



# Child Disability Benefits: An investment worth making

DEVELOPMENT  
  
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## 1. Child disability benefits: why should we care?

Children with disabilities are, arguably, the world's most vulnerable children. Compared to their non-disabled peers, they must confront numerous other barriers, including stigma, abuse and services not designed to accommodate their specific needs. The situation is even worse for young girls, who are doubly disadvantaged, facing both disability and gender-based discrimination.

In many low- and -middle income countries, the birth of a child with a disability is considered a curse. Sometimes this results in infanticide; very often it results in the child being institutionalised or hidden away in the home, invisible to society. Fathers often abandon the child's mother, while it is not uncommon for the mothers themselves to turn the child over to the care of his/her grandmother who can struggle to offer adequate care.

A disability can throw a child's family into destitution and often it is the child who is blamed. Families can face significant additional costs - for example, for medical treatment, therapeutic support and transport - while caregivers may have to give up work to become a full-time caregiver for the child. This can create a vicious downward spiral, frequently ending in absolute poverty. Unfortunately, past and future vulnerability are intimately linked, and poverty, exclusion and poor quality services hinder the child's ability to thrive and lead a full life. Indeed, children with disabilities generally have lower participation rates in school, which has long lasting social and economic costs.

But it doesn't have to be this way. One of the most effective ways to empower children with disabilities is to ensure that every child can access a universal child disability benefit. Such a scheme would provide much needed income security to help families cope with the significant additional costs of bringing up a child with a disability. It would also enable the child - and the child's family members - to lead fulfilling lives. If we are truly committed to 'leaving no-one behind', the international community must come together to support the universal right to social security of children with disabilities and their families.

## Kenya

Many Kenyans feel that the birth of a disabled child is a curse, and that it can be the result of a mother's infidelity to her husband. When the child is the first-born, it is a common belief that the child should be killed in order for the family to give birth to further children.

**37%** of women surveyed in Nairobi and **57%** of women in more rural areas said they felt pressure to kill their children with disabilities.

(Disability Rights International 2018)

## The Cook Islands

Although the implementation of disability rights has improved in the last decade, stigma continues and many persons with disabilities remain isolated in their homes, seldom taking part in community activities.

Even though the Cook Islands has a compulsory school attendance policy, in 2012 only around half of children with disabilities attended school (CRC 2012). Furthermore, many schools have not been made accessible for those with mobility impairments.



## Rwanda

Children with disabilities are often invisible to their community. Even within their families, their siblings are often prioritised.

Sometimes, families sell off their land to pay for therapy for the child. However, this is generally poor quality and families are not taught how to continue it within the home. As a result, children seldom receive the therapy they desperately need. This is made more difficult by the fact that the family no longer has any land to work on and so their economic situation worsens very quickly.

(Development Pathways Rwanda Case Study)

