**1. Please provide information on the legislative and policy framework in place in your country related to the status, establishment, resourcing, and functioning of representative organizations of persons with disabilities at the national, regional and local levels[[1]](#footnote-1);**

**Legislation and policy** related to disability in India is primarily the responsibility of the Federal Units i.e. the State Government[[2]](#footnote-2). However, the disability law in India is laid down by the Union by virtue of Item 14 in the Union list pertaining to implementation of treaties and conventions

**Establishment**of organizations representing persons with disabilities are governed according to their legal structure. They could be a registered Trust (under the Indian Trusts Act, 1882, or respective State legislations), a Company (under Section 15 of the Indian Companies Act, 1956 or Section 8 of the Indian Companies Act, 2013), or as a Society (under Section 20 of the Societies Registration Act). If the function of the organisation is to deliver services then it needs to be recognized by CHAPTER X of Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995[[3]](#footnote-3), organisations involved in capacity of rehabilitation professional also need to be recognised under Rehabilitation Council of India Act, 1992[[4]](#footnote-4). In addition to this, organisations representing persons with Autism, cerebral palsy, intellectual disabilities and multiple disabilities may register themselves with the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability Act, 1999[[5]](#footnote-5)

**Resourcing** of representative organisations of persons with disabilities, if registered under the Persons with Disabilities Act, 1995; the National Trust Act, 1999 or the Mental Health Act, 1987, are eligible for funding by the Ministry of Social Justice and Empowerment under the Union Government or the department responsible for welfare of persons with disabilities at the State level. Organisations can avail funds from both the Union and the State. This funding can be availed only if the project is within the guidelines of a specific programme or policy of the Government.

Another avenue for getting funds is the corporate sector and through charitable contributions. There are tax exemptions incentive options for the corporate sector contributions to civil society organisations under Section 80G of the Income Tax Act, 1961, if the representative organisation of persons with disabilities has been approved under this section of the Act. A new Corporate Social Responsibility Clause has been inserted into the Indian Companies Act, 2013, mandating 2% of the profits of Companies to go towards the same[[6]](#footnote-6).

To receive foreign funding, organisations have to be registered under the Foreign Contributions Regulatory Act, 2010[[7]](#footnote-7). All the representative organisations of persons with disabilities are mandated to submit audited accounts to the State Government that has funded the organisation.

Representative organisations in India primarily **function** as service delivery, capacity building or employment facilitation organisations. There are also few organizations working on advocacy and policy interventions.

**2. Please provide information on existing legislation and policies aimed at ensuring that persons with disabilities and their representative organizations, including children with disabilities, are consulted and involved in decision-making processes that directly or indirectly concern them;**

The legislation and policy are twofold – one is with regard to disability specific legislation, and the other is with regard to general legislations that have scope for participation of the general public.

**Legislation – Existing – Disability Specific Legislation**

**Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995**

|  |  |  |
| --- | --- | --- |
| **Decision making Body and role** | **Person with Disability mandated?** | **Comments** |
| Central Coordination CommitteeThe national focal point on disability matters and facilitate the continuous evolution of a “comprehensive policy towards solving the problems faced by persons with disabilities” (Section 8 (1)) along with various other responsibilities. | The composition of the Committee is quite wide and includes, *inter alia* five persons as far as practicable, being persons with disabilities, to represent nongovernmental organizations or associations which are concerned with disabilities, to he nominated by the Central Government, one from each area of disability (i.e. Blindness, Hearing Impairment, Locomotor impairment, Leprosy Cured, Mental Retardation, Mental Illness and Multiple Disabilities), and that while nominating persons under this clause, at least one woman and one person belonging to Scheduled Castes or Scheduled Tribes should be nominated.Section 3 (2) (l) | Any member who is “of unsound mind and stands so declared by a competent court” is disqualified for membership of the Committee, which is discriminatory against persons with psychosocial disabilities. There is no provision which mandates the opinion of these persons to be taken into consideration while framing policies or deciding on execution, and so they can be overridden. No decision of any of the Committees shall be called in question on the ground merely on the existence of any vacancy in or any defect in the constitution of such Committees. |
| State Coordination CommitteeSimilar function at the State level (Section 18) | Similar constitution in Section 13. | Similar position |
| Central Executive CommitteeConcerned with executing the policies framed by the Central Coordination Committee (Section 10) | Similar representation of persons with disabilities as the Central Coordination Committee (Section 9) | Similar position |
| State Executive CommitteeConcerned with executing the policies framed by the State Coordination Committee (Section 18) | Similar representation of persons with disabilities as the State Coordination Committee (Section 13) | Similar position. |
| Commissioner of Persons with Disabilities (Chapter XII)Role is coordinating the work of the Commissioners at the State Level; monitoring the utilization of funds disbursed by the Central Government; take steps to safeguard the rights and facilities made available to persons with disabilities | Not mandated to be a person with disability or consult persons with disabilities. | Till date, only one person with disability has been appointed as Commissioner. |
| State Commissioner for Persons with Disabilities (Chapter XII) Similar role at the State level | Not mandated to be a person with disability or consult persons with disabilities. |  |

