groups to stay HIV free. In order to prevent such hindrances, Clause 22 states,

> "Notwithstanding anything contained in any other law for the time being in force any strategy or mechanism or technique adopted or implemented for reducing the risk of HIV transmission, or any act pursuant thereto, as carried out by persons, establishments or organisations in the manner as may be specified in the guidelines issued by the Central Government shall not be restricted or prohibited in any manner, and shall not amount to a criminal offence or attract civil liability".[140]

The first illustration to this Clause gives greater insight into how this clause is to be operationalised. It cites an instance wherein A may supply condoms, a widely accepted HIV risk reduction strategy, to a sex worker, or to a client of the said sex worker, none of the three parties can be held criminally or civilly liable for such acts, nor can they be prohibited or prevented from implementing or using the said strategy.

This provision, if implemented effectively, can provide significant assistance to these groups in terms of reducing their risk to acquiring HIV and, thereby, enhancing their capabilities. As explained above, capability deprivations faced by HIV positive persons belonging to high risk group are

---

[137] *Id*.

[138] *Supra*, Part IV.

[139] Ruchira Gupta, *Survivors of Prostitution Changed the Law in India*, May 8, 2013, available at http://www.huffingtonpost.com/apne-aap/survivors-of-prostitution_b_3223183.html (Last visited on December 12, 2014).

[140] The Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Bill, 2014, Clause 32.

substantially higher due to coupling of disadvantages. This provision grants a measure of legality to attempts aimed at bringing such persons closer to the realisation of their capabilities. This is, indeed, a promising step forward in mitigating the spread of HIV. Many have also argued that, while the transfer of HIV is usually concentrated among particular groups in society[141], the use of preventive measures and antiretroviral therapy can significantly reduce the overall rates of infection in all groups of society.[142] Keeping this in mind, conditions aimed at preventing the spread of HIV within high risk groups ushers in the promise of enhancing capabilities and reducing prevalence of HIV across the country.

However, despite the great strides made by this provision in terms of enhancing capabilities of those belonging to high risk groups, it is significant to note that Clause 22 also significantly relies on guidelines being issued by the State. Thus, only strategies and mechanisms carried out in the manner specified in such guidelines would be protected under Clause 22. Although the illustrations do provide some guidance in this regard, what these guidelines will detail remains to be seen. In order to further the intent of this provision, the guidelines should, while providing for the manner in which these strategies must be adopted, account for the realities faced by NGOs and other social workers when attempting to approach these high risk groups. With the current illegality of homosexuality[143] and organised prostitution,[144] this is indeed going to be a difficult task for the government. However, given the delicate nature of the issues involved, guidelines that will concretise this provision have an extremely onerous task ahead of balancing the objectives of this Bill with the problematic positions of law on high risk activities.

D. CHILDREN AFFECTED BY HIV/AIDS

Often scholars find it difficult to apply to the Approach to children, and compare their capabilities against their adult counterparts. This is primarily because, unlike adults, children usually do not have the physical or mental development which can be applied practically in their day-to-day lives. In an interview, conducted by Madoka Saito[145], Sen answered questions in relation to the approach and its application to children. According to Sen the ca-

---

[141] Centre for Disease Control and Prevention (CDC), *HIV-Specific Criminal Laws*, 2014, available at http://www.cdc.gov/hiv/policies/law/states/exposure.html (Last visited on December 10, 2014).

[142] Centre for Disease Control and Prevention (CDC), *Prevention Benefits of HIV Treatment*, 2013, available at http://www.cdc.gov/hiv/prevention/research/tap/ (Last visited on December 10, 2014).

[143] Dhananjay Mahapatra, *Supreme Court Makes Homosexuality A Crime Again*, Times of India, December 12, 2013.

[144] The Immoral Traffic (Prevention) Act, 1986.

[145] Madoka Saito, *Amartya Sen's Capability Approach to Education: A Critical Exploration*, 37(1) Journ. of Phil. of Edu. 25 (2003).

pabilities of children should not be measured by the freedom they have at that point in time, rather, they should be measured in terms of the freedom that they will have in the future.[146] He gives an example of a child, who may not wish to receive a vaccination but if the child does receive it he or she would be free of the disease associated with that vaccination the rest of his or her life allowing a greater scope for achieving future goals, life ambitions and good physical health.[147] Thus, it is evident, that capability deprivations faced by children require one to approach the issue slightly differently from how one would do so for adults.