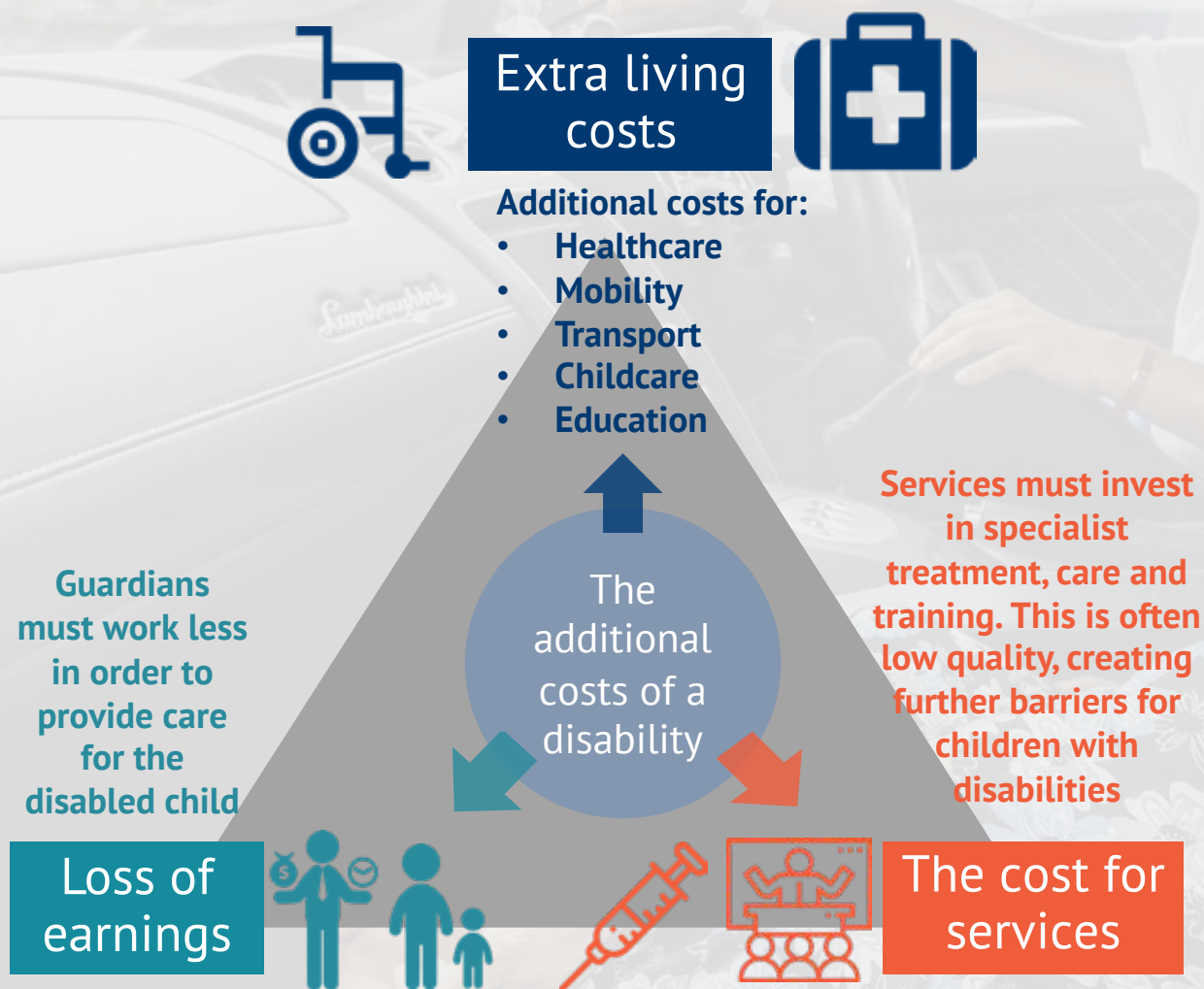
## Brazil

A key issue facing Brazil is the practice of fathers abandoning their children with disabilities, and this has been a leading contributory factor of household poverty. Furthermore, Brazil has a relatively high rate of institutionalisation, and this is partly due to disabled children being abandoned by both their parents.

(Development Pathways Brazil Case Study)

## 2. The additional costs of disability

Having a disability brings with it many additional costs, both for the family and for the state.



### 3. Additional costs experienced by persons with disabilities (applying the standard of living approach)



**China:** Between **8%-43%** for adults and **18%-31%** for families with disabled children (Loyalka et al. 2014)



**South Africa:** Around **40%** for households with a persons with a severe disability (Development Pathways South Africa Case Study)