**Mental Health Act, 1987**

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| --- | --- | --- |
| **Decision making Body and role** | **Person with Disability mandated?** | **Comments** |
| Central and State Authority for Mental Health Services (Chapter II) | Not mandated to have a person with disability on the Board or consult persons with disabilities. |  |
| VisitorsThere should be a panel of visitors in each State to monitor the conditions of persons in mental health institutions (Section 39) | Not mandated to have a person with disability on the panel or consult persons with disabilities |  |

**National Trust Act, 1999**

|  |  |  |
| --- | --- | --- |
| **Decision making Body and role** | **Person with Disability mandated?** | **Comments** |
| National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple DisabilityTo manage the functioning of the Trust | Section 3 provides, *inter alia,* nine persons to be appointed as members from amongst the registered organisations out of which three members each shall be from voluntary organisations, associations of parents of persons with autism, cerebral palsy, mental retardation and multiple disabilities and from associations of persons with disability. | The National Trust Rules do not provide that any of the persons from associations of persons with disabilities must be a person with disability themselves though it has been done in practice.  |
| Local Level CommitteesTo decide on guardianship applications made by or on behalf of persons with disabilities  | Section 13 (2) provides that the Committee shall include a person with disability as defined in clause (f) of Section 2 of the Persons with Disabilities Act, 1995.  | The law does not mandate the inclusion of persons with disabilities from amongst the National Trust impairments.  |

**Rehabilitation Council of India Act**

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| **Decision making Body and role** | **Person with Disability mandated?** | **Comments** |
| Rehabilitation Council of India to certify the institutions that can accredit courses in rehabilitation for persons with disabilities. | No. |  |
| Visitors to be appointed under Section 16 of the Act to inspect institutions. | No. |  |

**Non-Disability Specific Legislation**

**Representation of the People Act, 1950, and 1951**

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| --- | --- | --- |
| **Decision making Body and role** | **Person with Disability mandated?** | **Comments** |
| The Election Commission responsible for the registration of voters in India | There are no provisions for the specific and facilitated inclusion of persons with disabilities; persons with disabilities can be excluded from being registered as voters on account of being of ‘unsound mind’ | Persons with Disabilities are to have Disability Cards as per the Persons with Disabilities Act, 1995; however as there is no mandate in that Act for Persons with Disabilities to be given Voter ID cards they find exercising franchise extremely difficult.  |

**Local Self Governance (Constitution of India)**

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| **Decision making Body and role** | **Person with Disability mandated?** | **Comments** |
| *Panchayat*sare local self government institutions at the village level. The term *gram sabha* refers to those in the village on the electoral rolls and the *Panchayat* is the body directly elected by them. | No. | There are reservations for women, scheduled castes and scheduled tribes, in *Panchayats*. |

**National Commission for Women Act, 1990**

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| --- | --- | --- |
| **Decision making Body and role** | **Person with Disability mandated?** | **Comments** |
| National Commission for WomenInvestigation and examination of all matters relating to the safeguards provided for women under the Constitution and other laws. | No. | The qualifications in Section 3 (2) actually state that the members should be persons of ‘ability, integrity and standing’. |

**Commission for Protection of Child Rights Act, 2005**

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| --- | --- | --- |
| **Decision making Body and role** | **Person with Disability mandated?** | **Comments** |
| National Commission for Protection of Child Rights Investigation and examination of all matters relating to the safeguards provided for children under the Constitution and other laws | Section 3(1) provides that the members will include persons of eminence, ability, integrity and standing, *inter alia* in the field of child psychology. | None of the categories of children specifically identified as children in need of special care and protection are children with disabilities (Section 13 (1) (e)) |

