

SPRC Working Paper

Missing Elements of an Integrated Legislative Framework to realize the Vision ' No Person with Disabilities would be Left Behind' and the Way Forward

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The plight of Persons with Disabilities [PWDs] in Pakistan is stupendous in its proportions and the list of doable actions not done is long, reminding us that the gap between the Challenge and Response of the Care and Support of PWDs in Pakistan is very big. In Pakistan, we are not imagining and counting the severe Disability in Pakistan properly nor are we monitoring the adequacy and standards of the existing service provision in Pakistan.

In Pakistan many Bills have been introduced in the provinces and ICT to enshrine the rights of the PWDs. It is primarily done in compliance of the UN Convention on PWDs. Till date, these legislative exercises have not resulted in a major improvement in the condition of PWD. The Supreme Court of Pakistan has also taken some interest in the subject but there is nothing much to show. The same is the case with the Presidency and the Parliamentary Committees. We contend that the reason is that our Legislative Framework has not produced an effective, integrated policy framework to address the challenge. It is high time, the Pakistanis took notice of the dire situation in which the Persons with Disabilities [PWDs] are living in Pakistan, especially the Children, Women and old age PWDs. In the following paragraphs, major issues/principles have been identified, which, could illuminate the way forward.

Role of State in the provision of Services to the Persons with Severe Disabilities

In case of Pakistan, the root cause of the problem is that those Services to the PWDs are not yet defined clearly, which the State shall provide directly as the primary service provider. In our case, the care of the PWDs was thought to have been devolved to the provincial governments with the devolution of the Ministry of Social Welfare. This has resulted in a very grave violation of the Articles on Fundamental Human Rights enshrined in the Constitution of Pakistan. Notionally now, it is a provincial subject and the provinces are enacting Laws in compliance with the UN

Convention of the Rights of PWDs, which Pakistan ratified in 2011. [For example, the Sindh Empowerment of Persons with Disabilities Act 2018.] However, practically, the Pakistani state has left the care of the PWDs to the parents, philanthropy and market with heartbreaking exploitative practices when it comes to the selling of services to PWDs.

In Pakistan, our laws usually presume that the Disability is mostly congenital and some Disability is caused by the accidents. The new face of Disability all over the world, including Pakistan, is that the psycho-social disorders are up and man-made physical Disability is down. Though it is a very complex subject, but, bulk of the Psycho-social disorders are originating from the social environment. This needs an urgent attention. Be it corporal punishment at school, be it begging and prostitution due to poverty, or rejects of the Hazardous Foster Care eg Trans people, Begging and prostitution sub-cultures, Disability caused by pollution, particularly in cities, there is a need to separate the category of Man-made Disability and review the existing laws and introduce the principles of direct and indirect responsibility. In order to properly address the naturally occurring Disability as well as man-made Disability, there is a need to introduce a national integrated framework for the care of PWD focusing on the prevention, rehabilitation support to the PWDs with minor disabilities and full care to the Persons with severe and multiple Disabilities, in the light of which the provinces could also modify their laws.

Lack of Standards and Monitoring of Service Provision to PWDs

In the case of Education and Health, the state has virtually accepted a dependence on the private sector for the provision of these services and is adopting the Insurance as a preferred strategy. As the Care and Support Sector for PWD is extremely under-developed in Pakistan, only a minor, support role from the private sector is being provided at present. Still, the State has not put in place proper framework of Standards and Monitoring for the non-governmental and private sector providers.

Treating Man-made Disability separately

The situation of the PWDs has been worsening in Pakistan fast as the Disability is growing rapidly in the country, largely due to man-made factors. A recent survey by WHO has placed the incidence of Disability at around 14 % on the basis of its survey of Attock and Ziarat. This challenge is

virtually un-responded. Given the fact that the burden of the Disability is going to become huge for our Labour Markets in the coming days, it is essential that we undertake preventive and remedial measures to reduce the incidence of man-made disability quickly. The Social Environment, pollution, occupational and safety hazards and accidents are among the principle causes on the man-made disability.

The Article 25, [making child education a fundamental right] is not yet fully operationalized in Pakistan. The implications for the PWDs left out of school are far greater than the ordinary children. However, we need to separate the category of the Children who need special education and the children with severe and multiple disabilities, who need special care more than the education. In Pakistan, one major source of man-made Disabilities is the Child Labour, particularly as domestic workers. Trauma of the domestic child workers is very long, especially for the girls. A logical corollary of the Article 25 is to formally ban the domestic child labour, which the government did not do. The newly proposed framework/national law should propose this ban as this would significantly reduce the burden of man-made disabilities.

Our national framework should be based on the the fact that 80 % of the Disabilities in Pakistan are man-made and on the principle of 'Pollutor pays', the ones directly or indirectly responsible for causing the Disabilities must be brought to pay. In Pakistan, only 2 % of the PWDs who get a disability due to work place accident or road side accident are compensated and that also very meagerly. There is a need to ask the provincial governments to adopt clear Targets to reduce the man-made Disabilities by half by 2030.

Lack of Data on expenditure by the State on Disability:

Apparently, the direct expenditure on Special Education in Pakistan has stagnated. The Punjab Special Education is reaching out to only 7 % of the Children with Disability, if we presume that the incidence of Disability in Pakistan is 2.4 % as determined by the 1999 Census. Unfortunately, despite the Supreme Court directions to count the Disabled in March 2017, the last Census did not count them separately. The BISP also collects data for exclusion or inclusion in its Programme. Its existing Questionnaire is not counting the PWDs properly due to a poorly designed Question at the S. No. 11 C. There is some data generated by the randomly collected surveys such as PBS PSLM. But the way the expenditure on Education and Health is calculated and used for planning

purposes, the per capita expenditure on the Disability is not known in Pakistan, which hampers a more efficient planning.