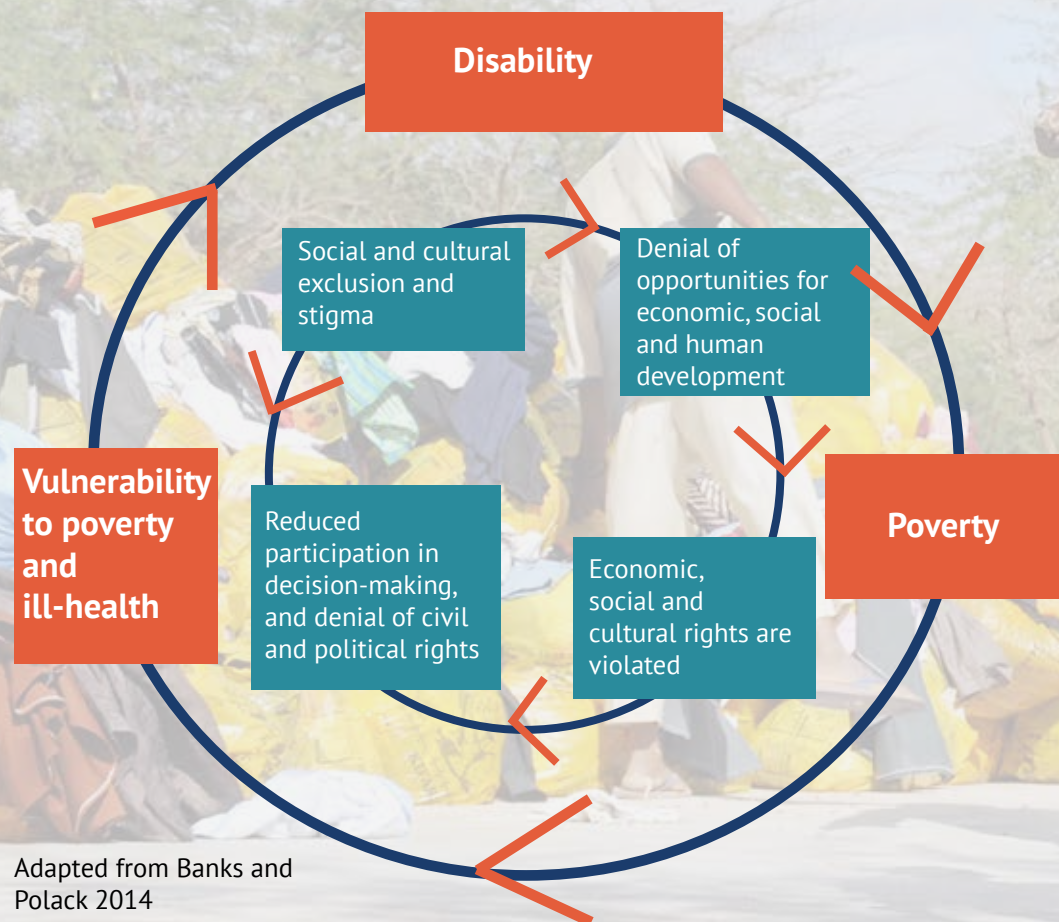
**Vietnam:** **11.5%** of income (Mont and Cuong 2011)



**India:** **20% to 58%** for households with a person with a severe disability (Development Pathways India Case Study)

## 4. The importance of getting the best start in life

Poverty, disability and vulnerability can be cyclically related, each reinforcing each other. Not only is a child with a disability more likely to live in a poor household, but conditions associated with poverty – such as poor sanitation and housing conditions, ill health, undernutrition and lack of access to clean water – increase the risk of disability. For example, a child living in poverty is less likely to be vaccinated against polio and, if they contract the disease, they may end up with paralysis in parts of their body.



Adapted from Banks and Polack 2014



In many low and middle-income countries, children with disabilities are much less likely to attend school than their non-disabled peers. Financial barriers are a serious issue, as caregivers struggle, for example, to find transport to send the child to school. Even when a child does receive an education, it is often poor quality because it has not been designed to accommodate the specific needs of the children.

The barriers that these children face follow them into their adult lives. Their exclusion from education, and then from decent work, not only increases their chances of living in poverty, but it also raises their level of vulnerability. And, without an adequate safety net, they are often the worst hit in a crisis.

However, with the right start to life, children with disabilities can grow up to lead their fullest and most dignified lives. This often cannot happen, however, without state support.

#### Estimated rates of primary school completion



UNICEF 2013



## Fighting to live her fullest life despite receiving no state help

Emily had a typical early childhood like many children in rural Kenya. She attended primary school and at age 5, had reached grade 1. But one day, she felt a burning sensation on the lower part of one of her legs while at school and was admitted into hospital. Although the medical teams tried every treatment, they could not heal the polio that left Emily's lower torso and parts of her hands paralysed.

Her father took her to a different hospital and Emily's sister dropped out of school to take care of her. But, when Emily was transferred to a referral hospital, her sister had to return home. The hospital staff could not provide the care that Emily needed and she became seriously emaciated because she couldn't feed herself. When her father visited her, he decided to take her home as it was the only way his daughter would receive proper care.

