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Equity in Health for All: Advancing Social Health Protection for Persons with Disabilities



International Labour Organization





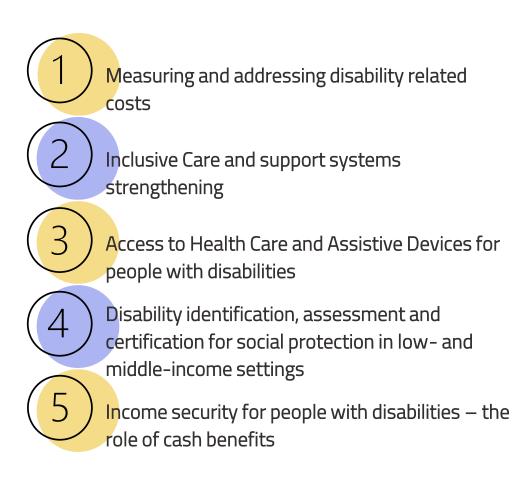






Following the adoption of the joint statement "Towards inclusive social protection systems supporting the full and effective participation of persons with disabilities" in 2019, a broad coalition of development partners, experts OPDs took part in a process facilitated by UNICEF, ILO and IDA with the support of the UNPRPD, the government of Norway and the European Commission to develop technical resources. The series is implemented jointly with these partners and will discuss some of the core modules of the guidance note.

social protection.org

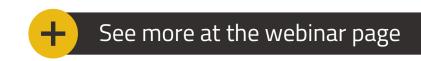






Equity in Health for All: Advancing Social Health Protection for Persons with Disabilities

This webinar aims to present critical insights from a recent study focusing on the access to social health protection (SHP) for persons with disabilities. This research, rooted in the principles of international human rights and the objectives of Sustainable Development Goals, examines the pivotal role of SHP in ensuring health care without financial hardship, particularly for individuals with disabilities who encounter increased health service needs and disability related costs.









Deputy Regional Director, Asia and the Pacific, ILO



Consultant, ILO



Nguyen Khanh Phuong

Director, Health Strategy and Policy Institute (Viet Nam)



Ket Boravin

Moderators

Program Coordinator, Agile (Cambodia)



Ketmany Chanthakoumane

Deputy head of the Division for Health Policy and Health System Research, Lao Tropical and Public Health Institute (Lao PDR)



Christine Phillips

Professor, Australia National University, Social Foundations of Medicine at the School of Medicine and Psychology (Australia)



Alexandre Cote

Social policy specialist, UNICEF



Lim Puay Tiak

Chairman, ASEAN Disability Forum (ADF)



Marielle Phe Goursat

Project Manager, ILO



Yuta Momose

Social Protection Officer, ILO



Moderators



Marielle Phe Goursat

Project Manager, ILO

Marielle is a social health protection expert at the ILO. She has been working in the field of social protection for 20 years across Sub-Saharan Africa and South-East Asia. She provides advisory services to governments and social partners in the design and implementation of social protection policies. Her expertise encompasses strategy and policy development, capacity building and fostering collaboration to drive sustainable change. She led the research on disability inclusive social health protection in Cambodia, Lao PDR and Viet Nam.



Yuta Momose

Social Protection Officer, ILO

Yuta is a SP Officer with the International Labour Organization in Bangkok and previously, in the Social Protection Department at the ILO Geneva Headquarters from 2022 to 2024. His areas of expertise include disability, long-term care and social health protection. He was previously Managing Director of the Myanmar Office and Overseas Director of the Japanese medical NGO, Japan Heart. He has more than eight years of experience in the areas of health and disability in South-East Asia. He holds a master's degree in public administration from the National University of Singapore.

Speakers



Panudda Boonpala

Deputy Regional Director, Asia and the Pacific, ILO

Ms Panudda Boonpala is appointed Deputy Regional Director of the ILO Regional Office for Asia and the Pacific, from 1 January 2018. Prior to that, Ms Boonpala has held the position of Director of the ILO Decent Work Team for South Asia and Country Office for India. Her professional experience covers several areas in the World of Work, working with Government, employers' organizations and trade unions, on issues such as social protection, fundamental principles and rights at work, labour market governance, and labour migration. Ms Boonpala holds an MA in Labour Administration and Management from the Thammasat University, Bangkok, Thailand.



Speakers



Charles Knox-Vydmanov

Consultant, ILO

Charles is an independent consultant with over 15 years experience in the field of social protection across more than 25 countries. His experience includes working as global technical lead on social protection at HelpAge International (2012-2018) and managing the development of social protection training activities at the ILO's training centre in Turin (2019-2020). As an independent consultant he has worked on a range of issues including social protection system and scheme assessment and fiscal analysis. Disability-related social protection has become an increasing focus of his work, for example, having been a co-author on a recently-published global guidance on inclusive social protection for persons with disabilities.