According to UNICEF, 220,000 children in India are infected with HIV and AIDS.[148] Moreover, 35% of all people infected by HIV and AIDS are below the age of 25, while 50% of new infections occur among 15-24 year olds.[149] In a UNDP study conducted by Miriam Lyons,[150] it is argued that the issues faced by children affected by HIV are significantly distinct from those faced by HIV positive adults. Therefore, there is compelling need for any law, as also the Bill, to incorporate provisions specific to children in order to facilitate and support a child's capabilities in order to further his or her future freedoms.

In order to examine capability deprivations faced by children infected by HIV, we will try and analyse capabilities that are particularly essential for children, in light of Nussbaum's central capabilities, and how future freedoms of these children would be affected by capability deprivations faced during childhood. As will be evident from elaboration of different issues below, the Bill recognising children as a distinct group with distinct needs is a very progressive step at a time when this need has been recognised internationally.[151] The following analyses will take a closer look at certain children specific provisions to assess their impact on the capabilities of these children and also suggest the manner in which these provisions can be better utilised to enhance children's capabilities even further.

---

146 *Id*.

147 *Id*.

148 United Nations Children's Emergency Fund (UNICEF), *HIV/AIDS: The Children*, 2012, available at http://www.unicef.org/india/children_2358.htm (Last visited on December 14, 2014).

149 *Id*.

150 Miriam Lyons, *The Impact of HIV and AIDS on Children, Families and Communities: Risks and Realities of Childhood during the HIV Epidemic*, 3 HIV and Development Program 1 (2008).

151 *Id*.

1. Lack of Shelter and Family Support Faced by Children Affected by HIV

In a study conducted by UNDP,[152] it was found that since 1981, the time when the HIV virus had been first discovered, till 2008, over three million children were born HIV-positive and over eight million mothers of HIV-positive children died from HIV/AIDS.[153] In India high-risk groups, like FSW, are found to have higher concentrations of HIV when compared to other members of society.[154] The children of these groups often have only a single parent to support them, who may already be suffering from HIV/AIDS[155] and the loss of that single parent can leave the child completely devoid of parental support. More recent studies reveal that over 17.8 million children under the age of eighteen have been orphaned by HIV/AIDS and it is predicted that by 2015, the number will go up to twenty five million.[156]

If we apply Nussbaum's capabilities in this context, it becomes evident that all of a child's future capabilities can be impaired as a result of HIV/AIDS. When analysed in terms of capabilities, the loss of a parent can impair a child's capabilities for her entire life not only in terms of being able to comfortably form 'affiliation' with a supportive figure like a parent, but also in terms of 'human life' and 'bodily health', due to low financial support for healthcare, shelter and lack of guidance that a parent may provide. The loss of a parent also puts a significant burden on the child in terms of finding shelter and earning a living. If a child is compelled to earn a living on his or her own, he or she loses the chance to enjoy the freedom to 'play', have 'control over one's surroundings', and being able to maximise his or her 'senses, imagination and thought'. Furthermore, due to lack of proper education, a child may be compelled to take up low paying jobs, when through education he or she could have achieved much more, both intellectually and financially and would enhance all of his or her capabilities substantially. This results in a domino effect that begins with one capability being affected but ultimately leads to the rest of the capabilities getting diminished as well.

In a similar vein, an inverse situation can also be understood. Children who face homelessness tend to become dependent on substance abuse as a form of recreation.[157] As seen in studies, India intravenous drug

---

[152] *Id*., 1-2.

[153] *Id*.

[154] *Supra* note 131.

[155] *See* Lyons, *supra* note 150.

[156] United Nations Children's Emergency Fund (UNICEF), *Towards an AIDS-Free Generation–Children and AIDS: Sixth Stocktaking Report*, (2013), available at http://www.unicef.org/publications/index_70986.html (Last visited on December 11, 2014).

