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A VERY SHORT POLICY BRIEF

Deepening partnerships in disability between Victoria and India

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Deepening Partnerships in Disability Between Victoria and India

The Australia India Institute's A VERY SHORT POLICY BRIEF series examines key questions facing contemporary India and the Australia-India relationship. It combines in-depth academic analysis with clarity and policy relevance.



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Summary

According to the WHO, more than 1 billion people in the world have a disability¹. Evidence from both Australia and India shows people with disabilities are more likely to experience poorer health outcomes, lower education achievements, less employment, higher rates of poverty and barriers to accessing services².

In India, the Modi Government has actively promoted disability inclusion through the *Rights of Persons with Disabilities Act 2016*³ and introduced or improved programs such as Accessible India⁴ and employment schemes.⁵ Although access remains an issue India offers some of the world's best private disability care and boasts a burgeoning disability assistive technology sector.

Australia has been a world leader in promoting disability inclusive development abroad and innovative financing solutions at home. The Development-For-All strategy and the National Disability Insurance Scheme (NDIS) are two examples. *Victoria's India Strategy*⁶ provides a framework for meaningful engagement between Victoria and India in the area of disability.

Together India and Australia can cooperate to promote inclusion enabling people with disability to realise their full potential.

This policy brief provides an overview of the diverse array of stakeholders involved in responding to disability in India. It also explores the burgeoning market for training of therapists, development of services, assistive devices and appropriate technology. It identifies the following areas for industry engagement and research collaboration between Victoria and India:

1. Co-design of training and curricula to support the disability sector
2. Leadership, training and education of the disability workforce
3. Building technology and ICT solutions for people with disability
4. Low cost solutions and production of devices at scale

1 https://www.who.int/gho/road_safety/mortality/traffic_deaths_rates/en/

2 https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3398431

3 <http://legislative.gov.in/actsofparliamentfromtheyear/rights-persons-disabilities-act-2016>.

4 <http://disabilityaffairs.gov.in/content/page/accessible-india-campaign.php>.

5 <http://disabilityaffairs.gov.in/upload/uploadfiles/files/Incentive%20Scheme%20under%20SIDPA.pdf>.

6 <https://www.vic.gov.au/victorias-india-strategy>.

Disability on the rise in India

In India, according to the latest Census,⁷ 2.2% or 26.8 million people had some form of disability. Studies using a functional definition rather than diagnostic definition have shown the prevalence to be three to four times higher.⁸ Indeed, in Australia the prevalence is around 20%. Numbers are expected to be much higher in the 2021 census given the expansion of the definition from seven to 21 disabilities in the 2016 Rights of Persons with Disabilities Act 2016. The prevalence of disability was found to be more in rural areas as compared to urban areas and more among males than among females.

Over the coming century the number of people with disability is expected to rise in India, population growth means India will soon become the world's most as populous country. In India young people are at higher risk of disability due to child and maternal malnutrition and high levels of poverty. All age groups experience a high burden of disability associated with injuries, particularly vehicle-related, given India has the highest number of road traffic injuries in the world⁹. An increase in metabolic and behavioural risk factors is resulting in increased risk of Non Communicable Disease (NCD)-associated disability such as diabetes. Demographically, India's population continues to grow as does the proportion of elderly and this will lead to dramatic increases in age associated disabilities such as hearing, mobility and visual impairments.

India's Response to Disability

In 2007 India signed and ratified the United Nations Convention on the Rights of Persons with Disabilities (Australia is also a party). In 2016 they adopted the *Rights of Persons with Disabilities Act 2016*¹⁰ and subsequently there have been a number of pro-active policies and programs.

India offers some of the world's best private disability care, has a rapidly growing MedTech sector (includes assistive technology¹¹), and is a world leader in low cost production and delivery of disability services. Yet despite excellent disability policies, campaigns and programs, accessing quality affordable disability care remains difficult for many with disability in India. There are opportunities for collaboration around funding models, workforce shortages, and access to quality affordable devices and services.

7 https://censusindia.gov.in/census_and_you/disabled_population.aspx#:~:text=Census%202001%20has%20revealed%20that,and%209.3%20million%20are%20females.