Nguyen Khanh Phuong

Director, Health Strategy and Policy Institute (Viet Nam)

Dr. Phuong is the leading health economist with more than 25 years of experience in health financing, health economic and health system reform in Vietnam. She is currently a member of HTAsiaLink Scientific Board, HTAi Asia Policy Forum Organizing Committee, Joint Learning Network. She has published many articles in Vietnamese and English on domestic and foreign medical journals. She graduated from Hanoi College of Pharmacy in 1994 and earned a master of science on Health Economics in Chulalongkorn University in Bangkok, Thailand in 1997. She earned a PhD degree on Public Health in National Institute for Hygiene and Epidemiology in 2011.



et Doravili

Program Coordinator, Agile (Cambodia)

Tree Regional Disability As the Bodhi Entrepreneurship Centre Lead and Program Coordinator at Agile, Ravin's work is centered around fostering economic empowerment for people with disabilities in Cambodia. He's led research on disability social health protection access for the ILO. Ravin helped design and implement four disability entrepreneurship programs, impacting 60 entrepreneurs with disabilities, and provided oneon-one mentoring to 15 women entrepreneurs with disabilities. Additionally, Ravin's developed 2 disability inclusion guidelines for inclusive employment for TVET institutes and private sector under the 3-year project with People In Need (PIN), contributing to a more accessible and equitable business environment.



Speakers



Ketmany Chanthakoumane

Deputy head of the Division for Health Policy and Health System Research, Lao Tropical and Public Health Institute (Lao PDR)

Ketmany Chanthakoummane is now working for Lao Tropical and Public Health Institute. Deputy head of the Division for Health Policy and Health System Research. I graduated Medical Doctor in 2000 from the University of Health Sciences, Lao PDR, and a master's degree in Public Health in 2010 from Mahidol University, Thailand. Research field that I conducted: SRH, protection of disabled children, and adolescent health research.



Christine Phillips

Professor, Australia National University, Social Foundations of Medicine at the School of Medicine and Psychology (Australia)

Christine is the Professor of Social Foundations of Medicine at the School of Medicine and Psychology, Australian National University, and the Medical Director of Companion House Refugee Medical Service. She trained in anthropology, medicine and public health, and researches equity in policy and practice in complex health innovations. She is an appointed member of the Australian Government's Culturally and Linguistically Diverse Health Advisory Group.



Alexandre Cote

Social policy specialist, UNICEF

Alexandre Cote is a Disability and Social Protection Policy specialist at UNICEF. Alex has been working in the field of inclusive development for 25 years supporting programs in the field of community support services, social protection, health and rehabilitation and humanitarian relief in Eastern Africa, Southeast Europe, and the Middle East. Actively involved in negotiation of the CRPD, he has contributed to its implementation and monitoring ever since.



Lim Puay Tiak

Chairman, ASEAN Disability Forum (ADF)

Lim is a founding member of the ASEAN Disability Forum (ADF) which was established in 2011. ADF is a network of Organisations of Persons with Disabilities (OPDs) in the 10 ASEAN countries to advocate for disability inclusive policy formulation and implementation. The ASEANI Secretariat has recognised ADF as an accredited Civil Society Organisation for disability matters. Mr Lim has been serving as its Chair since December 2017. He is also a Board member of IDA which was established in 1999 as a network of global and regional OPDs and their families.



Disability inclusive Social Health Protection

A human right-based approach



Three challenges for PwD in relation to health

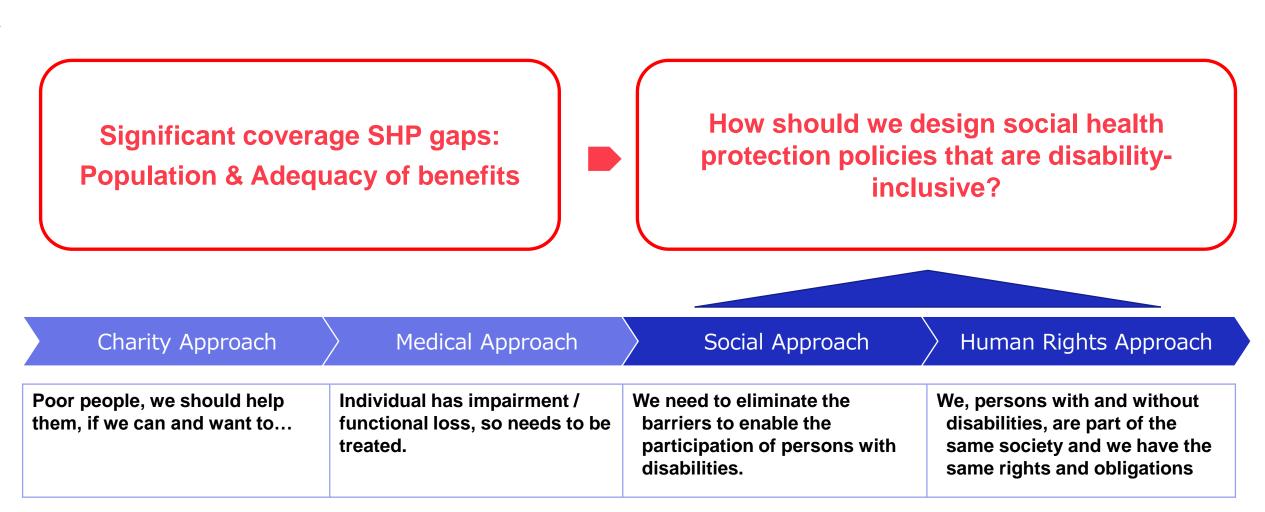






Half of people with Disabilities cannot afford health care 50% more likely to experience catastrophic health expenditures