**Amending Bills/re-enacting Bills post UNCRPD**

**Rights of Persons with Disabilities Bill, 2013**

|  |  |  |
| --- | --- | --- |
| **Decision making Body and role** | **Person with Disability mandated?** | **Comments** |
| Central Advisory Board on Persons with DisabilitiesTo be the national-level consultative and advisory body on disability matters, and shall facilitate the continuous evolution of a comprehensive policy for the empowerment of persons with disabilities and the full enjoyment of rights | The Board consists of, *inter alia*, ten Members, as far as practicable, being persons with disabilities, to represent non-Governmental Organizations concerned with disabilities or disabled persons organizations and that out of the ten Members nominated, at least five Members shall be women and at least one person each shall be from Scheduled Castes and Scheduled Tribes (Section 59 (2) (r) (ii)) | Similar to the Central Coordination Committee under the 1995 Act with the same limitations. Persons who have been declared to be of unsound mind are disqualified from these posts, and there is no provision that mandates the opinion of these persons to be taken into consideration while framing policies or deciding on execution, and so they can be overridden or their posts can even be vacant.  |
| State Advisory Board on Persons with DisabilitiesSimilar role at the State level | Same composition as the Central Board (Section 65 (2) (e) (iii)) |  |
| National Commission for Persons with DisabilitiesTo identify provisions of any law, policies, programmes and procedures, which are inconsistent with this Act, and recommend necessary corrective steps; to inquire, into deprivation of rights of persons with disabilities and safeguards available to them in respect of matters for which the Central Government is the appropriate Authority. (Section 73 (1)) | The Committee is to be headed by a Chairperson and there should be two other members. Of the two other Members, only one Member shall be a person with disability (Section 74 (2)) | The Bill disqualifies persons who have become physically or mentally incapable of acting as a Member (Section 76 (1) (c)). Any vacancy in, or any defect in the constitution of, the National Commission shall not invalidate any act or proceeding of the National Commission. (Section 79). |
| State Commission for Persons with DisabilitiesSimilar to National Commission (Section 86 (1)) | Similar to the Central Committee (Section 86 (2)) | Similar provisions as above in Section 89 (1) (c); Section 92. |
| Special CourtTo be notified to try the offences under this Act, and a Special Public Prosecutor will be appointed in each such Court. | Not mandated |  |
| Assessment Board for persons with high support needsSection 37 Board to decide the nature of high support needs to be given to a person with a ‘benchmark’ disability[[8]](#footnote-8) | Not specified, to be specified in the Rules framed under the Bill. |  |

**Mental Health Care Bill, 2013**

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| --- | --- | --- |
| **Decision making Body and role** | **Person with Disability mandated?** | **Comments** |
| Mental Health Review CommissionAppoint and remove members of the Mental Health review Board; give guidance to the Board on interpretation of the provisions of this Act and the procedures to be followed by the Board etc.  | Section 75 3(b) mandates that one of the five members should be a person with mental illness *or* representative of persons with mental illness.  | Danger of persons with psychosocial disabilities themselves excluded. Also Section (c) provides that a representative of families and care-givers to person with mental illness or of non-Governmental organisations working in the field of mental health will also be a member so there could be two such members, potentially. |
| Mental Health Review BoardTo be constituted in every district and any person being aggrieved by the decision of any of the mental health establishment (on supported admissions) or whose rights under this Act have been violated, may make an application to the Board seeking redressal or appropriate relief. | Section 8 (1) mandates that there should be two members who shall be persons with mental illness or care-givers or persons representing organisations of persons with mental illness or care-givers or non-governmental organisations working in the field of mental health. | Danger of persons with psychosocial disabilities themselves being excluded from the process. |
| Central Mental Health AuthorityConcerned with regulating/setting standards for mental health facilities, maintaining registers of such facilities and of mental health professionals and carrying out training functions | Section 34 (2) (l) mandates that two persons representing persons who have or have had mental illness, to be nominated by the Central Government should be members out of a total of 16 members. | Any vacancy in, or any defect in the constitution of the Authority shall not be a ground for invalidating any of the proceedings, so persons with mental illness could be excluded. |
| State Mental Health AuthorityConcerned with the registration of all mental health establishments in the State and maintain and publish a register of such establishments and to develop quality and service provision norms for different types of mental health establishments in the State etc. | Section 46 (2) has a similar mandate as above. | Similar issue |

