Empowering lymphatic filariasis affected individuals in India: acknowledging disability status and ensuring justice

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Comment

Lymphatic filariasis (LF) is the second most prevalent worldwide cause of physical disability, following leprosy.[1,2] India alone accounts for around 40% of burden with ~525,440 lymphedema and 1,44,645 hydrocele cases (2021), majority from the states of Bihar, Jharkhand, Odisha, Telangana and Uttar Pradesh.[2,3] India targets elimination of LF by 2027, three years ahead of global goal of 2030. In 2023, a revised five-pronged strategy was announced by the Indian Health Ministry which included *a)* multi-drug administration campaigns, *b)* early diagnosis and treatment, *c)* integrated vector control, *d)* inter-sectoral convergence, and *e)* leveraging on existing digital platforms and innovation in LF diagnostics.[4] Patients afflicted by LF frequently endure substantial physical, economic, psychological and social impairments, which further contribute to impoverishment.[5] In 2108, Government of India has officially notified the inclusion of 'lymphedema' as one of the physical disabilities under the criteria of 'locomotor disability'. This recognition enables the inclusion of lymphedema-affected LF patients within the disability framework outlined in 'The Rights of Persons with Disabilities (RPwD) Act, 2016'.[6] Thecurrent policy change represents a significant step towards promoting the rights of individuals affected by LF, a condition that may not have been explicitly recognized as a cause of disability in the past. Table 1 lists a few of the disability benefits currently available to physically disabled individuals in India under different criteria of locomotor disability which may be applied to the LF-affected individuals under the current policy change. Although the gazette notification has notified the inclusion of lymphedema patients within the disability framework however, it is crucial to note that the full potential of this initiative is yet to be fully harnessed, and there still exist several gaps towards ultimately realizing the intended benefits of this critical policy change.

Currently disparities persist in the enforcement of the policy, the provision of benefits and tangible realization of the intended benefits. Furthermore, LF affected individuals also encounter difficulties in accessing the entitled benefits and rights due to various reasons like uninitiated government machinery, application challenges, lack of disability identification and certification, lack of administrative support, inadequate outreach, poor implementation and inadequate support from healthcare and other sectors. The information on the number of LF individuals who received benefits under the government schemes is not available in public domain. Upon enquiries made by the authors to the state governments *via* emails and phone calls, it was observed that several departments could not elicit the number of LF-affected individuals who have benefited under the policy change. This indicates that mere recognition and the inclusion of lymphedema within the disability framework may not translate into the actual welfare of LF patients unless proactive steps are taken in that direction.

To overcome the above barriers, we propose a few strategies that can assist in creating a robust framework ensuring that the individuals with LF-related disabilities can utilize the provisions made under various schemes, fostering inclusivity and thereby paving the way for improved quality of life:

1. **Inter-sectoral convergence:** Inter-sectoral communication across various sectors such as public health and social welfare, disability rights department, employment and labour, finance, education, media, civil societies, legal and human rights is essential for effective implementation. Inter-sectoral collaborations have majorly contributed to polio elimination in India and human rabies elimination in Goa state.[7,8]
2. **Awareness and community engagement:** Targeted awareness campaigns are essential to inform both the public, healthcare professionals and other stakeholders. Traditional media, social media, community workshops, educational material and other channels can be used.
3. **Use of digital tools:** Digital tools can act as bridge between the government system and communities. The effective uses include record keeping, real-time monitoring, patient engagement, data integration with other sectors, mobile applications for awareness and education, follow-up and reminder functionalities, individual patient portals, and also platforms for community engagement. 'Nikusth' an integrated data portal in the context of leprosy