[157] Center for Disease Control and Prevention (CDC), *HIV Among Youth*, (March 2014), available at http://www.cdc.gov/hiv/risk/age/youth/index.html?s_cid=tw_std0141316 (Last visited on December 14, 2014).

users ('IDU') are found to have a 7.14% chance of being infected by HIV/AIDS, which is significantly higher than the national average that is currently at 0.27%.[158] To fuel their drug use, they may resort to exchanging sexual intercourse for drugs, money or shelter, which increased risk of both acquiring and transfer of HIV.[159] That compounded with the increased risk of suffering from HIV infection through the reuse of syringes, puts them at an extremely high risk of acquiring HIV.

In order to help bolster a child's capabilities by provision of long-term shelters and financial support steps should be taken to help sustain the same. The Bill, in order to address these issues, lays down certain provisions to further these interests. Clause 16(1)[160] of the Bill pertains to protection of property of children affected by HIV/AIDS. It imposes an obligation on the State to take measures to protect the property of a child affected by HIV/AIDS. Therefore, this provision has the potential to enhance a child's prospects to hold and retain property rights in future and protect the child from property related exploitation, etc. during his or her childhood. Followed by this is sub-clause (2), which protects the interest of the child in relation to his or her property. This clause states that a Child Welfare Committee[161] ('CWC') may be approached for the safekeeping of documents related to the property rights of any child affected by HIV/AIDS, by their parent, guardian or any other person protecting the child's interest. This sub-clause also vests the CWC with the power to accept complaints if a child is disposed from his or her property or if his or her property has been trespassed.

While these provisions can support a child if he or she can receive any property that can be monetised, , they must be supplemented with

---

158 *Supra* note 131.

159 CDC, *supra* note 157.

160 The Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Bill, 2014, Clause 16 (1). It states that:

("The Central Government or the State Government, as the case may be, shall take appropriate steps to protect the property of children affected by HIV or AIDS for the protection of property of child affected by HIV or AIDS.

(2) The parents or guardians of children affected by HIV and AIDS, or any person acting for protecting their interest, or a child affected by HIV and AIDS may approach the Child Welfare Committee for the safe keeping and deposit of documents related to the property rights of such child or to make complaints relating to such child being dispossessed or actual dispossession or trespass into such child's house.

Explanation— For the purpose of this section, "Child Welfare Committee" means a Committee set up under § 29 of the Juvenile Justice (Care and Protection of Children) Act, 2000").

161 The Juvenile Justice Act (Care and Protection of Children) Act, 2000, §29 (1). It states that:

("The State Government may, [within a period of one year from the date of commencement of the Juvenile Justice (Care and Protection of Children) Amendment Act, 2006, by notification in the Official Gazette, constitute for every district], one or more Child Welfare Committees for exercising the powers and discharge the duties conferred on such Committees in relation to child in need of care and protection under this Act").

guidelines in a manner that makes it easier for the child to be able to go back and reclaim her property at the age of majority. Clause 16(1) already provides that the Central and State Government must take appropriate steps in order to safeguard a child's property. These steps should certainly entail clarifying the procedure to assist the child to track the property that has been left in his/her name and the manner in which it could be claimed. In relation to dispossession or trespass, further guidelines should be laid down in relation to what action could be taken by the CWC in relation to these activities and whether the CWC could prosecute on behalf of the child. Essentially, it is critical that the legislation outlines the powers of the CWC in the Act itself, as opposed to a reference to the Juvenile Justice Act, 2000.[162] This can enhance the capability of 'control of one's environment', particularly in the context of 'material' environment. Therefore, although this Clause certainly enhances this capability, by making the possession and retention of material goods far easier, the lack of mechanisms that can help the child take such interests further impairs its utility. Such concerns must animate the formulation of guidelines in this regard.

Another provision which plays an important role with regard to family support is Clause 33 of the Bill, which talks about the living will of parents or guardians of children affected by HIV, whereby a friend or relative may be nominated to act as the child's legal guardian. This can be read alongside the statistics noted earlier[163] pertaining to disproportionate rates[164] of homelessness amongst children orphaned due to HIV. As pointed out by Lyons, in the context of the role of parents, the illness or death of parents or guardians due to HIV/AIDS can rob a child of the emotional and physical support that defines and sustains childhood.[165] It leaves a void where parents and guardians once provided love, protection, care and support.[166] Since HIV is often transmitted to sexual partners, children are more likely to lose both parents to HIV/AIDS. Someone is needed to step into parental roles so that children can survive and develop into healthy and productive adults.[167] In order for this clause to be effective, however, guidelines must be laid down in order to ensure that the nominee, who is supposed to take up the guardianship of the child, is notified well in advance along with the child in order to prepare them both in a potentially critical situation.