**National Trust (Amendment) Bill**

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| --- | --- | --- |
| **Decision making Body and role** | **Person with Disability mandated?** | **Comments** |
| The Board of the National Trust for Providing High Support to Persons with DisabilitiesTo manage the affairs and utilization of the Trust. | Section 3 (4) of the Bill provides that the Board will include the participation of persons with disabilities in the functioning of the Trust, and for this the Board may nominate three persons with disabilities on the Board as members. Such members shall have the right to participate in all proceedings of the Board and shall have the same powers and duties as elected members of the Board including the right to vote at Board meetings |  |
| Local Level CommitteesWill be under an obligation to take all such general and specific initiatives whereby all persons with disabilities can exercise their right to legal capacity; | Section 13 (2) provides that the LLC will include two persons with disability belonging to a self-advocacy or peer support group and with experience of community mobilization and rights based work, one of them will act as coordinator. |  |
| State Level CommitteesEnsuring functioning of the LLCs and coordination between them, monitoring of the implementation of programmes and schemes for persons with disabilities, etc.  | Section 17 B (2) provides that within the State Level Committee, five persons representing registered organizations shall be nominated, and as far as practicable these should be persons with disabilities themselves, one of whom shall be nominated as Member Secretary.  |  |

**Rehabilitation Council of India (Amendment) Bill, 2002**

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| --- | --- | --- |
| **Decision making Body and role** | **Person with Disability mandated?** | **Comments** |
| Rehabilitation Council of India | Under the amendment in Section 3 (f) the Council will include ten members as may be appointed by the Central Government representing all the recognized categories of disabilities, with at least ten per cent of the total being person with disabilities themselves or parents |  |

**3. Please provide information on any consultative body or mechanism established to consult and engage with representative organizations of persons with disabilities, including information about their composition, criteria for membership (nomination, appointment, election, etc.) and functioning;**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Date** | **Name of Committee** | **Mandate of Committee** | **Composition** | **Criteria for Membership** |
| 2010 | Committee to draft a new legislation to replace the Persons with Disabilities Act 1995. | To draft a new legislation to replace the 1995 law and introduce a CRPD compliant legislation | Headed by Dr. Sudha Kaul of the Indian Institute of Cerebral Palsy, of the 10 experts/NGO representatives only two members were persons with disabilities themselves. The other 28 members were bureaucrats.After objections were raised by the Sector, 5 other persons were inducted, of which there was one representative of the blind groups, one person with cerebral palsy, and one person from the psychosocial community[[9]](#footnote-9).  | Appointment by the Director (Disability) Ministry of Social Justice & Empowerment, Government of India |
| 2012 | Asok Kumar Committee for the Review of the Civil Aviation Requirements (CAR) for Persons with Disabilities (constituted by the Ministry for Civil Aviation) | Examination of the Civil Aviation Requirements (CAR) on the following:Need for redefining “Disabled person”;  Allocation of Responsibilities between airports and airlines; Accessibility of Ticketing System;  Complaint Redress System; Airports Facilities and Equipment;  Review of the CAR and Recommendations | Three representatives of organizations working for Persons with reduced mobility/ disabilities out of 13 Members (the rest being bureaucrats and representatives of airlines and airports), 6 out of 14 domain experts were persons with disabilities themselves (3 others being persons working in the field of disability) | Appointment by the Ministry of Civil Aviation |
| 2013 | Justice Verma Committee  | Constituted to recommend amendments to the Criminal Law so as to provide for quicker trial and enhanced punishment for criminals accused of committing sexual assault against women | The other members on the Committee were Justice Leila Seth, former judge of the High Court and Gopal Subramaniam, former Solicitor General of India. | The Committee was constituted by the Government of India and was assisted by a group of lawyers and academics that initially did not include persons with disabilities. The Committee invited a group of persons with disabilities to depose on the issue of sexual violence against women and the procedures issues therein.  |
| 2014/15 | Standing Committee On Social Justice And Empowerment (2014-2015), Sixteenth *Lok Sabha*[[10]](#footnote-10) on The Rights of Persons with Disabilities Bill, 2014 | Constituted for examination and Report of the Rights of Persons with Disabilities Bill, 2014. | 31 Members of Parliament and 3 persons from the *Lok Sabha* Secretariat, none of whom are persons with disabilities themselves. | Comments were open for persons to contribute to the views of the Committee and select organizations were invited to attend hearings in Delhi and Chennai. |
| 2015 | Core Committee, Accessible India Campaign | Constituted to implement the Incheon Strategy in particular**3.A** – Increase the accessibility of the physical environment in the national capital that is open to the public.**3.B** – Enhance the accessibility and usability of public transportation.**3.C** – Enhance the accessibility and usability of information and communications services. | Steering Committee comprising of a few National NGOs based in New Delhi. Other members include Ministers of Labour, Social Welfare, Health, Sport and Youth Affairs, Urban Development, Civil Aviation, Culture etc. | Applications were invited for civil society membership of the steering committee and Delhi based NGO representatives were appointed for ease of consultation. Regional committees have also been envisaged but are yet to be constituted.  |

**4. Please provide information on the efforts undertaken at national, regional and/or local levels to strengthen the capacity of representative organizations of persons with disabilities, in order to facilitate their participation in legislative, policy and other decision-making processes;**

Strengthening the capacity of representative organisations to facilitate participation in decision-making processes, for persons with disabilities or otherwise, is not mandated in any of the Union, State, or local legislations. The analysis of the policy documents of the Union and some of the States revealed that there was a failure to mention a category of ‘capacity building for effective participation’. There is no item head found in the financial documents of the Union and select States that were analysed for this purpose.