Transition of Approach



Disability Inclusive Social Protection

Guidance: International Standards



(Basic) Income security for adequate standards of living



Coverage of health care costs including early intervention, (re)habilitation and assistive devices



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Coverage of disability related costs including access to support services

Facilitate access to early childhood development, education and economic empowerment programs

Inclusion of PWD/OPD in design and implementation

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Accessibility of social protection administration and services, without discrimination



Disability inclusive SHP – Good practice



Coordination with broader social protection system



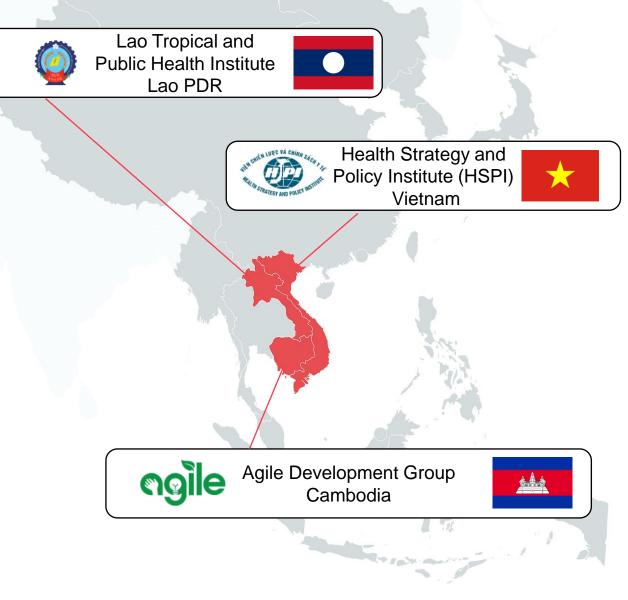
Access to social health protection for persons with disabilities in Cambodia, Lao PDR and Viet Nam

Summary of research findings



Introduction and research methodology

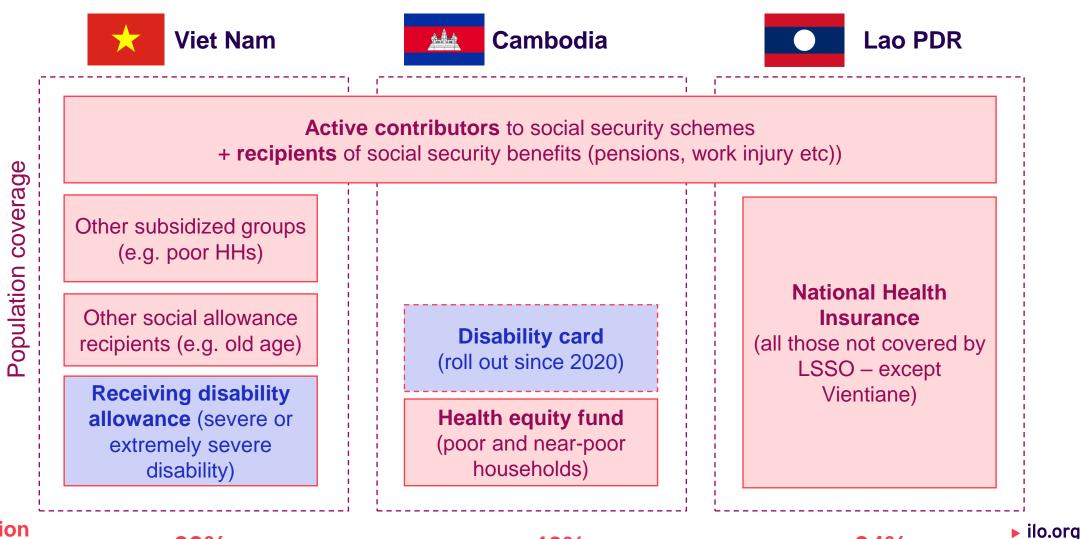
- Objective: Assess the extent to which social health protection schemes provide <u>population</u> <u>coverage</u>, <u>appropriate services</u> and <u>financial</u> <u>protection</u> to persons with disabilities, and the level of <u>access to long-term care services</u>.
- Countries covered: Cambodia, Lao PDR and Viet Nam - in collaboration with national research partners
- Methodology
 - Qualitative research combined with literature review (legal framework + existing research)
 - 30 focus group discussions with 280 participants (different types of disability)
 - 43 key informant interviews
 - Central/local government, organisations of people with disabilities, rehabilitation centres