---

[162] *Id*.

[163] Lyons, *supra* note 150.

[164] Sarah Flicker et al., *Falling Through the Cracks of the Big Cities*, 96(4) Canadian Journal of Public Health, 308 (2005).

[165] Lyons, *supra* note 150.

[166] *Id*.

[167] Avert, *Children, HIV and AIDS*, 2014, available at http://www.avert.org/children-and-hiv-aids.htm (Last visited on July 15, 2016).

2. HIV/AIDS Related Education and Children

Another issue which is particularly important when examining children specific concerns is education, communication and information with regard to HIV/AIDS and sexual health. Education plays a significant role in the prevention and management of HIV/AIDS. Over long-term periods, education can reduce the prevalence of HIV as it has been shown in some countries of the world.[168] Moreover, the awareness levels of HIV are relatively low in India among the youth population in India.[169]

HIV/AIDS related information can help children improve their capabilities[170] of 'life', 'bodily health' and 'bodily integrity'. To an extent it would also give children more 'control over their environment, by helping them take decisions that can determine their life opportunities and help them create an understanding on their illness and how it would affect them in society among their peers.

This is so because when analysed in terms of the child's future freedom education can help the child make better decisions in matters of sexual intercourse, drug use and other high risk HIV activities, thereby decreasing the chances of an infection. This can significantly improve a child's future prospects by avoiding infection altogether as prevention is far more financially and medically feasible, when compared to maintenance costs when one acquires HIV.[171]

Clause 17, which states that the government, both state and central, must formulate HIV and AIDS related information, education and

---

[168] United Nations Programme on HIV and AIDS (UNAIDS), *UNAIDS Report on the Global AIDS Epidemic*, (2013), available at http://files.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/UNAIDS_Global_Report_2013_en.pdf (Last visited on July 15, 2016) (Between the years 2001 and 2012 there had been an increase in education provided to youth in sub-Saharan Africa. In that time period the prevalence of HIV among young people dropped by 42%).

[169] Sanghmitra Acharya & Rajib Dasgupta, *HIV/AIDS and Adolescents: Some Issues and Concerns from India*, 35(1-2) Indian Anthropologist 132-133 (2005) (It was found in a study that 76% of all youth involved in the study 'knew' about the disease but only 22% knew one correct mode of transmission of the infection. In the same study the researchers pointed out that whatever medium the individuals heard about the infection may not provided sufficient information explaining how it is transferred and under what circumstances); *See supra* note 148 (It must also be noted that 50% of all new infections occur among 15-24-year-olds).

[170] Agarwal, supra note 64, 47-48.

[171] In 2013 the average cost of 1st line antiretroviral treatment is about $115 (about Rs.7000), which for many is still expensive although prices have fallen dramatically. This data is available at http://www.avert.org/antiretroviral-drug-prices.htm. It has been shown that the average cost savings per person in India, would be $1,900 each year, if he or she does not suffer from the infection; *See* Anonymous, *AIDS in India: The cost of living*, The Economist (New Delhi) June 15, 2013.

communication material in an age-appropriate, gender-sensitive, non-stigmatising and non-discriminatory manner can play a significant role in the long-term reduction of HIV among youth, thereby leading to significant capability enhancement in the long run. However, this provision too needs to be supplemented with guidelines that reflect the intent of this provision and ensure its effective implementation. In this regard, such guidelines could provide for mandatory HIV/AIDS related education in schools from the time a child is likely to be sexually active. The content of this education, too, could be provided by the State AIDS Control Society[172] in order to ensure that such education is provided in an objective manner, without being blighted by prejudice that administrative authorities in educational institutions may have towards HIV/AIDS.