Both key government officials at the Union and at the State of Tamil Nadu expressed lack of such systems and procedures ensuring capacity building for effective participation in decision making so far.

Organisations of persons with disabilities and representative organisations for persons with disabilities across the country are the only entities engaging in training and capacity building programmes. A telephonic interview with select organisations, including representative organisations for persons with disabilities, expressed that their training programmes largely focus on informing the rights and legislations, CRPD and specific articles such as Article 12 & 19 for DPOs at different levels. The organisations reach out to DPOs or Self Help Groups in their area of operation and they also depute people in their network for any capacity building programme conducted by other organisations. It was also expressed that these training programmes have facilitated DPOs at different levels to understand the issues and advocate for their rights at the local level and some of the DPOs have started using legal instruments such as the Right to Information Act effectively to build evidences for their advocacy.

The organisations also expressed that these programmes are yet to lead to effective participation in decision making at all levels.

All the organisations expressed the lack of space and system for effective participation in the decision making processes of the Government, lack of specific capacity building programmes run by the government for participation and inclusion.

**5. Please explain whether and how persons with disabilities participate in monitoring the implementation of the United Nations Convention on the Rights of Persons with Disabilities (art. 33, para. 3), and in the nomination of experts to the Committee on the Rights of Persons with Disabilities (art. 34, para. 3)**

With regard to the monitoring of the implementation of the UNCRPD, as of now, India has not enacted the Rights of Persons with Disabilities Bill, 2014, which is the legislation intending to implement the UNCRPD. The Department of Persons with Disabilities is, at present, the Governmental department entrusted with compliance with the UNCRPD, Incheon Strategy, and other such International covenants with regard to rights of persons with disabilities. Under the Rights of Persons with Disabilities Bill, a Central Advisory Committee on disability is to be constituted which is to monitor and evaluate the impact of laws, policies and programmes to achieve full participation of persons with disabilities[[11]](#footnote-11). The State Advisory Committee on disability has a similar mandate.[[12]](#footnote-12) These bodies also have a mandate to engage with International Organizations but only “to take up the cause of persons with disabilities with the concerned authorities and the international organizations with a view to provide for schemes and projects for the persons with disabilities” in the national/state plans[[13]](#footnote-13).

The National Commission for Persons with Disabilities has a mandate to study treaties and other international instruments on the rights of persons with disabilities and make recommendations for their effective implementation[[14]](#footnote-14), but this is not binding. The composition of the Advisory Committees and the National Commission with regard to the participation of persons with disabilities is discussed above[[15]](#footnote-15).

India has not signed the Optional Protocol to the Convention.

With regard to the nominations to the Committee on the Rights of Persons with Disabilities in Article 34 Para 3 by State parties, the process by which India nominates experts to the Committee is not clear and the time allotted to prepare this report has not permitted an application under the Right to Information Act to obtain this information. However from the records of the United Nations we can derive the following:

In the elections of 2008 and 2010, there were no nominations forwarded by the Indian Government to the call for nominations to the Committee on the Rights of Persons with Disabilities.

In the year 2012 the candidature of Dr. Sudha Kaul was put forth as a member. Dr. Kaul is the Vice Chairperson of the Indian Institute of Cerebral Palsy in Kolkata, India, and founder of its Centre for Special Education. She was also the chairperson of the Committee constituted by the Government of India to draft a CRPD compliant legislation. However, her candidature was withdrawn subsequently[[16]](#footnote-16).

In the 2014 elections again, the Indian Government did not forward any names.

It has not been established as to whether any member/organization representing persons with disabilities has lobbied for the nomination of a particular person to the Committee.