8 Ramachandra S, Allagh K, Kumar H, Grills NJ, Marella M, et al. (2016). Prevalence of disability among adults using RAD tool in a rural district of South India. *Disability and Health*, 9(4), 624-31.

9 https://www.who.int/gho/road_safety/mortality/traffic_deaths_rates/en/

10 <http://legislative.gov.in/actsofparliamentfromtheyear/rights-persons-disabilities-act-2016>

11 <https://www.makeinindia.com/article/-/v/sector-survey-medical-devices>

Disability care and services can be expensive for consumers. In India, with 370 million people living in multidimensional poverty,¹² many are unable to afford quality disability services which puts them at risk of falling into poverty due to high out-of-pocket expenditure¹³. In its 2018 Disability and Development report, the UN found that disability and poverty were mutually reinforcing¹⁴.

There is also an estimated shortage of 6.4 million allied health workers in India¹⁵. This is more acute in rural India where 69% of people with disability live. However, allied health professionals, including physiotherapists, occupational therapists, speech pathologists and special educators are concentrated in the private sector and major cities.

Disability policy and programs in India

Accessible India Campaign (Sugamya Bharat Abhiyan)

In 2017, the government launched the flagship disability program “Accessible India Campaign (Sugamya Bharat Abhiyan)” to achieve universal accessibility to enable persons with disabilities to gain access to equal opportunities and live independently and participate fully in all aspects of life in an inclusive society. The campaign aims to enhance the accessibility of:

1. buildings such as schools, academic and training institutions, offices and public buildings, recreational areas, health centres/hospitals
2. the transport system including air travel, rail travel and public transport
3. the information and communication eco-system ensuring that government websites are accessible, increasing sign language interpretation and captioning¹⁶

The “Unique ID for Persons with Disabilities”

Disability certificates are provided for people with significant disability and entitles them to benefits and concessions. A new scheme is now providing a unique Disability Identity Card to each person with disability which will increase the transparency, efficiency and ease of delivering government benefits to the person with disability and streamline the tracking of physical and financial progress of beneficiaries.

12 <http://hdr.undp.org/en/2019-MPI>

13 Selvaraj, S., Farooqui, H. and Karan, A. (2018) Quantifying the financial burden of households' out-of-pocket payments on medicines in India: a repeated cross-sectional analysis of National Sample Survey data, 1994–2014. *BMJ Open*. 8 (5); Keane, M. and Thakur, R. (2018) 'Health care spending and hidden poverty in India'. *Research in Economics* 72 (4): 435-51

14 <https://social.un.org/publications/UN-Flagship-Report-Disability-Final.pdf>

15 Patel, V., et al. (2015) Assuring health coverage for all in India. *The Lancet*. 386(10011).

16 <http://darpn.nic.in>

Skills and Employment

The *Rights of Persons with Disabilities Act 2016* (RPWD Act) requires government sectors to employ at least 4% of their workforce with disabilities and companies to aim for 5%. In addition, there are various legal requirements for making workplaces accessible and not discriminating against people with disability.¹⁷ There is also a National Action Plan for Skill training of Persons with Disabilities¹⁸ which has recently been reviewed and improved. Vocational training courses are offered by National Institutes of Disability and their affiliates whilst the Ministry of Labour and Employment supervises more than 20 Vocational Rehabilitation Centres for the Handicapped (VRCHs), more than 10,000 Industrial Training Institutes and more than 1000 employment exchanges. Community colleges, NGOs and private sector organisations also provide vocational training and skill development programs for people with disability.

Education

In India, a number of policies have been introduced to improve access to education for disabled children, including the *Right of Children to Free and Compulsory Education Act 2009*¹⁹ and the Education for All campaign (Sarva Siksha Abhyan-SSA). There are supporting activities relating to pre-school training for children with disabilities, counseling for parents, training for care givers, and teacher training programs for early identification.

The National Health Mission (NHM)

The Ministry of Health and Family Welfare (MHFW) established the National Rural Health Mission to increase access to equitable, affordable, and quality healthcare especially for those living in rural areas. The program is a comprehensive package of promotive, preventive, curative and rehabilitative services.

