

Chapter 4

Politics of Care and Isolation: Case Studies

4.1 Caring for children with disabilities in an advanced welfare state: Denmark

Denmark, an advanced welfare state, has a system of compensation for the disabled that is mainly administered by the commune or local government body. The Danish welfare model is anticipatory in recognising the unpaid carer's time poverty and having in place a system of assistance. However, the 2009 financial crisis and its aftermath have had a serious impact on time poverty.

Majbritt Nunnegaard Thomasen is a single mother and the primary carer of her 14-year-old son, who has cerebral palsy and multiple disabilities, and his twin sister who is doing well at school and in sports. Majbritt works as an accountant part-time. The children's father lives in the United Kingdom, pays child support and sees the children once a month.

This case study illustrates the differences in perceived needs and interpretation of social protection. These differences are evident when the state and the individual interact in the process of assessment of needs and the consequent dispensation of resources/benefits. The following interview with Majbritt Thomasen also illustrates how the right of an individual or carer to social protection is influenced by that person's ability to question and challenge policy, especially when cutbacks in social spending have had an impact on care budgets.

How did the commune compensate you for your time and provide information on benefits?

I work 18 hours a week and get compensated for the other 19 hours as the commune tops up my salary. When I was first granted salary from the commune because of my son's handicap, it was based at the level of my then salary when he was one-and-a-half years old. Since then that salary has been adjusted for inflation during the years, but not according to what I actually earn today. So I actually get less salary from the commune for the 19 hours than from the 18 hours I work as an accountant.

Since he was two-and-a-half years old, my son has been going to a relief home. A relief home frees up my time. He used to be with a family in private care for seven years; one weekend a month and one day per week. He is now at the school relief home; one day in the first week, two days for the second week, and for three days in the third week.

The commune provides salaries for the helpers who provide assistance with his special exercises. They pay for diapers and for the bibs used for his drooling; wear and tear of clothes is covered by a fixed amount every month as he uses up more clothes because of soiling them. Given that my son is wheelchair bound, a car is provided with insurance and the repairs are covered. I do not have to pay road tax and I am exempt from other special taxes on the car. Half the loan for the car is paid over six years without interest and the car can be changed once in six years. The house has also been fitted out for him. The commune pays the difference between my previous rent and the new mortgage since we could not stay in the rented house due to my son's handicap.

How have cutbacks in benefits affected you and how have you coped?

In 2011, the commune took away some of my work compensation and provided only for 14 hours instead of the 19 hours for my personal time and time for caring for my daughter. The commune also only provided payment for five hours a week as relief for my son's general care at home as opposed to the 17 hours they had covered earlier.

They used to pay for a cleaner but now they have removed that benefit because they maintain that the cleaning is not related to my son's handicap; that is, he does not have problems breathing and does not require special equipment such as oxygen. When they provided the benefit, it was seen as a compensation for my time.

They also took away costs such as for his bibs, car expenses (services and part of insurance) – they decided that their calculation was to be based on log use of the car for my son only, both direct and indirect. This cut into the needs of my daughter and myself.

I first opposed the commune in July 2011; I filed a complaint, which was to be reviewed in three weeks. They took longer and when they came back, it was still in dispute. We were required to go before the social court where hearings take up to a year because of backlogs. I complained in July 2011 and the decision finally arrived in February 2012 after intense pressure through local media and appeals. I won on all counts except for coverage of car tyre changes from summer to winter, to be paid retrospectively.

The judgment held that the assessment was done without considering the context and individual circumstances of the single mother, the family as a whole and my son's particular needs. This was the point on which the case was won. The court held that the 'legal certainty' for a citizen was in breach, as an individual assessment was not conducted.

The court asked the commune to make a new decision in four weeks. As the local newspaper coverage in the run up to court proceedings had kept the issue in the limelight, the commune reverted to previous arrangements and did not make any new assessment or raise new questions. Communes try to save budget through cutbacks and when the issue is under dispute awaiting hearing, they save money.

I have been made to feel that I am asking too much from the commune, but the law says that you will be compensated so you can lead a 'normal' life or near normal life. The commune said that as my daughter is old enough to look after herself, compensation for time caring for her is not required. But they are the same age and have very different needs. My daughter loves sports, she plays table tennis and football, and would have had to give it up and I would have had to work more hours.

The experience has taken a toll; I was on medication for stress but now have completely stopped. During the time of the dispute, when I was strapped for time and money because I had to pay the helpers and expenses from my savings, the stress was acute and the children were deeply affected. My son's school has said that now his well-being is better and my daughter is also happier.

What is most helpful? Which of the forms of help eats into your time?

Compensating for time is most helpful, especially having helpers for my son's special exercise sessions. Placing him at school over weekends and certain weekdays gives me time for my daughter and she is able to benefit from quality time.

However, I have to spend a lot of time on administrative requirements; salary slips have to be worked out for the helpers and I have to arrange time slots for the special exercises as I have to synchronise these timings with grocery runs, school meetings for my daughter and taking her for sports training and camps.

In terms of family vacations, although the commune pays for a helper's air ticket and food expenses and salary, the commune does not cover the helper's work over a weekend. I have to then juggle between looking after my son and spending time with my daughter. I also had to fight the commune to get expenses covered for the helper.

I do not have a normal life; more time and effort is required to do every day things like go shopping, so having more helpers to exercise or mind my son would free up my time. I've had to be creative about exercise arrangements to split the helpers' time-slots, so I can keep appointments at the hospital or attend meetings at my daughter's school. My employer's understanding has been critical; I have been lucky.

My life is all about care; I have lost my network of friends and hardly see my family. Much of my chosen social contact has been virtual.