**6. Please identify the main challenges faced by the diversity of persons with disabilities in participating in mainstream and disability-specific decision-making processes at the national, regional and local levels, including challenges faced by persons who experience multiple discrimination (e.g., on the basis of disability, age, gender, ethnic origin, geographical location).**

1. Organisations of persons with disabilities are not being called to be a part of the decision-making processes even on disability specific issues.
2. Besides the accessibility barriers both in terms of physical barriers and inaccessible documentation, attitudinal barriers and mindsets are barriers that people with disability find difficult to overcome in such bodies.
3. Representations of persons with disabilities with regard to mainstream legislation are often dismissed as not being the concern of persons with disabilities. For instance, a representation handed to the Minister of Women and Child Development on a draft policy for rape crisis centres was met by the response that this was “not her Ministry”. Even when they are included, invitations are sent in inaccessible formats and soft copies of documents are not provided, as an activist who is part of a committee under the Ministry of the *Panchayati Raj* (Ministry of Local Self Governance) explained. Also other members are not as sensitized as their interactions with persons with disabilities has been limited.
4. Lack of awareness and sensitisation among the implementing officials on the issues of persons with disabilities. There is a sense of low expectation from persons with disabilities. This has also resulted in planning and decision-making without the participation of persons with disabilities.
5. Lack of accessible environment including lack of availability of proper sanitation. This has lead to many groups of persons with disabilities to choose to be out of the decision making process of the Government. Poor sanitation has a direct impact on the quality of life and health of many groups of persons with disabilities.
6. Many groups of persons with disabilities, such as persons with Multiple Sclerosis, Achondroplasia and other medical conditions are not recognised as impairments leading to disability by the laws of the land. This has lead to lack of recognition to participation for diversity of persons with disabilities to participate in the decision-making processes.
7. In case of persons with psychosocial disabilities and persons with intellectual and developmental disabilities, only the association of the parents of persons with intellectual impairments or carers are consulted and not the individuals with impairments.
8. There are very few organizations that actually focus on the intersectionality of persons with disabilities with other forms of marginalization, except with regard to women with disabilities who appear to be relatively well represented.
9. Draft legislation is almost always issued in English, and occasionally in Hindi. The drafts are scanned copies of typed papers and so are not screen-reader compliant. The deadlines for responses are between one week to one month from the date of publication of the same and hence it is either impossible to convert the same into accessible formats and alternative languages and accessible hard copies, and hence the most marginalized groups who have such requirements tend to get excluded.
10. While other representative groups have the benefit of sophisticated and professional affiliates who can put their representations in concise formats, the disability sector has little if any such expertise. When such experts exist they tend to be asked to represent even marginalized sections, which they may not be exposed to.
11. As the centre of power is either in the State capitals or the Union capital of New Delhi, persons with disabilities who wish to contribute to the same find it very difficult and unaffordable to travel to these places on short notice for public consultations and depositions and no assistance is given for participation.
12. The lack of data makes it difficult to press for reform and budgetary allocations – the Indian census estimates has stated it to be only 2.3% of the population.
13. Government agencies tend to invite participants who require the least accommodation – urban based English speaking persons with disabilities tend to be involved the most, and persons with disabilities with communication and languages tend to be left behind.

**7. Please provide information on the existence of organizations of persons with disabilities in your country, including organizations of children and women with disabilities, as well as their composition and internal decision-making processes and procedures**

There are specific organisations for persons with visual impairment, and the Deaf (National Federation of the Blind, All India Confederation of the Blind, National Deaf Association). They have federated at the National levels and have affiliates at the State, district and sub-district levels.

These decision making body of these organisations are composed mainly of persons with the disabilities. Women with disabilities constitute one third of the total members of the decision making body in these organisations.

NPRD (National Platform for the Rights of Persons with Disabilities) is an association of organisations of and for persons with disabilities across the country. 6 out of the 11 office bearers are persons with disabilities. The president of this body is a woman with disability. The executive committee includes 27 disabled people out of the 35 members. In this 4 members are women with disabilities, one member is Deaf, 4 persons with visual impairment and one person with psychosocial disability and one person with multiple disabilities. The rest are persons with locomotor impairments.

At the State Level the affiliates of NFB and AICB follow similar structure.

The federations that are originally formed with persons with locomotor impairments are now moving towards being a cross disability organisation. Their compositions:

1. The decision making body comprises of only persons with disabilities.
2. One third of this body comprised of women with disabilities
3. The majority of members are persons with mobility impairments.

The State Federations have mostly formed separate women’s federation (example Tamil Nadu Women’s forum). Similar format is followed in some of the other State units of the country as well. These federations identify themselves as cross disability organisations though the membership majorly comprised of women with mobility impairments. In Tamil Nadu, parents represent women with Intellectual impairments.

There are no formal organisations of women with disabilities at the national level. The National Platform for Women with Disabilities formed recently facilitated by the Shanta Memorial Rehabilitation Centre, is also not a formal structure.