Pathways to population coverage for persons with disability (Simplified view)





Total population coverage (legal)

93%

c.40%



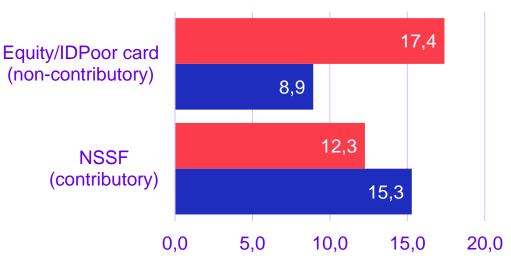


Findings: **Population coverage**

- Persons with disabilities benefit where countries are moving to universal population coverage
- Subsidized/non-contributory components are particularly key for persons with disabilities
 - Persons with disabilities more likely to be covered by subsidized schemes, less likely to be covered by contributory components.
- Disability-specific components can be valuable part of coverage extension
 - In Viet Nam for persons with severe and extremely severe disability
 - In Cambodia new disability card although health entitlement unclear
- Disability assessment and determination matter
 - Positive steps towards community-based and social models of disability assessment in Cambodia and Viet Nam

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Households with health insurance cards (Cambodia – 2019/20)



Households with persons with disabilities

Households without persons with disabilities

▶ ilo.org



Findings: **Population coverage**



Viet Nam: Relative simplicity of disability assessment

Cambodia: Limited coverage of poverty-targeted system...

...new disability card but entitlements unclear

Lao PDR: Access to National Health Insurance despite limited information "Registering and enrolling in the scheme is not difficult at all. The commune staff did all the things for me and I just needed to ask for a referral." **Female, 58** (Physical impairment, Phu Tho, Viet Nam)

"It's difficult because mostly people with disabilities don't pass for the poor ID cards." **Female, 42 (Visual Impairment, Battambang, Cambodia)**

"[The disability card] has just been announced, but we can't use this card at the hospitals, yet. The health staff do not acknowledge them still." **Focus group discussion respondent (Visual impairment, Phnom Penh, Cambodia)**

"Last year I was admitted in provincial hospital for 3 weeks, and I paid only 30000 kip. Health staff in hospital just asked me about family, then I was admitted, they did not explain that service named NHI." **Male, 32 (Physical impairment, Champasak, Lao PDR)**





- General goods and services
 - Benefit packages often limited
 - E.g. Viet Nam certain medicines and tests require co-payment

Service coverage

Rehabilitation and assistive devices

- In Viet Nam, rehabilitation is integrated within health insurance package...BUT...
 - Limits in services covered and service provision
 - Assistive devices not generally covered

Findings:

- In Cambodia and Lao PDR:
 - Provision via rehabilitation centres in parallel to health insurance schemes (limited referral / continuum of care)
 - Availability highly dependent on geography, information and funding (government or NGO)

"My daughter was hospitalized one month ago and I had to buy medicine out of pocket. The health insurance only paid for her hospital bed, ultrasound, and X-ray. There were still many things I had to pay out of pocket. That's all I know." Female, 59 (Physical impairment, Hung Yen, Viet Nam)

"My son often uses rehabilitation services. However, the health insurance only pays for few services. I have to pay many other services out of pocket." **Caregiver of male, 15 (Intellectual impairment, Phu Tho)**

" [An important] challenge is the financial issue. They live in rural areas. The transportation is difficult and their financial status as they earn for a day and eat for a day, so they don't have money to come." (Rehabilitation Centre, Kampong Cham)

"Many people do not know about this [rehabilitation] center yet, while many family face to this problem and they do not know where to go." Male, 40 (Physical impairment, Vientiane, Lao PDR)





Medical costs	Uncovered population – required to pay relevant user fees
	Gaps in services covered – general services + rehabilitation and assistive devices
	Co-payments – e.g. VSS contributors in Viet Nam / NHI beneficiaries in Lao PDR
	Use of private healthcare/pharmacies (availability, service quality, convenience)
	Accessing higher-levels of health care without referral – notable in Viet Nam
Non-medical costs	Transportation – influenced by (in)accessibility and geographical location
	Human assistance – sign language interpreters, support for physical impairment etc
	Inpatient related costs – Meals, accommodation (depending on national service packages)
	Opportunity costs – For persons with disabilities and those that support





Positive impact of social health protection scheme

Costs of services not covered by health insurance

Use of private health care and pharmacy

Non-medical costs (assistance and transportation)

Coping strategies

"Before I had the health equity card, I had to spend so much on my eye treatment, now that I have the card, I don't spend a single dime, and I'm also well taken care of. The service was great and very welcoming." Male, 42 (Visual impairment, Kampong Cham, Cambodia)

"We have to pay for brain tonics and medicine for epilepsy when accessing health services under the health insurance at health facilities." **Caregiver of female with epilepsy (Hung Yen, Intellectual impairment, Viet Nam)**