4.2 Caring for the aged in a developed economy: South Korea

The Government of South Korea introduced the Long-Term Care Insurance (LTCI) scheme in August 2008 to deliver appropriate health care services to the rapidly aging population. South Korea was facing major increases in health care expenditure for the elderly. The purpose of LTCI is to preserve and improve the quality of life for senior citizens and their caregivers, and to promote better health and stable livelihoods while reducing the burden of care on family members.

The rapid aging of the South Korean population is a result of increased life expectancy and the sharp decline in fertility. According to the Report on the Population and Housing Census, in 2005 the fertility rate was below 1.1 and the proportion of elderly people is forecast to increase at an unprecedented rate (Statistics Korea 2007). Changes in the traditional family structure, increases in the labour participation of women, a limited ability to pay for the elderly and the financial burden of elderly care in health insurance systems all contributed to the introduction of LTCI in South Korea.

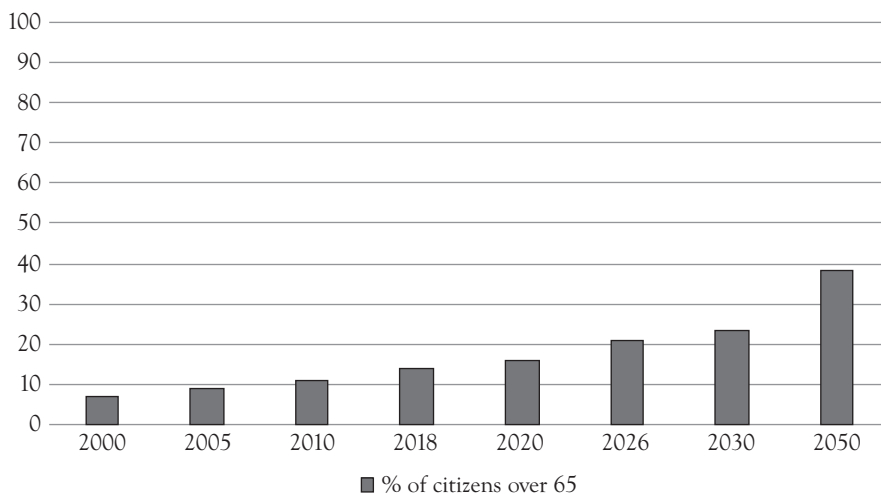
Figure 4.1 shows an estimate of the percentage of citizens over 65 to the year 2050, according to official predictions based on the population dynamics of fertility and mortality in 2010.

In response to this growing demand, the state moved to provide sufficient care facilities and support efforts to train more staff. This would ease the burden on families (including the elderly relatives) working in unpaid care work, so they were better able to participate in economic activity.

The choice was between the provision of services and the payment of a benefit to those in need to purchase the services. A countrywide response from women was that elderly men would spend the money on gambling, smoking, drinking and their social life, and women would still be expected to do the unpaid caring. The loud message women sent to the government was, 'We won't do it!'. The result was the introduction of the LTCI scheme.

Eligibility is dependent on certification. Local agents of National Health Care Insurance visit applicants (or their carers) and assess them according to two criteria defined by the LTCI law:

Figure 4.1 Estimate of the percentage of citizens over 65, 2000–2050



Source: Compiled by authors with information drawn from South Korean government sources

- Physical condition, which covers physical and mental functions and the nursing and rehabilitation care required.
- The degree of independence for the essential tasks of everyday living, which takes into account living conditions and environment.

The results of the assessment are used to calculate a standardised score to estimate the level of care needed. The maximum score is 100 and individuals must score 55 or over to be eligible for insured care. An assessment committee of 15 (including a chairman) consisting of doctors, nurses and experts in health and social care review the scores (taking into account the statement of the primary care physician and specific comments from the first assessment) then decide on the eligibility of the applicant. Based on individual needs, care is then (mainly) delivered in kind according to the client's wishes. The client has the freedom to choose a service provider.

Long-term care benefits consist of community-based home care, institutional care and cash benefits.

Home care, designed to help with activities of daily life, includes:

- bathing, toileting, dressing, cooking, cleaning, shopping;
- bathing services (a vehicle fitted out with a portable bath is used to provide this service at home);
- nurses to give care and treatments prescribed by physicians, oriental doctors or dentists;
- day and night care, including functional therapy and medical treatments;
- short-term respite care in a long-term care facility on occasions where the family member who looks after the elderly person is not available; and
- medical and orthopaedic equipment such as wheelchairs and orthopaedic mattresses.

Institutional care includes:

- care in long-term care facilities, licensed nursing homes, retirement homes and licensed residential establishments.

Cash benefits are used to:

- help with elderly people and their families who live in a remote region or island;
- assist those who need care but whose physical, mental or psychological condition makes them unsuitable for admission into long-term care facilities; and
- assist with costs where a non-registered service provider offers long-term care.

Before the introduction of LTCI health care spending, welfare expenditure and pension spending were rising rapidly. Since LTCI has been meeting the needs of the

elderly there has been a rise in LTCI spending. However, 'healthy aging' of the aging population has resulted in a decrease in health care spending and a decrease in hospitalisation for the elderly from 15.7 days to 11 days.

The increase in healthy elderly care means more elderly are remaining in the working population for longer and 95.8 per cent of families of the elderly have reported that LTCI insurance has helped them participate in economic activity, all of which benefits tax revenue.

In comparison with other sectors where employment levels decreased or remained stable because of the economic recession, in health and social work, under which LTCI industry falls, the workforce has increased by more than 190,000. In the field of technological innovation and manufacturing in elder care support, the workforce has increased by more than 40,000.