The primary role of the MHFW with regard to persons with disabilities is in the area of prevention. In addition to initiatives like polio and leprosy eradication²⁰, the Rashtriya Bal Swasthya Karyakram (RBSK) was established to provide early identification and intervention for children with birth defects, deficiencies, diseases, development delays and other forms of disability.

Recreation and Sport

India has focused on construction of special recreation and sporting centres for people with disability. India's investment in Special and Para sports movements is evidenced by excellent performance in special and para sports such as the 2019 Special Olympics where India won 368 medals.

17 <https://private.disabilityin.org/global/india/>

18 https://www.msde.gov.in/assets/images/PWD_National_Action_Plan_booklet%20A5.pdf

19 Government of India. (2009). Right of Children to Free and Compulsory Education Act, 2009. Available at: <http://mhrd.gov.in/rte>.

20 Patel, V, et al. (2015) Assuring health coverage for all in India. *The Lancet*. 386 (10011).

The institutional framework for India's response to disability

India's disability response relies on integration across various state and union government departments with services being provided via not-for-profits, private-for-profits, government services and public-private partnerships.

There is a growing startup and commercial sector producing assistive technologies which tends to capitalise on the large market in India and frugal innovation whereby low-cost aids and appliances are produced at scale.

There is also a large NGO and Not-For-Profit sector that has strong linkages to Victorian partners and could be built on. These NGOs tend to work closely with government and are often also funded by them. Examples include the Catholic Health Association of India whose community level disability program stretches across India. Other entities include social enterprises such as BillionAbles, an all-inclusive platform focused on connectivity and inclusivity of differently-abled people across the globe and providing a range of connectivity services including employability, entertainment, lifestyle and assistive tech.

Specific Government institutions tasked with leading the disability response include:

Department of Empowerment of Persons with Disabilities (DEPwD)

The Ministry of Social Justice and Empowerment handles disability affairs through DEPwD (Viklangjan Sashaktikaran Vibhag) and the Ministry of Social Justice and Empowerment (MSJE). The DEPwD is the umbrella for disability work across ministries such as the MSJE, Ministry of Health and Family Welfare (MHFW), Ministry for Education (MOE) and Ministry of Labour and Employment (MLE). The Rehabilitation Council of India (RCI) and National Institutes report to DEPwD. The DEPwD, on behalf of the Indian Government, leads the ongoing engagement with Australia in disability.

The Rehabilitation Council of India (RCI)

Created by the *Rehabilitation Council of India Act 1992* the RCI is tasked with training rehabilitation professionals and promoting research in rehabilitation and special education. It reports to the secretary of the DEPwD. The mandate given to RCI is to regulate and monitor services given to persons with disability, to standardise syllabi and to maintain a Central Rehabilitation Register of all qualified professionals and personnel working in the field of Rehabilitation and Special Education.

National Institutes on disability

Under the DEPwD there are nine National Institutes working in the field of disability.²¹ They are autonomous bodies and each focuses on a particular area of disability. They provide rehabilitation services to people with disability and run courses for rehabilitation professionals.

Victoria has closely engaged with the National Institute of **Empowerment of Persons with Multiple Disabilities** to develop training in mental health. It runs programs to train rehabilitation professionals and provides services such as physiotherapy, speech therapy, occupational therapy, psychological intervention, vocational training and special education.

The National Trust

The National Trust is a statutory body of the Ministry of Social Justice and Empowerment established to:

- enable and empower persons with disability to live as independently and as fully as possible within, and as close to, their community as possible;
- facilitate the realisation of equal opportunities, protection of rights and full participation of persons with disability;
- extend support to its registered organisations to provide need-based services; and
- evolve procedures for appointments of guardians and trustees for persons with disabilities.

District Disability Resource Centres

The District Disability Rehabilitation Centres are set up and funded centrally and are slated to be functioning in every district to lead the response to disability locally. To date, 262 have been established across all Indian States but many of them need extra support to be fully functional.