The pain continued for a year as she continued to use medicine at home. But after it ended, Emily was determined to continue her education. She taught herself, by reading books, and then asked to be re-admitted to primary school. Even though the school was two kilometres away, she walked there every day with the support of a stick. She was able to attend school until grade 8 but did not progress to secondary school.

Now, Emily runs a small business in the local town and lives with her sister. She is in need of constant care. Throughout her life, Emily fought to receive the same opportunities as her non-disabled peers, and had she received state help, especially at childhood, she would likely have been able to go even further in her life.



## 5. The current system is not working

### Additional costs are not being covered

A child benefit alone – given to both disabled and non-disabled children alike – does not sufficiently compensate for the additional costs of having a disability. Families with a disabled child need extra income in order to maintain the same standard of living as their non-disabled peers. Although needs are dependent on the social and economic environment of each society, there is a minimum amount that all disabled children – and their caregivers – should receive. Ideally, this should cover the additional costs experienced by the family, while a family member who has given up work to care for the child should also receive a caregiver's benefit.

### Conditions and means tests

Often, countries and international donors implement social protection schemes that can discriminate against children with disabilities. When payments are conditional on households complying with certain behaviours – such as attending school – disabled children lose out. They are less likely to attend school due to barriers outside their control, and their caregivers are likely to be overburdened and to struggle to comply. Yet, despite their high levels of vulnerability, children with disabilities are sanctioned by the reduction or removal of the benefits. Further, when programmes are targeted at families living in poverty, means tests typically do not take into account the additional costs faced by families.

### Evidence from the Philippines on the exclusion of children with disabilities from conditional cash transfers

In the Philippines, **42%** of children with disabilities (3-14 years) did not attend school, and were therefore excluded from the Philippines Pantawid conditional cash transfer.



**33%** of children with disabilities experienced difficulties using transport to get to school



**42%** of households with disabled members experienced challenges in travelling to health centres

Live Haven (n.d)

## 6. Child disability benefits: a part of the solution to the international crisis

Child disability benefits provide extra income to families to cover the additional costs they experience. If such schemes were in place across low- and middle-income countries, the situation for disabled children and their families would be very different. Families would receive regular financial support and be better able not only to cover the essential costs, but to purchase items, such as assistive devices and medicines, that would help reduce the barriers faced by children with disabilities.

But the advantages of child disability benefits go beyond covering the additional costs of disability. The greater visibility that child disability benefits would provide to those children in society would enable the state to provide other key services – such as good quality inclusive education and free health care – which, together, would improve the life chances of disabled children.

**Persons with disabilities in rural Andhra Pradesh in India  
said the disability pension is their**

**“only hope for family respect”**



**South Africa's Care Dependency Grant has  
encouraged families to increase the  
visibility  
of their children with disabilities and  
overcome stigma,  
increasing access to other services**

Gooding, K. and Marriott, A. (2009);  
Development Pathways (2018)  
South Africa report



## 7. What is already out there?

Very few low- and -middle income countries have established child disability benefits, but there are some including:



### South Africa:



+ South Africa provides a Care Dependency Grant to children with disabilities up to age 17 who 'require and receive permanent care and support services.' It is accessed by almost one per cent of all South African children, and pays a transfer equal to the country's Old Age Grant (or US\$ 120 per month).

Nonetheless, it is estimated that almost half of eligible children are still excluded, while the value of the benefit does not cover the additional transport, educational and medical costs incurred by many families. In part, the exclusion is due to the use of a means-test, which should be removed. Further, disabled children are not allowed to access the Child Support Grant if they are in receipt of the Care Dependency Grant, once again preventing them from receiving the full support they require to lead fulfilling lives.



**16%** of households in South Africa with at least one member receiving disability benefits live below the food poverty line.