LTCI is an example of a social protection 'sweet spot', a partnership between the state, the private sector and the individual (Figure 1.4).

4.3 Community action in support of marginalised sex workers: India

In India, women sex workers are mainly portrayed and treated in public discourse and policy as vessels of moral hazard, vectors of disease and objects of pity. They rely on their communities to provide social protection, in a situation where economic and socio-cultural realities determine access to health information and services.

Sex workers have become the focus of research and health programmes since the beginning of the HIV pandemic. Despite this, the stigma associated with sex work and other barriers such as gender identity, including identity as the third gender, often prevent sex workers from organising themselves. However, the experience of women sex workers who formed a collective in 1996 and called it VAMP (Veshya AIDS Muqabla Parishad or Women in Prostitution Confront AIDS) demonstrates that efforts to mobilise and support members of the sex worker community can be successful.

VAMP offers a form of social protection that is mediated by the community in the absence of any state-provided social protection.

This form of social protection helps to combat harassment by authorities, offers support during bereavement and assists with childcare, education and health needs. Of significant importance is that it provides a support system during old age. VAMP's social protection model is anticipatory and transformative as members are able to provide support and care as needs arise through a community-based support system and the peer education in place helps towards women's empowerment.

Before the VAMP collective was formed, women sex workers could not do much about routine police harassment. Now, they are treated with more respect when they

approach police officers for help. In some cases, VAMP has successfully negotiated an end to police hostility and brothel raids. However, this does not mean that all VAMP members are able to confront and challenge police harassment. What has happened is that more women have become aware of their rights and recognise that they have the capacity to negotiate with others, including those in authority, to diffuse threatening situations. They are no longer in a position where they are willing to accept the dictates of others about how to act. They have the confidence to know what they want to do about problems and to decide on processes for conflict resolution.

In addition to peer educator programme and advocacy initiatives that are the basis of its identity formation, leadership development and mobilisation efforts, VAMP has expanded its work focus with an initiative directed towards helping the children of its members to cope with the stigma of their mothers' sex work. Having a mother who is also a sex worker brings with it more than its share of stigma and marginalisation. VAMP members felt that the children needed a safe space to explore and strengthen their ability to deal with the mainstream attitude towards them. The Supplementary Education for Kids intervention has established classes for the children as an entry point to teach them core life-skills. The children examine their identity and explore ways to reclaim spaces for respect given the type of work and lives that their mothers lead.

VAMP asserts that violence – social, emotional, psychological, legal and economic – is more acute for women and third gender members in sex work. They are often denied health care treatment. Being labelled vectors of HIV, blamed for the violence inflicted upon them and living under the constant threat of violence damages self-esteem and results in poor health-seeking behaviours and exposure to health risks. VAMP works by helping sex workers tackle violence in order to reduce vulnerability to HIV. VAMP's peer activists have become the de facto families and caregivers of women who fall ill. They assist women to go to the hospital, organise food for them, look after children and even ill lovers in their absence, and support them through painful moments.

The care of sex workers living with HIV is part of the peer activist portfolio. VAMP has a system where two women from the community are assigned day and night duties, rotating as care workers for women admitted into the civil hospital. They carry food for the patient, wash clothes and boil and cool drinking water. The community also cares for the children of sex workers living with HIV when they are hospitalised. This includes sending the children to school and caring for them both physically and emotionally.

Making funeral arrangements for those sex workers who have died from HIV-related symptoms involves liaising with relatives who sometimes perform the last rites. Where women are left with no one to do their last rites, VAMP arranges for a community funeral through individual contributions from women in sex work.

4.4 Community action for dignity and rights: India

Clothing is one of the basic needs to which every human being is entitled. In a conservative country such as India lack of appropriate clothing leads to shame, humiliation and discrimination, especially for poor women. The ability to lead a life of dignity is one of the basic freedoms that every individual should enjoy, failing which their capability to take part in the life of the community is jeopardised.

Goonj is a non-government organisation established in 1999 in India to bridge the clothing divide between rich neighbourhoods and adjoining poor slums, and between thriving urban centres and rural areas where the majority of the poor people live. Goonj organises the collection of old items of clothing as well as cotton cloth, like bedspreads and towels. With the help of paid staff and volunteers, these items are sorted, labelled and sent to remote villages most in need of extra supplies of clothing, as per the expressed needs of the recipients. This is different from the usual approach to charitable distribution, which does not take into account the needs of the people being served, considering them to be passive receivers rather than individuals and communities with a right to request clothing according to their needs.

Goonj performs a particularly important service for the millions of poor women in India who do not have access to sanitary napkins. This crucial need must be viewed in the context of existing cultural taboos whereby women are required to stay indoors and are not allowed to touch food items or enter temples during menses. There are health implications for women who cannot access sanitary towels; they generally use rags and even ash as absorbents, leading to severe vaginal tract infections. Adolescent girls are not allowed to go to school during their menstrual period, which has educational as well as psychological impacts. Before Goonj, however, there were no social protection measures in place to fill this basic need and address the multiple violations of human rights.

Goonj converts donated old cotton cloth into sanitary napkins using a strict quality controlled but replicable process. It runs campaigns among urban residents who are likely to have spare items of cloth or clothing, sensitises them on the issues facing poor women, produces and distributes the sanitary napkins in villages and urban slums accompanied by information campaigns on health and hygiene aspects of menstruation, and encourages partnerships between NGOs and community groups to undertake similar activities in their own area of operation. This activity builds trust between the community and poor women, which ultimately helps them to lead a dignified life. In our anticipatory framework, Goonj would occupy the space where social protection is mediated through a collective action – communities providing social protection through promotion of women's reproductive health rights, as well as ensuring that inadequate clothing and hygiene products do not lead to indignity and social ostracism.