3. Guidelines for Care, Support and Treatment of Children Infected with HIV

Irrespective of whether or not there are measures put in place to prevent and reduce the spread of HIV or AIDS among children, there has to be a good system in place to provide them with care, support and treatment if they do suffer from the infection. This is indispensable if their capabilities are to be truly enhanced. To address this, Clause 18(1) of the Bill imposes obligations on the Central Government to lay down guidelines for care, support and treatment of children infected with HIV or AIDS.

Statistically, it has been found that antiretroviral therapy starting from twelve weeks of life, amongst HIV infected children, irrespective of the CD4[173] count, decreases chances of death by seventy five percent.[174] This highlights the importance of receiving early and regular antiretroviral therapy. This clause can, therefore, significantly take children forward in terms of medical therapies available and the different types of options available to them. It can improve their life expectancy and overall well-being.

This provision, therefore, has the potential of enhancing capabilities[175] like 'life', 'bodily health' and 'bodily integrity' immensely. 'Practical reason' is another capability that can improve significantly as this can enable a

---

[172] Acharya & Dasgupta, *supra* note 169.

[173] AIDS.gov, *What is CD4 count and why is it important?*, available at http://www.aids.gov/hiv-aids-basics/just-diagnosed-with-hiv-aids/understand-your-test-results/cd4-count/ (Last visited on December 14, 2014). It states that:

> ("CD4 cells or T-cells are a type of white blood cells that play a major role in protecting your body from infection. They send signals to activate your body's immune response when they detect 'intruders', like viruses or bacteria. Once a person is infected with HIV, the virus begins to attack and destroy the CD4 cells of the person's immune system. HIV uses the machinery of the CD4 cells to multiply (make copies of itself) and spread throughout the body").

[174] *Supra* note 169.

[175] *Id*.

child to rationally create and assess future prospects for himself or herself as their life expectancy can rise with the use of antiretroviral therapies.[176] Thus, it could allow for children to stably account for future plans and keep achievable goals in their hands.

Having said that, the provision is extremely widely phrased and leaves much room for substantiation. As in the case of guidelines pertaining to many other provisions, these guidelines must be framed bearing in mind certain practical realities. For instance, guidelines under Clause 18 must be framed bearing in mind that since children have to, on an average, go through 20 years of antiretroviral therapy they tend to build more resistance to antiretroviral therapy drugs. Thus, they might have to change the drugs they use.[177] Moreover, these guidelines must also provide for means of support that enable a child to balance his or her educational and personal life in order to maintain affiliations with other people and have literary skills that can be compounded to improve his or her capabilities.

4. Guardianship of Siblings

Despite its laudable attempts in the aforementioned Clauses, one area that the Bill does not address suitably, with reference to children, pertains to guardianship. As provided in Clause 32,

> "a person below the age of eighteen but not below twelve years, who has sufficient maturity of understanding and who is managing the affairs of his family affected by HIV and AIDS, shall be competent to act as guardian of other sibling below the age of eighteen years for any purpose that he may be required to discharge as a guardian for certain purposes".[178]

---

[176] *Id*.

[177] *Id*.

[178] The Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Bill, 2014, Clause 32. It states that:

("Notwithstanding anything contained in any law for the time being in force, a person below the age of eighteen but not below twelve years, who has sufficient maturity of understanding and who is managing the affairs of his family affected by HIV and AIDS, shall be competent to act as guardian of other sibling below the age of eighteen years for the following purposes, namely:—

(a) admission to educational establishments;
(b) care and protection;
(c) treatment;
(d) operating bank accounts;
(e) managing property; and
(f) any other purpose that may be required to discharge his duties as a guardian.

Explanation— For the purposes of this section, a family affected by HIV or AIDS means where both parents and the legal guardian is incapacitated due to HIV-related illness or

While this clause gives any young individual who may need to support his sibling additional rights, which may or may not improve the capabilities of a child affected by HIV, it could possibly affect the capabilities of the sibling who takes on the role of a guardian. Lyon's talks extensively on young individuals who have to stay back and support their HIV affected siblings and parents.[179] She points out that children in such situations often take up responsibilities of decision-making and are in charge of doing household tasks and managing an income.[180] Moreover, due to lack of proper training, they often bear an extremely high risk of being exposed to the disease.[181] They often forfeit their education in order to generate an income for their family, thereby limiting the possibility of a successful childhood, which goes on to affect their future as adults.[182]