It was expressed that building specific organisations of persons with psychosocial disabilities and of persons with developmental disabilities is difficult due to discriminatory nature of the existing legislations, which restricts contracts on the grounds of unsoundness of mind. Therefore there is a huge bottleneck for some constituencies of persons with disabilities to be a part of the decision making body of either a cross disability group or their own organisations.

Excepting two organisations, parents associations represent persons with developmental disabilities.

As far as children with disabilities are concerned, there are no advocacy groups of children with disabilities. There is a lack of children’s committees, parliament etc. for children with disabilities. The concerns are majorly raised by organisations working for children with disabilities.

**8. Please identify the main challenges faced by the diversity of persons with disabilities as members of mainstream or disability-specific non-governmental organizations, and in participating in the activities of such organizations, including challenges faced by persons who experience multiple discrimination.**

Persons with disabilities working in disability specific non-governmental organisations do not face discrimination by way of denial of access and reasonable accommodation though there are instances of lack of personal assistants services impacting quality work. It is also reported that persons with psychosocial disabilities face problems in cross disability organizations at times.

In the mainstream set up the following issues were shared by persons with disabilities:

1. Lack of accessible environment is a major issue for effective participation.
2. There are also instances of neglect from colleagues and management towards persons with disabilities.
3. Most of the time employers do not engage employees with disabilities in challenging tasks due to the assumption of incapacity to complete a task.
4. Many persons with disabilities are not given reasonable accommodation and face attitudinal barriers that prevent them from working effectively.
5. Women with disabilities often find it difficult to leave the house and join such organizations and hence there is very little representation among women with disabilities in mainstream organizations.
6. Persons with disabilities who are from formerly ‘untouchable’ castes, tribal persons, do not have access to education on par with persons with disabilities from affluent backgrounds and so they do not meet the minimum criteria for employment in such organizations.
7. The salaries of persons with disabilities do not add up to much when the costs of disability are also to be factored in and hence mainstream and disability specific organizations, at the current accepted salary levels, are not viable career options.
8. NGOs can often be exploitative as there are no employment or labour laws that ensure job security. Even statutorily mandated grievance cells and accessible processes to approach them do not exist for example, sexual harassment.
9. Persons with communication requirements like the Deaf, deaf-blind, persons who use other forms of AAC, are not employed by organizations due to inability to communicate with these persons.

**Annexure A: Methodologies**

**Q1:** Survey of all legislation related to registration of legal entities, of corporate responsibility, taxation. Also the four disability specific legislations and schemes under them were examined to gather information on specific registration of organizations representing persons with disabilities therein.

**Q2** : Survey of bother disability and non disability specific legislation pertaining to involvement in political participation, monitoring bodies, ‘mainstream’ bodies like the women’s and children’s bodies, and collation of the same. Since all four disability specific legislations are up for amendment at present and three of them are in light of the provisions of the UNCRPD, the Bills pending before Parliament have also been included.

**Q3** : A selection of 5 Governmental Reports in the last 5 years were selected – these included committees constituted to prepare green papers on issues concerning persons with disabilities, Parliamentary Standing Committees constituted according to the various Ministries, which are to examine, clause by clause, provisions of Bills placed before Parliament. For these, they have the option of referring the Bill to the public for responses. These responses are not binding on the Committee, and the Reports themselves are not binding on the Ministry that has introduced the Bill.

**Q4** : A set of questions are prepared for the Government to understand the efforts taken by the Government. Since we are geographically placed in the southern part of the country, we chose electronic media to communicate with the Union Government and had a personal interview with the key official in the State of Tamil Nadu. At the Non-Government level we chose to reach out to organisations both of and for persons with disabilities representing the 4 regions. In Tamil Nadu we reached out to local (sub-district level organisations).

Questions for Government:

1. What steps have been taken by the Government to facilitate participation of persons with disabilities and their representative organisations in the decision making process such as Legislative process, Policy Formulation and other processes.
2. What is the basis of selection of these organisations / individuals with disability for this process.
3. Is there any effort taken by the Department towards strengthening the capacity of the representative organisations towards full and effective participation in these processes.
4. If efforts such as trainings are conducted to capacity building of persons with disabilities and their representative organisation in order to facilitate them to participate in the decision-making processes, how often it is been conducted?
5. What are the domains of training? (Planning process, Legislative process, implementation, monitoring and accountability).
6. How does the participation of different persons belonging to different constituencies of impairments encouraged in these training programmes and the decision-making processes?