4.5 HIV care and access to land, the GROOTS Model: Kenya¹⁰

GROOTS Kenya is a national network of 2,500 grassroots women's self-help groups, which began organising a home-based care alliance for HIV-affected families in 2003. Working from the bottom up, GROOTS Kenya creates greater co-ordination and peer learning to enable carers to advocate for recognition of their work, greater integration into formal health responses to HIV and strengthened livelihoods. Self-help, savings and credit, revolving loan and income generating initiatives have been established to help caregivers make a living. Caregivers have also spearheaded the creation of community land watchdog groups – partnerships between community members and government officials – to prevent and redress land grabbing from widows and orphans.

GROOTS Kenya views access to land as a critical form of social protection, in addition to routine policy mechanisms such as school grants to reintegrate orphaned children back to school, food rations and cash to buy basic commodities for survival, and provision of shelters. Land and inheritance matter for widows and orphans as land is not only a productive asset, but also a source of identity that promotes their dignity. GROOTS found that the HIV pandemic often results in disinheritance and asset stripping among widows and orphans as the extended family seeks control of land and property by invoking customary practices. These practices emphasise inheritance through males and tend to exclude women and children from decision-making and land ownership.

In Kenya, only 5 per cent of registered land is in the hands of women, yet women contribute up to 80 per cent of agricultural labour. The majority of poor women are only able to access or control significantly small portions of land, in both rural and urban areas, which tend to be less fertile and are often seen as insecure. Through an elaborate community organising model, access and control over land has proved to be an important 'buffer' in protecting the livelihoods and dignity of many widows and the inheritance rights of orphans.

The following testimonies from GROOTS attest to the transformational nature of community organised social protection:

'When R's husband was bedridden, his relatives shunned her house. She was weak too with only an unpaid home-based carer to provide assistance. When R's husband died, the family appointed his brother to 'administer' her husband's three acre sugarcane farm while R was given access and control to a half acre piece to cultivate vegetables and subsistence food crops. The community land watchdog group assisted R to process the death certificate and gain legal administration of her late husband's properties, including the entire three acres and a rental house that the husband co-owned with his sister, of which R was not previously aware. She now has enough money to feed her family and educate her five children through university.

P's mother, a former clinical officer, and his father, a civil servant, died of AIDS-related symptoms in 2000 and 2002, respectively. The family took control of all the properties and P and his siblings were assigned to different relatives. At the age of 15, P and his younger sister moved to the slums after being thrown out by the uncle's family. A home-based carer collected food rations from the community clinic, negotiated a school bursary and helped to reintegrate them into a slum school. P later got married and had two children. He now relies on casual labour and the home-based carer for guidance and basic survival. Members of the community land watchdog group traced down P's uncles and, through negotiations, he and his siblings have regained two commercial vehicles and eight acres of cash crops. They have appointed a manager for the properties and no longer require support with basic livelihood needs, shelter and education.'

The community land watchdog groups engage with all stakeholders and advocate for responsible actions to protect the most vulnerable. Members of the community land watchdog groups were actively involved in the writing of the 2010 constitution and the national land policy. They have sought to transform governance in land boards and provincial administrations through lobbying for membership. In 2007, there was only one woman among 24 provincial administrators; by 2011, there were nine women provincial administrators, five of whom are former members of the community land watchdog group with in-depth knowledge of legal issues and community problems. Some of the women provincial administrators are also champions for transformative leadership.

At the community level, the land watchdog groups have created surveillance groups that identify, report and address potential dispossession cases.

GROOTS's efforts on information sharing and support for care giving have enabled carers to increase their effectiveness, link the government to NGOs, eliminate duplication and fund the people most in need in their communities. One important evaluation finding has been that because of GROOTS's organising and community mobilisation efforts, when new programmes and resources come into communities, they can be of immediate benefit to the community because they can build on and invest in what has already been prioritised.

4.6 A revived land tradition protects HIV-affected children: Swaziland

Swaziland reported the first case of HIV in 1986. The pandemic spread rapidly leaving in its wake social inequities, poverty and unemployment, increased morbidity and mortality rates and a rise in the number of OVC. Realising the impact of the pandemic on government resources, the Swaziland National Emergency Response Council on HIV (NERCHA) Secretariat had to think outside the box, be innovative and draw on traditions and culture that could be revived to protect the rights of children.

Community Leaders (Chiefs) were invited to get involved in the care of orphans and needy children, in keeping with the tradition that destitute people could find protection at the Chief's kraal. It was also traditional for the Chiefs to secure the land of deceased members of a community until the children of the deceased were old enough to use it. Some of the positive traditional structures had been eroded over time because of social dynamics.

The *Indlunkhulu* or 'traditional chiefs' fields for OVC initiative, began in 2004 as a programme of NERCHA and is an example of community-based social protection. The initiative sought to revive a tradition where chiefs set aside fields in order to provide for destitute members of their communities or those unable to cultivate fields for themselves because of illness, accident or old age. The tradition was found to offer a long-term solution to food security for OVC. By 2007, 360 of the 369 Swazi Chiefdoms were participating in the *Indlunkhulu* programme.

Following the willingness of the chiefs to take action in their communities, chiefdom committees responsible for HIV and OVC, were set up. They were mandated to:

- Establish food security programmes for OVC in their communities - through cultivation of *Indlunkhulu* fields (community fields), which are fields under the authority of the chief. The fields provide food to any member of the community in need. This is one of the oldest traditions that earned respect for the chiefs because of the paternal roles they played among the people they led.
- Appoint responsible women in each community to serve as caretakers - *Lihlombe lokukhalela* (shoulder to cry on) - of child-headed households and keep the chiefdom committees updated on the state of these households. This system of support is also a traditional practice, wherein neighbours cared for each other; if there were a sick person in the community, it would be every neighbour's duty to visit the family and assist where necessary without payment.