Giving young individuals extra rights to help support their HIV affected sibling could help to a very limited extent, while in the long run it could impair his or her capabilities. In terms of future freedom, a child's capabilities go down in terms of 'senses, imagination and thought', 'emotions', 'affiliation' and 'control over one's environment'. He or she may no longer be able to interact with the outside world with complete freedom, primarily because assisting his or her sibling would take up a significant amount of their time. In order to address this concern, the Clause could be modified, to be more useful by giving an older sibling the ability and rights to help his or her younger sibling as and when required, while also enabling him or her to seek professional and long-term support for his or her sibling.

E. GENERAL COMMENTS

Apart from the aforementioned central provisions, there are certain other provisions in the Bill that merit immediate attention. *First*, although under-specification in terms of excessive reliance on guidelines has already been emphasised on, it is necessary to point out the significance of the same again. Although it is not advisable to have all details of an Act listed in the parent legislation and often delegated legislation is a better means to achieve certain end, it is crucial that the guidelines are framed at the earliest, keeping in mind earlier suggestions. To ensure this, the Bill could provide for a time period of, perhaps, three hundred and sixty days from the date of the Bill becoming effective to lay down all the necessary guidelines. Moreover, although individual provisions make it obligatory for the government to issue guidelines by using the word 'shall', Clause 46 of the Bill states that the government, both Central

AIDS or the legal guardian and parents are unable to discharge their duties in relation to such children").

179 Lyons, s*upra* note 150.

180 *Id*.

181 *Id*.

182 *Id*.

and State, 'may' make guidelines consistent with the Act. This discrepancy is problematic and it is suggested that it be remedied at the earliest by altering Clause 46 to make the obligation mandatory and not discretionary, seeing as how the fruit of the Bill is going to depend largely on these guidelines. Absence of such a mandatory obligation would render this legislation fruitless and would reflect mere lip service by the Government so far as interests of those affected by HIV/AIDS are concerned.

Second, while the substantive provisions pertaining to anti-discrimination and informed consent for testing and disclosure are laudable, it must be noted that the Bill does not prescribe consequences for not abiding with these provisions. Therefore, though these provisions entitle one to approach the court for enforcement, the real impact of these provisions must be seen in preventing discriminatory acts and non-consensual testing and disclosure from happening. Perhaps including certain penalties for not conforming to these provisions could be included in Chapter XIII of the Bill in order to strengthen these provisions.

VI. CONCLUSION

HIV/AIDS, apart from being a life threatening disease, is a persistent source of capability deprivation for millions across the world. Although merits of the Approach continue to be debated, one must not forget the amount of research and academic contributions that it has generated in the recent past. Indeed, in the case of HIV/AIDS affected persons, the Approach proves to be a normatively superior framework as it allows us to couch the DSD faced by HIV/AIDS affected persons in most the most appropriate terms: as deprivation of capabilities and real opportunities to achieve functionings that these individuals may have reasons to value.

Viewing HIV/AIDS related DSD, thus, the paper attempted to analyse the Bill's contribution to enhancing central human capabilities of those affected by HIV/AIDS in light of the ten central human capabilities listed by Nussbaum. A detailed analysis of some of the central provisions of the Bill throws light on the significant leaps its effective implementation could make in terms of capabilities. The fact that age, gender and high risk groups have particularly been taken account of and attempted to be accommodated throws light on how progressive, and largely in tune with the international consensus on these issues, the Bill is.

Having said that, the real success of the Bill is largely contingent on delegated legislation that is likely to follow in the forms of rules and guidelines under the Bill. Absence of timely guidelines that are framed in a manner so as to not render this legislation meaningless has the potential to render the Bill futile and achievement of its objectives impossible. Be that as it may, it is

crucial for one to appreciate the progress made so far in terms of attempting to include HIV/AIDS affected persons in the mainstream society and control the spread of the epidemic, thereby saving many from a lifetime of capability deprivation. The Bill certainly gives reason for hope as it is an evidence that voices of these marginalised individuals are finally being heard, resulting in legislative recognition of hardships faced by a significant part of the population marginalised due to HIV/AIDS.