²¹ <http://disabilityaffairs.gov.in/content/page/national-institutes.php>

Victorian engagement with India in the disability sector

There is significant potential for collaboration and research engagement on disability between Victoria and India. There are numerous complementarities between the Australian and Indian sectors, with areas of strength in Australia matching areas of need in India and vice-versa. Increasing disability-related engagement between India and Victoria is an opportunity to action a number of aspects of *Victoria's India Strategy: Our Shared Future*, including innovation and collaboration in the priority sectors of health, business and education.²²

Consistent with *Victoria's India Strategy*, the Victorian Government should seek to capitalise on both the burgeoning disability services and devices market in India whilst also supporting equitable and universal access to disability services. This requires a commitment to the Sustainable Development Goals (SDGs), many of which include the phrase “inclusive” or “for all” in their objective.²³

Recent policy initiatives represent potential areas where Victoria can build on its engagement in disability. In 2017 the Victorian government, facilitated by the Australian Department of Foreign Affairs and Trade and the University of Melbourne, hosted the secretary of the Department of Empowerment of People with Disabilities. The delegation met with senior government representatives from the Department of Education, Disability, Health and Human Services and Sport.

This engagement led to a bilateral **Memorandum of Understanding (MoU)** on disability being signed between the Australian and Indian Governments during the President of India's visit to Australia in December 2018. This MoU outlined areas of cooperation under which collaborative projects are now being implemented, including:

1. Co-design of Community Disability Program: learning from NDIS and India
2. *Nae Disha* intervention to build mental health resilience in schools in India
3. Modelling an NDIS for India
4. Partnering in the new National Institute on Mental Health Rehabilitation/ Research

²² Government of Victoria (2018) *Victoria's India Strategy: Our shared future*.

²³ WHO (2018) The Astana Declaration on Primary Health Care.

Two subsequent Indian Government disability delegations have met with Victorian Government Departments, University representatives and the Royal Children's Hospital to develop projects under the MoU.

The disability MoU builds on the bilateral MoU on health (2017) which identified areas, many relevant for disability, where Australia and India can cooperate in research and industry partnerships. For Victoria these might include digital health, mental health, pharmaceuticals, medical devices and health services.

Most recently, in February 2020, the Aii arranged a roundtable for the Joint Secretary of DEPwD to discuss the way forward with Victorian Government officials from departments responsible for transport, education, sport, health and disability. The roundtable and subsequent report identified areas of future cooperation. Victoria is well-placed to capitalise on these strong relationships.



Meeting to discuss joint areas of cooperation in disability in Delhi, with Mr Allan Myers (Chancellor, Melbourne University), Prof Bruce Bonyhady (Melbourne Disability Institute), Associate Professor Nathan Grills, Tim Kendall (Australia High Commission Delhi), The Honorable Dr Thaawarchand Gehlot (Minister for Social Justice and Empowerment), Ms Shakuntala D Gamlin (Secretary, DEPwD) and Dolly Chakraborty (Joint Secretary, DEPwD)

Deepening Victoria-India disability partnerships

The dynamic relationship between the DEPwD and Victorian government, championed by Minister Donnellan, Minister for Disability, Ageing and Carers, has potential to further link Victorian institutions to Indian partners so as to generate significant exchange, research and commercialisation. Victoria has the potential to leverage its expertise in medical research and disability policy development to deepen partnerships with the Indian disability sector in key areas of mutual benefit including in the following areas. Many of these initiatives can be undertaken at little cost:

1) Leadership program in disability

Victoria boasts leaders in area of public health, disability and research, such as Professors Bruce Bonyhady and Rob Moodie. Victoria could bring together people of influence in disability from both India and Victoria, under a joint leadership training program. This would ideally be a partnership between the Victorian Government, university and private sector disability stakeholders and would increase cooperation and sharing in the field of disability. It would increase the networks with key disability partners in India including the National Institutes, the DEPwD and the disability NGO sector. The program could be jointly resourced by the Indian government, universities and the Victorian government (in-kind).

2) Researching disability financing models

Australia developed a world first disability insurance scheme which was based on economic modelling which clearly demonstrated the significant return to society from investing in people with disability. India will need to increase its investment in disability to respond to the growing numbers of people with disability. Professor Bruce Bonyhady, founding chair of the NDIS, has been part of a Melbourne group working with the Indian Government on developing an economic case for investment in disability. Victorian experts and government officials have significant expertise in this area and have already contributed significantly to the discussion.