Establishment of Employment Exchanges for PWDs linked with a National Disability Information Management system

In case of employment opportunities, Pakistan does have the requisite legislation, fixing the employment quota for PWDs. But the effectiveness of the laws passed since many decades is not known. Instead of taking a pro-active approach by establishing the Employment Exchanges for PWDs, we take a passive approach. We suppose that the PWDs, who, would be employed, would be excluded from the State Care and Support System. This is in principle workable. Our new laws should cause the quick establishment of a National Disability Information Management System, necessary for the functioning of Employment Exchanges. Apart from such an MIS, we need a national Register of the permanent, severely disabled persons, to assess the efficacy of the Support reaching them. This would require the revamping of the Disability Certification System in Pakistan, which the new institutional framework should stipulate.

The rampant neglect of the PWDs in Pakistan requires that the State take on itself the responsibility of the primary provision of services to the PWDs. [Primary Services to PWDs defined as the provision of minimum support to the Parents of the Children with Disability and to the Adults with Parents with Disabilities, education, health, Minimum Income Support and Care for the Persons with severe disabilities, guardianship in case of PWDs with severe and multiple disabilities in vulnerable conditions, inheritance rights]. Given the importance and extent (infrastructure needs, education, health care facilities with nationwide coverage and minimum support to every individual with Disabilities) the federal government needs to retain its exclusive power to protect public interest of the societal responsibility towards the PWDs and the enforcement role and/or tasks as the State should not transfer this responsibility to the provincial entities, considering the proven risks of leaving the matter to multiple jurisdictions. Even the strong federations like Australia, Canada, India, the Disability Services are National.

Establishing a Public Financial Management System for PWDs and National Disability Service

Pakistan unfortunately has followed a residual social policy historically i.e., allowing the market a free hand and supporting the lowest rungs of the society with income support. In fact, the philanthropy in Pakistan provides more services and support to the most vulnerable citizens of Pakistan than the government. The countries where the State provides universal Social Protection to its citizens, it is rather easy to strengthen the National Disability Services. Though we have BISP, EOBI, Workers Welfare Fund, Baitulmaal and provincial Social Security Institutes but we are not yet there. The provincial Social Protection Authorities are also coming up as is the case with Punjab. [They are paying Rs. 1500 to the PWDs.] The global evidence overwhelmingly highlights the efficiency of national Social Security systems. In a federation, a National Social Protection System essentially means the establishment of a national Public Financial Management mechanism for the integration of the resources spent on Disability and ensure the effectiveness of the public expenditure on Disability. The delivery of the services in any case would be done at the provincial and local level. The new Government is talking about the Right to Development of ordinary Pakistanis. Pakistan actually does spend a lot on the social sector but in a highly ineffective way. The Citizens of Pakistan would be better off, if our provincial governments and the federal government sit and agree on combining all these resources to develop a National Social Protection System. This should also include the setting up of a national Trust for the Persons with Severe Disabilities as this should be a national responsibility as is the case in India.

It is high time that a Pilot, in the regions like Islamabad Capital Territory, GB, AJK, Baluchistan, the federal government, of a National Disability Service is established.

Rights of the Care-givers of PWDs

In Pakistan, we have ignored the need to have separate Caregivers Support Law. We somehow presume the parents of the Children with Disability and the Adult children of the Parents with Disability have super-human emotional strength and unlimited material resources to care for the Children and Parents with severe disabilities. This is a huge failure of our collective consciousness. Even the middle-class parents of the Children with Disabilities have to spend on average 25 K more on the care of even one child with disabilities. The life-long trauma is apart from it. As we

do not have the temporary care facilities for the Children and or parents with Disabilities, the individual rights of the caregivers are very seriously compromised. The birth of a child with Disability practically becomes a life sentence for the parents. Similarly, the care of the Disabled or chronically ill parents pushes a large number of people into poverty as they sell their assets for the treatment and pushes the already very poor households into destitution. The educated and affluent to an extent cope, though with huge every day stresses. In the poorer classes, they chain their Children with Disabilities when they go out to work and in most of the cases, they unburden themselves by letting these poor souls to the crime syndicates of begging, prostitution etc. The latter are again put on street when they earn less due to age. We need new laws, which should come up with a robust institutional mechanism to support the caregivers of PWD. It could be, to start with, the BISP coming up with a scheme of non-conditional cash transfers to the parents of the Children with severe Disabilities and for the caregivers to the Parents with severe Disabilities. Auch laws could provide for the establishment of temporary shelters on the model of Day Care Centres for giving relief to the Care-givers of PWDs. The UK Law on the Rights of the Parents of the Children with Disabilities was promulgated four decades ago.

Ensuring the Inheritance Rights of PWDs

Philanthropy and State can provide Care if the parents and relatives are not in a position. But the Laws of Guardianship in Pakistan are dated. Though the data is not systematically compiled, but in Pakistan, there are very few cases where the Court has given the PWDs in another person's care. The provincial legislations, in current form, do not attend to the untapped source of care i.e., the inheritance of PWDs. In most of the cases, the Persons with severe disabilities do not get their due share in inheritance. We need new laws, which should address this issue in detail. Due to poor Counting system, the plight of the PWDs on this account is hidden and the PWDs are consciously 'left behind' by their own caregivers. The SDGs want nobody to be left behind in case of Education and Health. We need laws, which should adopt it as a Goal i.e., No PWD would be left without Care and Support. Our existing laws do not distinguish between Care and Support. We must address this gap.

Conclusion

The development of a national framework for the care of PWDs for the up-gradation of the services for the PWDs in Pakistan is long overdue. In order to accomplish it, we need a paradigm shift in our imagining, counting and serving of PWDs.