"For my eyes, I go to the private clinic. ... or buy eye drops at the pharmacy. But in terms of General health issues that are not serious, I go to the communal hospital." (Visual impairment, Battambang, Cambodia)

"I always need to be accompanied by a family member when visiting health facilities for examination. My father often takes me to the doctor. My family is poor and we cannot afford travelling by coach or taxi." **Female, 18 (Visual impairment, Phu Tho, Viet Nam)**

"For me, first I use my saving money, and then I mortgage family land. And I also borrowed money and sold my gold." **Female caregiver of male, 8, with autism** (Champasak, Lao PDR)



Findings:

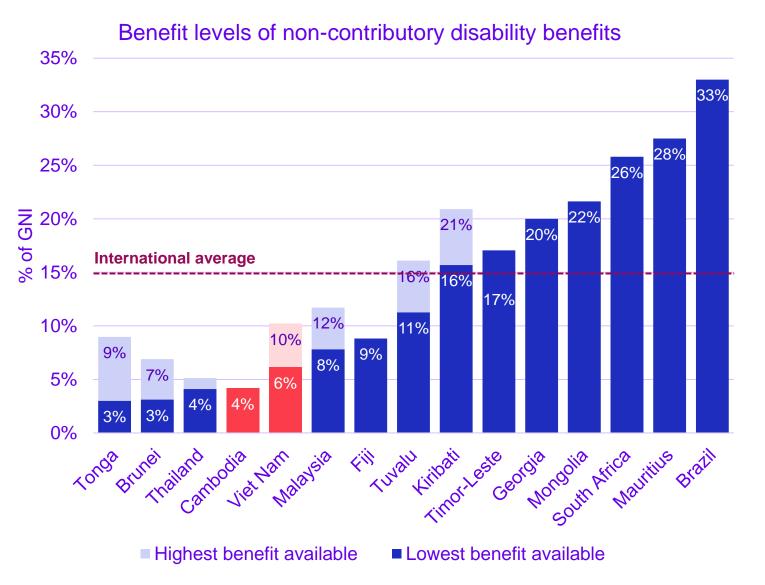
Financial protection – role of cash benefits



- Cash benefits can contribute to covering both non-medical and medical costs
 - But cannot compensate for major gaps in social health protection schemes

"I spend my social allowance on medicine. If I can't afford medicine, I'll ask my children for help." Male, 68 (Physical impairment, Phu Tho)

- Cambodia and Viet Nam both have cash benefits in place
 - However, benefits relatively low by international standards





Findings:

Long-term care / Care and support services

- Care and support needs vary considerably among persons with disabilities
 - Physical impairments needs highly variable old age is key intersecting factor
 - Visual and hearing impairments main needs are support outside the house (incl. communication)
 - Intellectual impairments highest support needs with activities of daily living
- Long-term care / support service provision very limited in all countries
 - Minimal/non-existent legal framework, financing and formal provision
- Existing care and support almost exclusively provided by families, friends and OPDs/NGOs

"It is difficult to go to shopping, I need someone to take me to market." **Female, 28 (Physical impairment, Vientiane, Lao PDR)**

"I need assistance; for example, if I go to the market, I might need a friend to go with me." **Female, 42** (Visual impairment, Battambang, Cambodia)

"He needs support for all activities related to living independently. He cannot do anything himself and has to rely completely on family members. As we get older, we cannot take care of him forever."

Caregiver of person with intellectual impairment (Hung Yen, Viet Nam)



Key messages/recommendations

Population coverage

- Make specific legal provision for persons with disabilities as part of efforts to extend universal population coverage
- Adopt specific measures, including financing to extend coverage for example, specific subsidies for persons with disabilities, with inclusive disability assessment.
- Strengthen information and awareness of disability-specific and mainstream schemes

Service coverage

- Include rehabilitation and assistive devices within social health protection benefit packages, and integrate services within health systems
- Consider expanded package of both general and disability-related services for persons with disabilities (e.g. Philippines)

Financial protection

- Consider specific measures (e.g. reduced/eliminated co-payments) for persons with disabilities
- Expand coverage and adequacy of cash benefits, not least to support non-medical costs associated witho.org accessing health care





Australia's National Disability Insurance Scheme



Christine Phillips

Australian National University

Overview

- Background to the NDIS
- The model
- Implementation of the NDIS
- Successes and challenges
- A new improved NDIS

Mental disability

The challenge

17% Australians have a disability53% Australians 15-64 yrs with a disability are in the workforce

82% of children with disabilities attend school regularly

In 2014, Australia ranked lowest in the OECD on relative income for people with disabilities



Source: Australian Institute for Health and Welfare, 2022 Health of people with disability draws on 2018 Australian Bureau of Statistics Household survey Disability, Ageing and Caring