Between 2003 and 2004, the Chiefs made land available for the construction of Kagogo Centres in almost all chiefdom kraals in the country. A total of 325 were built, 37 of which are in peri-urban areas and managed by city councils. The centres are used to serve meals, as play schools for young children and as offices where records of OVC are kept (each centre has a clerk). In addition to the Kagogo Centres, communities, municipalities, and private sector and religious groups assisted in the construction of neighbourhood care points (NCP) in most communities, where children staying too far from the Chief's kraal are able to have at least one meal a day. Mapping of these NCPs has been done and the number now stands at 1,550, evenly distributed throughout the country, which accommodate 40 to 100 children.

The committees also compile lists of beneficiaries in each community and are responsible for the allocation of inputs like tractor services or seeds between beneficiaries. The criteria for beneficiaries are fairly broad in scope to allow for local interpretation, and causes of OVC vulnerability such as disability may be overlooked.

Complementing the *Indlunkhulu* initiative is a programme funded by the Japanese International Co-operation Agency which allocates 0.5 hectare plots in 320 chiefdoms to be farmed individually by child-headed households. The programme recognises the erosion of social cohesion caused by the loss of customary land entitlement of children who have become orphans and the farms have been set up to redress this.

The women carers, or *Lihlombe lokukhalela*, have been hailed as the backbone of the programme, but the additional responsibility of supporting the young and the aged with feeding and home-based care, leaves them time poor. Moreover they are resource poor, as they often have to overstretch their family budgets to look after OVC. In many cases, the *Lihlombe lokukhalela* lack adequate information on sexual and reproductive health issues to counsel adolescents. OVC and girls in particular, are very vulnerable to older predatory males, with rape and harassment a common problem.

The Centre for Social Protection, UK, asserts that HIV has shifted the realities of care for children in Africa, boosting social protection, and other shifts are taking place including:

- the strain on traditional support structures and the ageing and deaths of grandparents, which place new challenges on protection and care for children;
- rapid urbanisation, which is changing the location as well as options for care and the ‘face’ of marginalisation and risk for children; and
- changes in information and communication technology may lead to fundamental changes in children’s risks and opportunities as well as for new modes of programme design and delivery.

Anticipatory social protection systems need to engage with these changing realities in determining options for transformative policies and strategies.

4.7 Building peace through anticipatory and transformative social protection: Rwanda

The genocide took place when I was too young. Until today, I didn’t know its extent. I had a lot of questions. This gave me some answers. It’s not easy to say, ‘This happened in our country,’ but it’s important we learn from it. – Jean-Claude Rikorimana, 21, student, after participating in the ‘Learning from the Past, Building for the Future’ course.

In 1994, over the course of 100 days an estimated one million men, women and children (20% of the population) were killed in the Rwandan genocide.

The genocide was the result of longstanding tension and ethnic rivalry between the minority Tutsi, who had controlled Rwanda for centuries, and Hutu who came into power during the rebellions of 1959–1962.

In 1990, a rebel group consisting mostly of Tutsi refugees attempted to defeat the Hutu-led government of Juvenal Habyarimana. Civil war broke out and ethnic tensions heightened. Many Hutu (meaning 'servant' or 'subject') believed that the Tutsi (meaning 'rich in cattle') intended to enslave them.

International pressure on the government resulted in a ceasefire in 1993. However, the assassination of Habyarimana in April 1994 set off a violent reaction. Hutu groups conducted mass killings of Tutsi and pro-peace Hutu, who were labelled as traitors and collaborators. The murderers used machetes, clubs, guns and any blunt tool they could find to inflict as much pain on their victims as possible. Women were beaten, raped, humiliated, abused and murdered, often in the sight of their own families. Children were forced to watch as their parents were tortured, beaten and killed, before their own lives were brutally taken. The elderly, the pride of Rwandan society, were despised and killed without mercy. Neighbours turned on neighbours, friends on friends, and even family on their own family members. Eighty-five per cent of the Tutsi population in Rwanda were murdered.

The Rwandan Peace Building programme, 'Learning from the Past, Building the Future' is designed for those born after the genocide or who were young at the time. It is an example of transformative, rights-based and anticipatory social protection in action.

The programme was launched in 2004 at the unveiling of the Kigali Peace Memorial. Both the peace-building programme and the memorial have resulted from a partnership between the Aegis Trust and Rwanda's Ministry of Education. Aegis (meaning 'shield' or 'protection') is a registered public charity in the UK and US and a registered NGO in Rwanda, which campaigns against crimes against humanity and genocide.

The peace building programme acknowledges that youth all have different stories in their past and they are not responsible for that past, but they do have a common future and they are responsible for their decisions in that future. Educators teach that hatred and violence can lead to mass violence, and why peace and reconciliation is vital for the future, both personally and nationally. Survivors of the genocide are trained as guides at the centre and work hand in hand with the educators.

The programme also acknowledges and explores current conflicts in the lives of young people because of ethnicity. For example, in school children supported by the Genocide Survivors Support and Assistance Fund have had their notebooks thrown in the toilets; genocide orphans are considered inferior because they cannot afford school fees or decent clothes; the children of parents who are in prison are called *Interahamwe* (name of the Hutu militants that participated in the genocide).

It is evident that children not born during the genocide are subject to bullying from other children who adopt their parents' ethnic prejudice.