Questions for Organisations of and for persons with disabilities:

1. What efforts are taken by your organisation to facilitate participation of persons with disabilities / their representative organisations in the decision making processes.
2. Do you engage in capacity building of persons with disabilities / representative organisations?
3. What are the areas of training?
4. Does your training facilitate disabled people and their representative organisations participate in the National / State level / local decision making processes?
5. How do you think the training facilitates full and effective participation?
6. How often do you conduct capacity building programmes that facilitate participation in decision-making processes of Government such as Legislative, policy and other processes?
7. How many persons with disabilities you have reached so far?
8. How often you encourage persons with disabilities participate in the capacity building processes of other organisations?
9. Does your organisation participate in the decision-making processes of the Government? And at what level?
10. How do you reach out to disabled people or their representative organisations to take part in these capacity building programmes?

Civil Society organisations participated in the interview:

1. Bapu Trust ,Pune, Maharashtra
2. SMRC, Bhubneshwar
3. Humanity Welfare Organisation, Jammu & Kashmir
4. TARATDACS, Tamil Nadu

**Q5**: The first part of the response was gathered by the evaluation of the Rights of Persons with Disabilities Bill, 2014; the second was prepared by records on the Committee website for the details of the 4 elections that have taken place till date, and open questions on forums of disability rights activists as to the background of the nomination process in India, that was not responded to.

**Q6:** Responses were gathered by way of telephonic interview with persons with disabilities who represent different constituencies.

People contacted:

1. Smitha Sadasivan, Vidya Sagar
2. Mageswari, SFWWD
3. Bhargavi Davar, Bapu Trust
4. Amba Salelkar, formerly with the Inclusive Planet Center for Disability Law and Policy
5. Rajive Raturi, formerly with the Human Rights Law Network.
6. Pavan Muntha, Swadhikaar

**Q7:** Responses were gathered by way of interviews with the representatives of different National and Tamil Nadu level organisations:

1. Bapu Trust, Pune, Maharashtra
2. SMRC,Bhuvaneswar
3. TNHFCT, Tamil Nadu
4. TARTDACS, Tamil Nadu
5. SFRADW, Tamil Nadu
6. December 3rd Movement, Tamil Nadu
7. National Platform for the Rights of Disabled
8. All India Confederation of the Blind, Chennai
9. National Federation of the Blind, Chennai.
10. Ektha, Chennai.

**Q8.** Information is gathered through telephonic conversations with persons with disabilities.

1. Smitha Sadasivan, Vidya Sagar
2. Prabhakaran, Vidya Sagar
3. Mageswari, SFWWD
4. Rajive Raturi, formerly with the Human Rights Law Network.
5. Pavan Muntha, Swadhikaar
1. The methodology for each question can be found at **Annexure A** to the document. [↑](#footnote-ref-1)
2. The Constitution of India includes “Relief of the disabled and unemployable” in Item 9 of the State list of the Seventh Schedule. [↑](#footnote-ref-2)
3. *Persons with Disabilities Act, 1995* http://socialjustice.nic.in/pwdact1995.php?format=print [↑](#footnote-ref-3)
4. *Income Tax Act, 1961* http://www.incometaxindia.gov.in/pages/acts/income-tax-act.aspx [↑](#footnote-ref-4)
5. *National Trust Act, 1999* http://www.thenationaltrust.co.in/nt/images/stories/act-englsih.pdf [↑](#footnote-ref-5)
6. http://www.mca.gov.in/SearchableActs/Section135.htm [↑](#footnote-ref-6)
7. *Foreign Contributions Regulatory Act, 2010* http://bit.ly/1OPgYZH [↑](#footnote-ref-7)
8. A person with benchmark disability is defined as a person certified to have more than 40% of impairment and is in need of high support. [↑](#footnote-ref-8)
9. Three of the these committes [↑](#footnote-ref-9)
10. “House of the People” of the Indian Union Parliament, an elected body consisting of 543 members. [↑](#footnote-ref-10)
11. Section 64 (2) (f) Rights of Persons with Disabilities Bill, 2014 [↑](#footnote-ref-11)
12. Section 70 (2) (f) Rights of Persons with Disabilities Bill, 2014 [↑](#footnote-ref-12)
13. Section 64 (2) (d) and Section 70 (2) (d), Rights of Persons with Disabilities Bill, 2014 [↑](#footnote-ref-13)
14. Section 73 (1) (e) Rights of Persons with Disabilities Bill, 2014 [↑](#footnote-ref-14)
15. See page 6 of the present document. [↑](#footnote-ref-15)
16. http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Elections2012.aspx [↑](#footnote-ref-16)