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S.No	Scheme	Details of the benefits	State/central	Benchmark disability
1.	National fellowship for students with disabilities-	Financial assistance to students with disabilities to pursue M. Phil. and Ph.D. degrees.	Govt. of India	40% or above[a]
2	Skill development of persons with disabilities	Skill development	Govt. of India	40% or above[a]
3	Saksham scholarship-	Annual scholarship of ₹50,000/to pursue technical education	Govt. of India	40% or above[a]
4	Post matric scholarship-	pursuing a post-matric qualification from UGC/AICTE recognized universities	Govt. of India	40% or above[a]
5	Scholarship for differently abled students	Financial assistance for school and college students ranging from ₹300–₹1000/-	Govt. Of Kerala	40% or above[a]
6	Scheme for aids and appliances	Financial assistance for purchase/Fitting of aids And appliances	Govt. of Manipur	40% or above[a]
7	Providing assistive devices	Providing assistive devices such as automated wheel chair	Govt. of Kerala	40% or above[a]
8	A.P Differently abled & Senior citizens assistance corporation- scheme	Providing tricycle	Govt. of Andhra Pradesh	Orthopedically challenged individuals[b]
9	Scheme of Assistance to Disabled Persons for Purchase/Fitting of Aids/Appliances (ADIP Scheme)	Financial assistance of towards providing durable, modern and scientifically manufactured aids and assistive devices–	Govt. of India	40% or above[c]
10	Deen Dayal Divyangjan Pension Scheme	Financial assistance-monthly pension of ₹1000/-	Govt. of Assam	40% or above[a]
11	State Disability Pension	Subsistence monthly allowance of ₹2500	Govt. of Delhi	40% or above[d]
12	YSR Pension Kanuka	Social security scheme-monthly allowance of ₹3000	Govt. of Andhra Pradesh	40% or above[a]
13	Special ability relief allowance	Monthly allowance of ₹700	Govt. of Himachal Pradesh	40% or above[a]
14	Maintenance allowance	Monthly assistance of ₹1500/- to the severely affected persons	Govt. of Tamil Nadu	Severely affected individuals[e]
15	Indira Gandhi National Disability Pension Scheme	Monthly pension of ₹300 from 18 to 79 years; ₹500 for 80 yrs and above	Govt. of India	40% or above[a]
16	Financial assistance	Financial monthly assistance of ₹1500 to 40–65% disabled, ₹2000 to 66–85% disabled and ₹3000 to 86–100% disabled	Govt. of Puducherry	40% or above[f]
17	Reservation in Govt. employment	4% quota in direct recruitment in Government jobs	Govt. of India	40% or above[g]
18	Assistance for self-employment	Financial assistance ~ ₹1,50,000/- for self-employment	Govt. of Maharashtra	40% or above
19	Economic support scheme for self-employment	Subsidy and financial assistance upto Rs 1 Lakh for establishing industries, service, business and agricultural & allied activities etc	Govt. of Andhra	Differently abled-18 - 60 years[h]
20	National Handicapped Finance and Development Corporation (NHFDC)-Swavalamban Yojana	Providing concessional loan for economic and overall empowerment/income generation.	Govt. of India	40% or above[i]
21	Marriage incentive 50,000.	Financial assistance up to ₹50,000.	Govt. of Maharashtra	40% or above[a]
22	Incentive award for marriage with disabled person	Financial assistance ranging ₹15,000–₹35,000/-	Govt. of Manipur	40% or above[a]
23	Indian railways	Travel in specially designed coaches, concessional tickets ranging from 50 to 75%, 4% job reservation	Govt. of India	Orthopedically handicapped individuals who cannot travel without an escort[j]
24	Air India airlines	50% concession in basic fare on domestic tickets	Air India Ltd.	80% locomotor impairment[k]
25	Ticket concession within the state run buses.	50% ticket concession within the state run Government buses.	Govt. of Punjab	40% or above[l]
26	Fuel subsidy	50% subsidy to disabled individuals using motorized vehicles	Govt. of Punjab	40% disability or more[m]
27	Fuel subsidy	50% subsidy to disabled individuals	Govt. of Puducherry	40% disability or more[n]
28	Ticket concession within the state run buses.	Travel concession free of cost up to 100 kms to go to schools/colleges/hospitals/training centres/work spot from their residence and return.	Govt. of Tamil Nadu	Orthopedically handicapped[a]
29	GST exemption certificate scheme	Concession of 10% on GST and zero cess for purchase of cars	Govt. of India	40% or above[o]
30	Distress relief fund	Distress Relief Fund- Rs.5000/year for medical treatment and including surgery	Govt. of India	40% or above[a]
31	Niramaya scheme	(Health Insurance Scheme)-insurance cover of Rs.1 lakh/annum	Govt. of India	Multiple Disabilities[p]
Existing schemes for LF affected individuals				
32	Pension scheme	Financial assistance-monthly pension of ₹1000/-	Govt. of Tamil Nadu	Grade IV LF affected individuals[q]
33	Financial Assistance	Financial assistance of Rs 500/kit for morbidity management	Govt. of India	LF affected individuals[r]

(Table 1 continues on next page)

S.No	Scheme	Details of the benefits	State/central	Benchmark disability
(Continued from previous page)				
34	Pension scheme	Financial assistance-monthly pension of ₹5000/-	Govt. of Andhra Pradesh	Bilateral elephantiasis Grade-IV affected individuals[s]
35	Financial Assistance	Financial assistance-monthly pension of ₹2016/-	Govt. of Telangana	LF affected individuals Grade-II onwards[s]