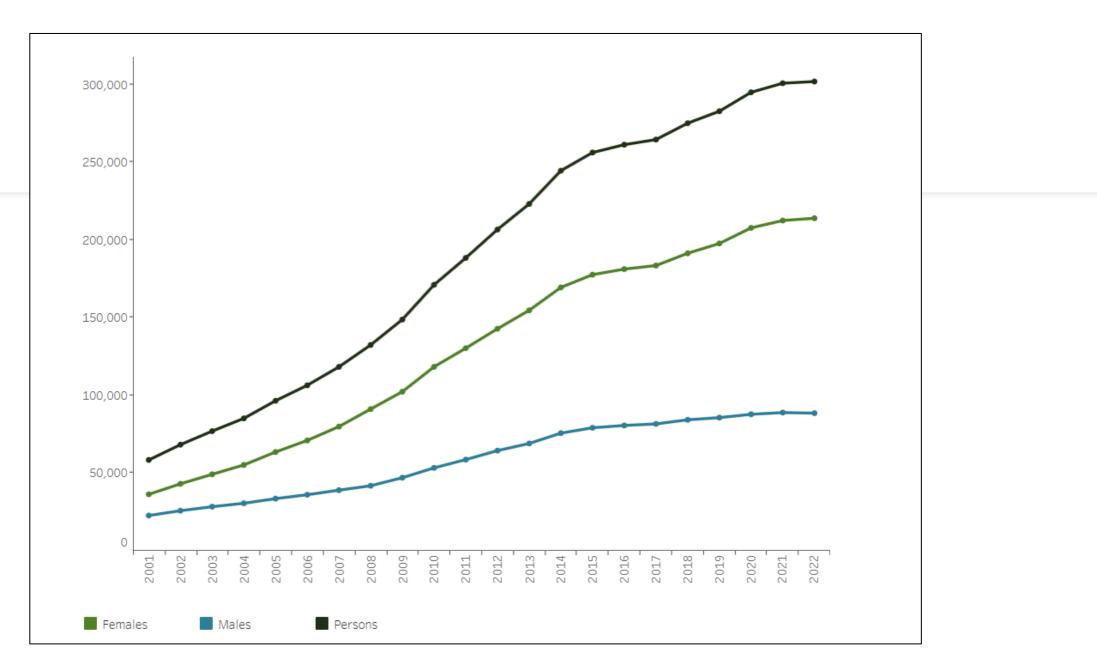
Disability SHI before the NDIS

- Disability support pension
 - Provides income stream, exempted from looking for work
 - Regularly review for work function
 - Lost if person returns to work
- Carer payment (income support)
- Carer allowance (income supplement)

770,000 people receive DSP

310,000 people receiver carer payment

630,000 people receive carer allowance (income supplement)



Trends in recipients of carer payment, 2001-2022 Source AIHW 2023

"Underfunded, unfair, fragmented and inefficient"

"There should be a new national scheme - the National Disability Insurance Scheme (NDIS) - that provides insurance cover for all Australians in the event of significant disability. Funding of the scheme should be a core function of government (just like Medicare).

The main function (and source of cost) of the NDIS would be to fund long-term high quality care and support (but not income replacement) for people with significant disabilities."

Productivity Commission, Disability Care and Support, Inquiry Report, 2011



National Disability Insurance Scheme

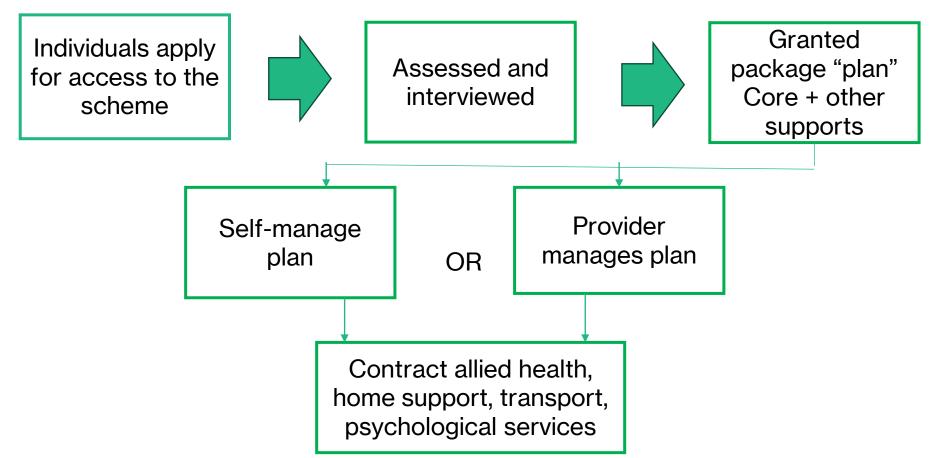
- Funded by Government and by states and territories
- Uses WHO functional model of disability
- Customised, package of services to improve functional quality of life
 - mobility
 - communication
 - social interaction
 - self-management
 - learning
 - self-care

- Not intended for those with chronic illnesses
- Includes psychosocial disability
 - Disability resulting from mental illness affecting someone's ability to function in society
- Not intended to replace state-funded services or supports for people with disability