3) Tertiary sector involvement in education in disability

Victoria has strong linkages with India in tertiary education and continuing professional development. India is the second largest international consumer of Victorian education.²⁴ Victoria's university and vocational education sector offer advanced training, PhDs and professional degrees in disability related areas. The DEPwD has expressed interest in enrolling in existing university courses. As domestic education reform and COVID-19 drives more acceptance and recognition of foreign online education qualifications in India, Victoria's education sector is well placed to capitalise on demand. India is also an important destination for Australian scholarly experience.

DEPwD has also requested assistance to work with the Rehabilitation Council of India and the National Institutes to co-design Strategic Educational programs in disability that can be delivered and accredited in India. For example, the University of Melbourne and Rehabilitation Council of India (RCI) have been working together to co-design competency-based training programs for disability training programs. The RCI have expressed interest in working with Australian partners to reconfigure all their courses using competency-based approaches.

4) Cooperating on Inclusive Education

The Victoria-India Disability Roundtable in February 2020, convened by the Australia India Institute, highlighted Inclusive Education as an area of joint interest. Victoria's model of inclusive education is advanced. The Victorian Department of Education and Training has established an Inclusive Education Professional Practice unit to guide progress towards universal design for teaching and learning. In India, the education sector is undergoing a significant overhaul as the new National Education Policy is implemented. The time is right to collaborate on promoting effective inclusive education. Accordingly, a training session on Inclusive Education is being undertaken for DFAT by the University of Melbourne supported by the Victorian Government.

²⁴ <https://internationaleducation.gov.au/research/International-Student-Data/Documents/MONTHLY%20SUMMARIES/2019/Dec%202019%20MonthlyInfographic.pdf>

5) Cooperation in accessible transport

Transportation System Accessibility is a vital component for independent living and has been a focus for the Accessible India campaign. It aims to increase accessibility of air, bus, taxi and train travel. At the 2020 Aii Victoria-India Disability Roundtable, accessible transport options were identified as a priority area for cooperation.

During her visit to Victoria, the Joint Secretary was able to see a number of innovative approaches to making public transport more accessible. This included the traveller's hub at Southern Cross Station, beacon technology for blind commuters and a ground-breaking training program for all staff called "Travelling in the Shoes of Others". The Victorian and Indian Government's could support a consultancy to explore collaborative approaches in promoting accessible transport.

6) Commercialisation of disability technologies

The industry around assistive products and technology is rapidly expanding. In Australia, companies are seeking to innovate in response to increased demand generated from the NDIS. India has expertise in frugal innovation and production at scale. Valued at \$5.2 billion, the MedTech sector in India is growing at an annual compound growth rate of 15.8%. Further cooperation in commercialisation will require universities, industry and governments to work more closely together. A disability innovation trade fair could be arranged in Australia or India and/or included as part of future trade delegations. Extension of collaborations with IITs could also facilitate low cost technology solutions for disability.

7) Information Technology (IT) solutions

Information Technology will be important in responding equitably to disability needs. India is a leading innovator when it comes to M-Health, app-based approaches, and digital monitoring. Victorian disability services and industry partners should work more closely with Indian counterparts to jointly develop new IT products and solutions to improve disability care. Facilitated by the Victorian Government, companies and institutions could begin by growing strategic partnerships for technology start-ups in incubator locations in cities such as Hyderabad, Bengaluru, and Chennai, with strong links to the growing start-up community in Melbourne.

Partnering in the face of COVID-19

As the COVID-19 pandemic continues to affect populations of both countries, the collaboration between India and Victoria has become even more important in the long term. In a global economic recession with huge disruptions to existing systems, we need to consider how we can innovate to make services and programs affordable, efficient, effective and accessible by working together.

However, the actioning of this Victoria-India cooperation in disability, and exploration of further ideas for collaboration, is best delayed until the immediate health crises are passed, which is likely to be in 2021.

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Ms Shakuntala D Gamlin (Secretary, DEPwD) with Dr Subodh Kumar (Head of Rehabilitation Council of India) and Joint Secretary Tarika Roy, launching a joint disability training manual developed between institutes in Melbourne and India.



Assisting a child with disability to learn

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