At the 'Learning from the Past' centre, students spend the mornings revising their country's history and learning to develop empathy, leadership skills and critical thinking using role-play, storytelling, problem solving and discussions. In the afternoons students visit the memorial exhibits, walking through rooms filled with victims' clothes, photographs, skulls and bones stacked behind glass. Pictures of smiling children are accompanied with notes that depicting their name, age, favourite things and how they died (Box 4.1).

Sixty per cent of the Rwandan population is under the age of 24 and so far 11,000 students have attended the course. Minerva Research and Media Services report a dramatic popular impact after a detailed analysis of the programme. After attending the course there was a greater empathy for other ethnic students and people in need, materials for the poor survivors and anti-genocide groups were established.

Today Rwandans are urged to leave their ethnic diversity behind. They are encouraged to think of themselves simply as 'Rwandan' and ID cards no longer list tribes.

Box 4.1 Facing the reality of the genocide

Students attending the 'Learning from the Past' memorial exhibition are confronted with pictures of smiling children with personal details of their lives and how they died.



Francine Murengezi Ingabire

Age: 12

Favourite sport: Swimming

Favourite food: Eggs and chips

Favourite drink: Milk and Fanta tropical

Best friend: Her elder sister Claudette

Cause of death: Hacked by machete

Source: www.kigalimemorialcentre.org/old/centre/childrens.html

4.8 An endowment fund protects education of HIV-affected children: Papua New Guinea

There are more women than men living with HIV in Papua New Guinea. Almost all people living with HIV, most of whom are parents, struggle to survive socially as well as economically. This is particularly true for HIV-infected women. Indifference is

endemic. It is a daily struggle to provide their children with the necessary care and protection to which they have a right.

Children with HIV-infected parents feel the impacts long before the parents die or disappear. These children are more likely to fall behind in grade level and on payment of their school fees. Under the strain of living with HIV, affected families become distressed, unstable and dysfunctional. Children whose parents have died may be in the care of other family members or in informal fostering arrangements. Sometimes these are caring arrangements; too often they are exploitative of children's labour and their bodies. Others are abandoned, living under houses, on the streets, on the edges of villages.

The Serendipity Education Endowment Fund (SEEF) seeks to mitigate the negative impacts of the HIV epidemic on children's education and well-being in the absence of attention to HIV-affected children in the national and local responses. The strategy is to help those from the poorest families to complete their education and to ensure that girl children are also educated so that they and their families might, over time, be able to move out of the cycles of poverty and social marginalisation (Checchi and Salvi 2010; Sabates-Wheeler and Roelen 2011).

4.8.1 Background and structure

SEEF was started with a gift to the Asia and Pacific Business Coalition on AIDS (APBCA) from the Italian tenor, Andrea Bocelli, after his 2008 tour of Australia. He asked that it be used to fund an HIV project in Papua New Guinea. APBCA joined forces with the Papua New Guinea Business Coalition Against HIV and Aids (BAHA PNG) and in 2009, after consultation, they set up SEEF.

SEEF is an autonomous fund governed by a small Board of Trustees, one of whom is responsible for the management of the programme. It works in partnership with organisations providing care, support and treatment to people living with HIV to enable these organisations to provide educational support alongside HIV treatment, counselling and care.

It was decided that SEEF would reach out to HIV-affected children through their parents and carers. Traditionally, programmes designed to meet the needs of children affected by HIV targeted individual children rather than working with children in their family settings (International HIV/AIDS Alliance with Save the Children UK 2012). However, there is evidence that children cared for in families develop better cognitively, physically, educationally and socially (International HIV/AIDS Alliance with Save the Children UK 2012; JLICA 2008a, 2008b).

It was anticipated that SEEF could also assist in strengthening the HIV care work of its organisational partners by helping them work with families affected by HIV. Traditionally HIV counselling, support and treatment organisations work with

HIV-infected individuals (International HIV/AIDS Alliance with Save the Children UK 2012). By giving partners the capacity to assist with children's educational needs, SEEF could help these organisations see their patients and clients as socially inter-connected, as parents and carers of children, as well as individuals living with HIV.

SEEF puts the rights of the children at the centre of the programme. It honours their right to education and an equal chance to grow up to be responsible and useful, but also to develop physically and spiritually in a healthy and normal way, free and with dignity (UNGA 1990). It pays particular attention to ensure that girl children can access these rights alongside their brothers.

By 2010, SEEF was working with five partner organisations across the country – three in the Highlands, one in Western Province and one in Port Moresby – to support 106 children – 57 boys and 49 girls – in 43 families. By 2011, it had eight partners, adding one in the Highlands, another in Port Moresby and one in Lae, and was working with 185 children in 84 families – 109 boys and 76 girls.¹¹ By working through HIV care and support programmes, SEEF has been able to reach marginalised children – those of abandoned women, of widows, of sex workers, of *sista girls* and men who have sex with men, of landless settlers, the homeless and more.

The selection of partners is critical to the success of the programme. Partners must have the trust and respect of the people living with HIV that they work with and must 'work from the heart'. Clear roles and responsibilities are delineated between SEEF and the partners and between the partners and the SEEF families.

Partners select SEEF families according to principles laid out in the SEEF guidelines. Participants have to be HIV-infected or caring for children whose parents have died of HIV, experiencing financial hardship, prepared to contribute towards their children's education and willing to educate their girl children. People living with HIV who work as HIV volunteers are particularly welcomed. In SEEF, the term 'family' is used to describe HIV-affected children and the person or persons who care for them. Where a child does not have parents or carers, the partner organisation has taken on the carer role.

Once a family enters the programme, all children in the family are eligible for SEEF support and the support lasts for as long as they want to and can continue their education, including after the death of their parents. SEEF supports primary, secondary, technical and tertiary education. Because so many of the children have lived and are living with trauma and pain, consistent attendance at school, rather than academic performance, is the determinant of continuing support.