[a]https://www.myscheme.gov.in/schemes/sn2408. [b]https://apdascac.ap.gov.in/Schemes/schemedetails/4. [c]https://thenationaltrust.gov.in/content/innerpage/aids-and-assistive-devices.php. [d]https://discomm.delhi.gov.in/discomm/schemes-and-facilities-persons-disabilities. [e]https://scd.tn.gov.in/Mintantance_allowance.php. [f]https://services.india.gov.in/service/detail/online-application-for-financial-assistance-to-differently-abled-persons-puducherry#:~:text=75%2C000%2F%2D%2C%20are%20provided%2C%20monthly,)%2C%20through%20their%20respective%20Anganvadis. [g]https://dopt.gov.in/sites/default/files/FAQ_Disabilities.pdf. [h]https://apdascac.ap.gov.in/Schemes/schemedetails/11. [i]https://www.nhfdc.nic.in/. [j]https://indianrailways.gov.in/railwayboard/uploads/directorate/stat_econ/pdf/ANNUAL_REPORT_ACCOUNTS_ENG_2011_12/18.pdf. [k]https://www.airindia.com/in/en/book/concessionary-fares/other-concessions.html. [l]https://sswcd.punjab.gov.in/en/scheme-of-free-concessional-travel. [m]https://services.india.gov.in/service/detail/online-application-for-fuel-subsidy-to-physically-handicapped-persons-puducherry#:~:text=A%20Fuel%20Subsidy%20of%2050,not%20exceeding%20%E2%82%B975%2C000%2F%2D. [n]https://services.india.gov.in/service/detail/online-application-for-fuel-subsidy-to-physically-handicapped-persons-puducherry. [o]https://gecs.heavyindustries.gov.in/. [p]https://thenationaltrust.gov.in/content/scheme/niramaya.php. [q]https://tnhealth.tn.gov.in/tngovin/dph/dphdbfil.php. [r]https://ncvbdc.mohfw.gov.in/index4.php?lang=1&level=0&linkid=461&lid=3739. [s]https://ncvbdc.mohfw.gov.in/Doc/Newsletter-Lf-2023.pdf.

Table 1: **Benefits extended by central/state governments to the disabled individuals in various fields.**

eradication and 'CoWIN' web portal for managing COVID-19 vaccination programme are successful examples of use of digital tools for health. The use of mobile application such as the 'TB Aarogya Sathi' is reported to enhance the information access among TB-affected communities, enabling individuals to monitor their health, receive direct money transfer and serve as a direct interface with the healthcare system leading to empowerment of TB-affected patients/communities.[9]

4. **Public-private partnerships (PPPs):** PPPs have often proven effective by harnessing the strengths of both the public and private sectors. Private agencies can contribute in the form of services like identification of LF patients, streamlining disability assessments, creating communication linkages between different sectors and LF affected individual. PPPs have been successful for malaria in India and outside.[10]
5. **Advocacy:** Advocacy at all levels and with different key departments will play a central role in ensuring that individuals with LF-related disabilities receive the entitled support. Advocacy is needed for resource mobilization, engaging local and national stakeholders, patient empowerment, ensuring patients' rights, enforcement of legislation and regulations, monitoring and accountability, education and sensitization and networking.
6. **Regular reviews and updates:** Regular reviews and updates from stakeholders *viz* government departments, health authorities/providers, affected individuals are crucial. These can help in identifying any bottlenecks and adapting to evolving circumstances. These reviews preferably at one platform can help identify lacunae or any lag that can be rectified.
7. **Helplines and information centers:** Establishing dedicated helplines or information centers for individuals with LF related disabilities can significantly improve their access to support. Linkages between various sectors and information across the departments *via* these information centers would be extremely useful to the patients and government systems.

Conclusion

The current policy change represents a significant step towards promoting the rights of individuals affected by LF, who have long endured the burden of the disease. However, there still remains a critical gap between the existence of a policy to include lymphedema patients under disability Act and its full utilization. A collective multi-sectoral approach, and sustained commitment at various levels of government and civil society can help towards creating an enabling ecosystem of care that not only recognizes and acknowledges the diverse needs of the affected individuals but also empowers and ensures justice to them.

Contributors

MR conceptualized the manuscript; SJ contributed to literature survey, drafting and compiling the data sources for the manuscript; SJ and MR contributed to formal analysis; interpretation and editing of the manuscript; MR critically revised the manuscript. Both the authors read and approved the manuscript.

Declaration of interests

The authors have no competing interests to declare.

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