Launched July 2013, reached full rollout across Australia 2020

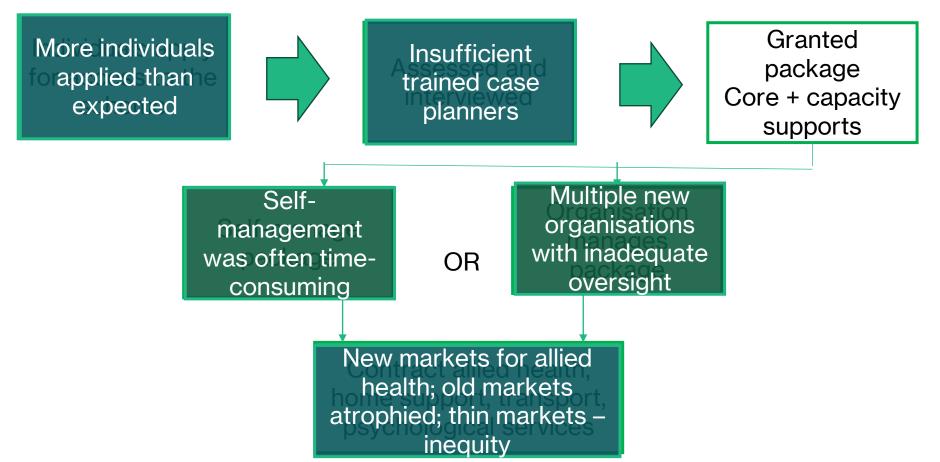
Implementation

National Disability Insurance Agency



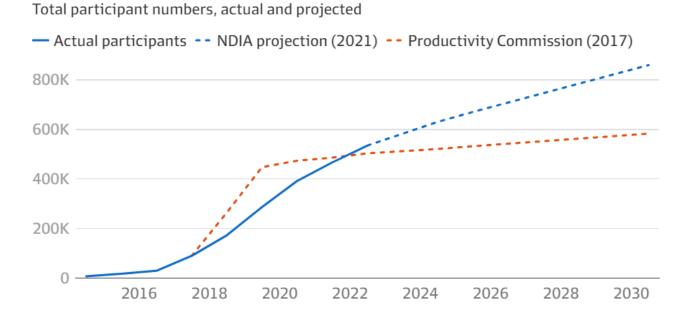
Implementation challenges

National Disability Insurance Agency



10 years of the NDIS

- 649,623 people enrolled (March 2024)
- Transformative for many
- "Making disability present"



Forecasts are from the NDIA's 2020-21 Annual Financial Sustainability Review Chart: Michael Read • Source: National Disability Insurance Agency





Reflecting on the first 10 years

- Loss of service infrastructure for people not on the NDIS
 - States have defunded many of their previous supports for disabled people
- Better governance systems to ensure good practice by providers and prevent fraud
- Cost and quality controls over services
- Innovations for thin markets
 - Aboriginal and Torres Strait Islander people, rural people, people from culturally and linguistically diverse backgrounds)
- Capacity development for workers, planners and providers

Considerations for the future

- Psychosocial disability is a unique category with fuzzy boundaries
 - 30% rejection of applications
 - Few state-funded services
- Responding to the increase in autism diagnoses
- Administrative burden is significant for persons and providers
- Monitoring and managing emerging markets

Thank you!

Contact: Christine.phillips@anu.edu.au Social Protection and access to assistive technology in low- and middleincome countries

Alexandre Cote, social policy specialist, Social protection and Disability inclusion UNICEF HQ



What can be expected from Inclusive Social Protection systems across the life cycle?

 $\overbrace{\bullet \bullet \bullet}$

(Basic) Income security and adequate standards of living



Coverage of health care costs including early intervention, (re)habilitation and assistive devices

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Coverage of disability related costs including access to support services



Facilitate access to early childhood development, education and economic empowerment programs

Building disability inclusive social protection systems

CATEGORIES OF INSTRUMENTS	EXAMPLES OF TYPES SCHEMES ACROSS THE LIFE CYCLE			FUNCTION
	CHILDHOOD	WORKING AGE	OLD AGE	
CASH BENEFITS	Poverty assistance cash transfer, cash for work			
	Child grant/family benefits/	Unemployment, maternity, sickness, parental leave benefits,	Old age pensions	INCOME SECURITY
	Care giver benefits	Disability related income replacement benefits		
	Child disability benefits			COVERAGE OF
	Third person support / caregiver benefits		HEALTH CARE AND DISABILITY- RELATED COSTS	
IN KIND BENEFITS THAT REDUCE OOP COSTS	Concessions Free or discounted public transport, subsidized utilities, insurance or services, tax exemptions			
	Services Health insurance/free, early intervention, rehabilitation, assistive technology, Community care and support, case management, personal assistance schemes, interpreters, counselling, point to point transport, respite care			
INTERLINKAGE	Early childhood development, childcare, educationEconomic empowerment programs, return to work programs, women's empowerment, protection services, financial inclusion services			CONNECTION TO OTHER SERVICES