SEEF supports education-related costs. Fees are paid direct to educational institutions; partners or retailers supply uniforms, books, stationary and such like where needed. SEEF supplements contributions made by the families, in cash, kind or labour, towards the costs of the children's education. SEEF also supports partners to hold

meetings or celebrations to bring together its SEEF families to create and strengthen networks of friendship and support amongst the children and amongst their parents and carers.

4.8.2 Bringing hope to HIV-affected children, families

The outcomes of the programme have been impressive. Partners report that SEEF has helped them move from providing services to individuals to providing care and support to families, and to integrate health, education and social support for children and their families.

SEEF brings hope to HIV-infected parents and to the carers of HIV-affected children. It lightens the burden of parenting, lessens feelings of inadequacy or failure and gives parents a sense that they can provide a future for their children. As they become more engaged in the children's schooling, their desire to stay alive and well so that they can see their children through their education is increased. Their health and well-being improves as does their health-seeking behaviour and treatment adherence.

SEEF helps parents and carers keep their families together, or re-assemble them, and to care for the children within their families. By working with the social structures within which HIV-affected children live, SEEF reduces stresses within families and lessens the likelihood of child abuse, exploitation and neglect.

SEEF helps the children feel valued and socially visible. The children find themselves in networks of concern and support and are being given the chance to continue their education. They feel better when their parents are healthy and are taking an interest in them and their schooling. They attend school diligently, appreciative of being there. Most of them are doing well academically. SEEF's policy of including the carers' children in situations of need, removes the likelihood of resentment and can result in better care and greater social justice.

The true value of SEEF is in giving children a sense of belonging, in their families and socially, and in lifting the bleakness of their previous lives. SEEF is anchoring them in the present and future, preventing them from disappearing into invisible spaces. It offers them hope, a scarce commodity in many of their lives, so that they can dream of a future.

4.8.3 Limitations

As a social protection and development measure, SEEF has some limitations:

- It is not government led, neither nationally nor locally. Instead it links with civil society and the private sector and, through these partners, has weak ties with government agencies and other service providers.

- It does not address questions relating to the quality of the education received or the competencies and motivation of the teachers.
- It reaches only families attending the centres and programmes of its partners, although it is also bringing people into these programmes.
- It is small scale.

In 2012, the Government of Papua New Guinea introduced a free education policy and despite innumerable obstacles implementation is proceeding. Although tuition in government-funded primary and secondary schools is now free, parents still have to contribute to school development funds, purchase school uniforms and materials and meet other education-related costs. SEEF families live in poverty and distress and, even with the free education policy, struggle or fail to meet these costs. This is documented elsewhere in similar circumstances (Kidman et al. 2012). The free education policy does not include technical or tertiary education fees, which are high.

4.8.4 The HIV-protective effect

The value of SEEF also lies in its HIV-protective effect, that is, in the lessening of the likelihood that the children it works with will become HIV-infected. Experience across the world has shown that the simple fact of going to school offers a strong measure of protection against HIV and that each additional year of schooling brings additional protective benefits, in particular for girls (Jukes et al. 2008; Kelly 2006; Global Campaign for Education 2004; World Bank 2002). In addition, where the education system includes HIV-related content, this protective effect is greater (IATT 2008; Kirby et al. 2006; Kirby et al. 2005). SEEF's partners actively seek to help the children remain uninfected.

4.8.5 Anticipatory, transformative and energising

SEEF is an anticipatory social protection initiative. It starts when parents come into HIV care, before children become HIV orphans. It anticipates and helps reduce the impact of HIV illness and dying on children. It helps extend the life of the parents so that they can care for their children. It anticipates and aims to pre-empt the withdrawal of children from education.

SEEF is also a transformative social protection initiative. It is gender sensitive and child sensitive (Sabates-Wheeler and Roelen 2011; DFID et al. 2009). It addresses the underlying social structures that give rise to social vulnerabilities (Commonwealth Secretariat 2012). It harnesses the transformative potential of education and the transformative power of hope (*The Economist* 2012b).

SEEF energises those involved. It creates a sense of agency. It is conceptualised and delivered in respectful and empowering ways. It strengthens social solidarity and

embodies the principles of gender equity and social justice (Reid et al. 2012). It is transformative, of its families, its partners and its Trustees.

4.9 Social protection models: New Zealand and India

4.9.1 Crown Corporation accident compensation, New Zealand

The Accident Compensation Corporation (ACC) is a New Zealand crown entity that is responsible for administering the Accident Compensation Act 2001. ACC is the sole and compulsory provider of accident insurance for all work and non-work related injuries in the country.

The Act provides financial compensation and support to New Zealand citizens, residents and temporary visitors who have suffered personal injuries in New Zealand. New Zealanders returning from overseas with an injury are also included, as long as they are permanent residents and have been away for six months or less.

The scheme is administered on a no-fault basis, so all who meet these criteria are eligible for coverage regardless of the manner in which they were injured. Coverage includes the cost of medical treatment (short-term and long-term), home and vehicle modifications for the seriously injured, and compensation for loss of earnings (paid at 80% of the person's pre-injury earnings).

ACC is funded by a combination of levies on people's earnings, business payrolls, petrol taxes, fees from motor vehicle licensing and government funding.

When calculating how much money to collect through levies, ACC balances the likely cost of claims against the need. This keeps the levies fair and stable. This money is then distributed into one of five accounts. Each account covers a specific group of injuries and is funded differently.