Without the disability grants, **57%** this would be



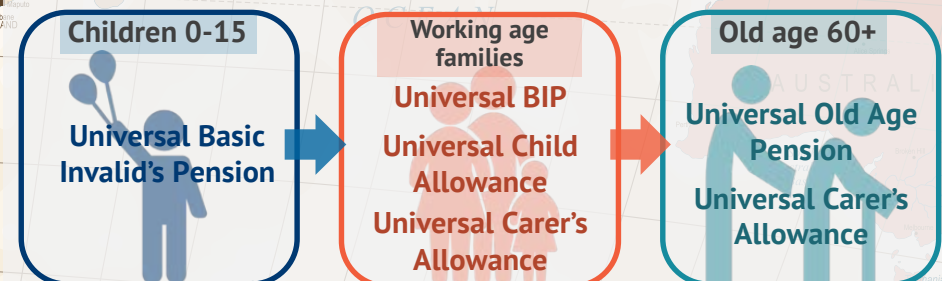
### Mauritius:



+ The 'Basic Invalid's Pension' is a universal benefit of MUR 5,250 per month (US\$ 148) for people assessed with at least 60% disability according to a medical assessment. In December 2016, it was expanded to children below the age of 15. In addition, a means-tested Carer's Allowance of MUR 1,907 (US\$ 54) per month is available to parents of children with disabilities from 6 months old to 15 years. Parents' income must be below MUR 250,000 (US\$ 7039) (or MUR 350,000 (US\$9854) for children with severe disabilities) to qualify.

However, given that the Basic Invalid's Pension is the same value as other universal pensions, and the Carer's Allowance is means-tested, these schemes do not adequately compensate for the additional costs of living with a disability for many families

### A life-cycle approach to social protection for persons with disabilities





## 8. In high-income countries, child disability benefits are the norm

Most high-income countries have in place child disability benefit schemes. In general, payments are linked to the disabled child and are paid until they reach a specific age, which usually ranges from 16 to 26 years.

### Denmark

Parents of disabled children are provided with financial support to cover the additional cost of disability. The amount of support provided depends on the actual needs that arise as a result of the disability. Typically covered costs include: special food, medicine, transport, clothes, washing and personal hygiene, and holidays. The support is not means-tested.

In addition, parents can receive financial compensation for loss of earnings as a result of having to care for a disabled child. This benefit is means-tested.

At least **28 out of 34**



**OECD countries provide a child disability benefit, in addition to caregiver allowances and mainstream child benefits**

## The changes that a child disability benefit can bring

Rebecca – who has Downs Syndrome – lived her first years in Paraguay and received no state support. This put a significant strain on her family, as they had to pay for all her support and medical costs, which was made more difficult by the fact that her mother could not work due to her caregiving responsibilities.

This all changed when her family moved to the United Kingdom. Rebecca received a Disability Living Allowance which helped cover the extra costs such as special car seats, shoes and toys. Furthermore, her mother received a Carer's Allowance, which enabled her to spend time with her daughter, taking her to various services such as physiotherapy, speech and occupational therapy. Altogether, these services and assistive devices enabled Rebecca to grow up to become a semi-independent and intellectually stimulated young adult.

As a 25-year-old, Rebecca now lives in supported living with a group of friends. She cooks and does her own washing, with help from caregivers, and is involved in drama and swimming clubs. Although she doesn't work, she volunteers at a fabric shop. All this is possible because of the services and financial help that her family received. Had she remained in Paraguay, she almost certainly would not have the fulfilling life that she now has.



## 9. Leaving no-one behind: An investment worth making

The level of investment required for a child disability benefit scheme is minimal: the costs of South Africa's and Uzbekistan's are only 0.07 per cent and 0.15 per cent of GDP, respectively. In a country like Kenya, a US\$20 monthly child disability benefit for all children – equivalent to the value of Kenya's universal old age pension – would require an investment of only 0.08 per cent of GDP. The investment required would be similar in most other countries.

The financial benefits for the country would be immense. Not only would a child disability benefit help to lift up the country's most vulnerable children, but losses in productivity due to not effectively addressing disability can range from 1 to 7 per cent of GDP. Persons with disabilities, along with their caregivers, possess a wide range of skills and talents that should be harnessed and maximised.

Child disability benefits have an essential role in enabling children with disabilities to enjoy the best start in life. If the international community is truly committed to 'leaving no-one behind', then it must prioritise these schemes in social protection systems around the world.

**In Bangladesh, the exclusion of people with disabilities from the labour market results in a total loss of: **US\$891 million/year****

**Loss of income among adult caregivers increases losses by:  
US\$234 million/year**

Banks and Polack 2014



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