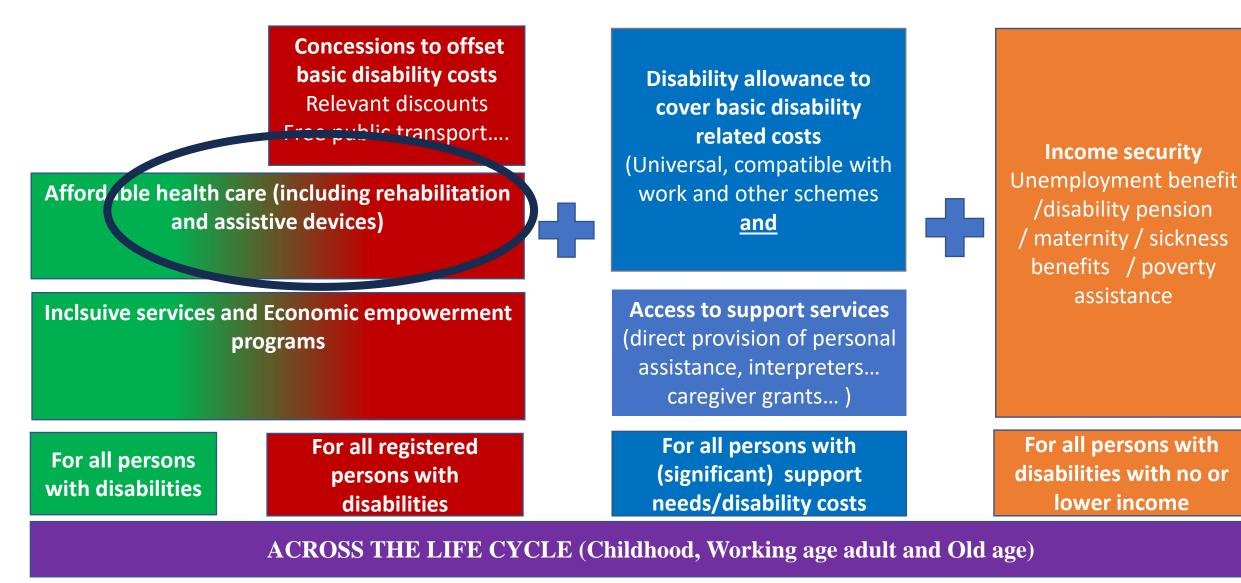
Linking AT and social protection

- In many higher income countries, social protection systems contribute to cover costs of AT through health insurance and/or dedicated schemes.
- However, in low- and middle-income countries, the broader issues of access to AT are compounded by barriers to access social protection with less than 20% of persons with significant disabilities receiving disability benefits.

Linking AT and social protection

- While AT represents a lower share of disability related costs than human assistance, it represent often a significant one-off expenditure amounting to catastrophic health expenditures.
- The CRPD Committee has repeatedly recommended governments to cover disability related costs through social protection and with specific reference to AT
- Overall, in most LMICs, persons with disabilities rely on out-of-pocket payment and support by families to procure AT as few countries effectively cover AT costs.
- While a growing number of LMICs seek to cover health care costs of persons with disabilities, very few include AT through UHC or health insurance subsidies schemes (Rwanda, Philippines, Namibia, Indonesia, Thailand), but often with limited offer and long waiting time.
- Several countries have set up specific programs or even bodies (Kenya, Sudan, India, Georgia...) to improve access to AT but often with limited coverage and scope.

AT, social protection and disability status



Way forward

The risk of double exclusion:

- As in high income countries, social protection support to access AT is often conditioned by obtaining an official disability status, which is still a significant challenge in many LMICs
- Poverty targeting of disability support can also exclude many persons who amy not live in households considered as poor by social protection system but who nonetheless do not have the resources to purchase needed AT

To address those issues several countries :

- are seeking to improve both the coverage of disability certification mechanisms as well as the information collected during disability assessment on met and unmet needs for support and AT (Rwanda, Cambodia, Georgia, ect...)
- adopted a universal approach to disability support acknowledging the broad impact of disability related costs (Namibia, Fiji, Thailand, Vietnam...)
- Those evolutions can contribute to greater coverage and adequacy of support to access AT but will not eliminate the risk of exclusion from needed support

Way forward

- There may be a reluctance from social health insurance bodies to take on the sole responsibility for covering the cost of assistive technology.
- With the development of both UHC policies and social protection systems in LMICs, a possible transition model seems to emerge with the combination of
 - an increasing inclusion of most common AT (WHO Priority Assistive Products List) in UHC package accessible to wider diversity of persons irrespective of disability status and
 - the coverage by specific SP schemes of more expensive or rare AT required by fewer persons with disabilities with high support needs
- Such approach could distribute the budgetary costs of AT across ministries and level of governments and facilitate the required progressive increase of resource allocation to ensure universal access.



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Thank you for joining!

Make sure to answer our survey, available when you leave the session, and join us for the next session on July 11!