The five ACC accounts are as follows:

Work Account

Covers claims for all work related injuries. The work account is based on payroll or liable earnings. The level of risk and the cost of injuries associated with individual industries are also taken into account.

Earners Account

Covers claims for people in paid employment who are injured outside of work (for example, in sporting activities or in the home) but does not include motor vehicle injuries. Everyone in the paid workforce pays levies into this account. For employees, this is deducted from gross pay. The self-employed are invoiced.

Non-Earners Account

Covers claims for injuries to people outside the workforce, such as students, beneficiaries, retirees and children but does not include motor vehicle injury. The New Zealand Government funds this account using money from general taxation.

Motor Vehicle Account

Covers claims to all injuries involving motor vehicles on public roads in New Zealand. This is funded by a levy included in the price of petrol and motor licensing fees.

Treatment Injury Account

Covers claims for treatment injuries (injuries connected with the medical treatment received). Funds for this account are drawn from the Earner Account or the Non-Earner Account, depending on whether the patient is in paid employment or not. The scheme is certainly anticipatory and is focused on rehabilitation back to paid employment for those injured.

4.9.2 Private sector distributes free milk to New Zealand's primary schools

Up until 1967, the Government of New Zealand supplied milk, free of charge, to every student in New Zealand schools. In 2012, New Zealand's largest company, Fonterra, began a nationwide programme to re-introduce the scheme. Fonterra is a multi-national dairy co-operative owned by 10,600 New Zealand farmers and responsible for 30 per cent of the world's dairy consumption

By February 2013, 58 per cent of all New Zealand primary schools had started receiving free milk or had registered interest in joining Fonterra's free-milk-in-schools scheme.

The scheme involves distribution of one free 180 ml carton of Anchor Lite milk to every school child in years 1–6 (ages 5–11). All schools, regardless of wealth, public or private, are invited to join. Early registrations covered 45 per cent of children in the 10 richest schools and 66 per cent in the 10 poorest. Dairy farming regions of New Zealand have signed up in the greatest numbers and in Auckland, New Zealand's largest city, the least.

It has been observed that since being introduced in schools, teachers and principals alike have reported improvements in children's overall physical health. As their diets have shifted, from more milk to less sugary drinks, there have been fewer trips to the dentist. In addition, attendance has risen, the children are more focused and there has been overall behavioural improvement. Kaitia Primary School principal, Brendon Morrissey commented, 'You notice little things, like the colour of the kids' eyes, the state of their fingernails, the condition of their hair. They are little things but they make the world of difference to the kids' self-esteem. If the kids' self-esteem is in the right place they are far more receptive to learning.'

Patricia Andersen, a school teacher from Ngatoki Primary, a low decile school in the upper north island, noted that sometimes the children drink up to five cartons a day. Welfare rolls in New Zealand have jumped to 12 per cent of the population, with those beneficiaries caring for 22 per cent of New Zealand's children. Households that said they could 'afford to eat properly' only 'sometimes' or 'never', rose from 14 per cent in 1997 to 20 per cent in 2009. Milk in New Zealand supermarkets is priced at NZ\$4.15 for 2 litres (March 2013), compared with NZ\$3.67 for 2.25 litres of Coca-Cola. The community of Ngatoki Primary School acknowledges that the free milk provides essential nutrition to the children.

After a pilot project, Fonterra reduced the size of the carton from 250ml to 180ml, and the big fridges that the company originally supplied to schools were found to be using too much power and are being replaced with smaller ones. Each school also received a recycling bin, which is collected daily. Thus far the scheme has created 20 new jobs at the Fonterra processing plant, with the possibility of more as the scheme rolls out to the whole country by the end of 2014. The approximate cost to Fonterra is NZ\$10–20 million per year.

4.9.3 Programme design for financial inclusion in India

The NREGS being implemented in India is the largest public employment scheme in the world. Over 126 million households have been enrolled into the scheme, which entitles them to 100 days of employment in a year. In the 2012/13 financial year, nearly 49 million households demanded their entitlement and 47 million were provided employment.

Learning from the implementation experiences of previous public employment schemes, NREGS has sought to institutionalise two elements:

- Tackling the issue of transparency and accountability through social audits. A social audit ensures that malpractices (such as inclusion of false names in the beneficiary list, non-existent worksites, unfair determination of work performed and calculation of wages to be paid) are brought before the general public for discussion.
- Encourages financial inclusion by opening bank or post office accounts for the beneficiaries. The final wages are paid directly to the bank account of the beneficiary - male and female separately - through the financial inclusion initiative.

Challenges

There are several challenges to the financial inclusion approach. The major constraints identified are the inadequate coverage of financial institutions, especially banks, and the difficulties for beneficiaries to negotiate the transactions in the banking system due to lack of literacy and numeracy skills. The latter is critical since moving from cash

payments to direct benefit transfer through bank accounts is dependent on empowering the beneficiaries to obtain their entitlements correctly and efficiently. Having them depend on others for accessing their entitlements makes them vulnerable to malpractices. This is especially true for poor women who make up over half of the NREGS beneficiaries.

Helping women to take charge of their lives

Field studies, however, have shown that despite these challenges, nearly 80 per cent of beneficiaries prefer receiving their wages through bank or post office accounts than in the form of cash. The popularity of bank transfers was even higher for women. The main reason cited was that wage payment through individual bank accounts enabled them to have control over their own income for the first time. This income is spent primarily on paying off small debts and children's education, and part of it is saved for future exigencies, especially medical costs. The anticipatory nature of financial inclusion under NREGS lies in the fact that it affords women the choice to use their own earnings in ways that they deem appropriate, especially in their ability to invest in the future. It is therefore a tool for a sustainable empowerment of women and their ability to take charge of their own lives.