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SOCIAL SCIENCE RESEARCH

The Influence of Disability-Related Cash Transfers on Family Practices in South Africa

Gabby Kelly
CSSR Working Paper No. 414
June 2018

Legislating and Implementing Welfare Policy Reforms

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL
UKaid from the British people
Research jointly supported by the ESRC and DFID
CSSR Centre for Social Science Research F·A·S·R·U

Published by the Centre for Social Science Research
University of Cape Town
2018

http://www.cssr.uct.ac.za/

ISBN: 978-1-77011-401-2

Acknowledgements:
This paper is a product of the ‘Legislating and Implementing Welfare Policy Reforms’ research project funded by the Economic and Social Research Council (ESRC) and Department for International Development (DfID) in the United Kingdom

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Abstract

This paper explores the ways in which the design and implementation of social assistance policy for people with disability structures family practices and configurations, care arrangements and household composition in South Africa. The paper draws on ethnographic work conducted in a low-income Cape Town community along with interviews with social and healthcare workers and state administrators. Findings show that disability grant income is shared within households and the contribution of a stable income provides opportunities for disabled people to exercise agency, be seen as valuable household members and secure care and support from other household members. However, conflicts may arise over how income is shared and may lead to the extortion, abuse and neglect of disabled people, particularly in cases of severe disablement. Given the lack of adequate social provisioning for those who are able-bodied and unemployed, disability also becomes highly valued in households and the potential suspension or cancellation of a grant can interfere with adherence to treatment. This study emphasises the influence of policy structures and economic conditions on family relations and contributes to the sparse evidence-base on the role that disability welfare benefits play in household dynamics and care outcomes in South Africa.

Keywords

Care policy, care practices, disability, household dynamics, social grants

Introduction

South Africa’s well-developed system of social cash transfers or ‘social grants’ is its largest poverty alleviation programme, reaching over 17.4 million individuals monthly (SASSA, 2017). These grants are categorically targeted at designated vulnerable populations: children (via their primary caregiver), the elderly (over the age of 60) and persons with disabilities and their caregivers. Although these grants are paid to individuals, research has demonstrated that households tend to pool resources (Budlender and Lund, 2011; Makiwane et al., 2016) and social grants perform an important welfare function in poor households as they are typically shared. As a result of high levels of structural unemployment and poverty in South Africa, many households are vastly, if not completely, reliant on the income of social grant beneficiaries. The payment of grants has been shown to influence kin support networks and household formation (Klasen and Woolard, 2009; Bertrand et al., 2003), with dependents often becoming ‘unintended beneficiaries’ (Burns et al, 2005) of the social grant system.

There is a fairly large body of literature on the household dynamics and politics of social grant sharing around the Old Age Grant (OAG) and Child Support Grant (CSG). Research on the OAG has shown that older female beneficiaries take on financial and care responsibilities within their families, supporting their unemployed children and grandchildren in multi-generational households (Burns et al, 2005; Sagner and Mtati, 1999; Schatz, 2007; Kimuna and Makiwane, 2007; Schatz and Ogunfemun, 2007). Feelings of obligation to support younger household members arise from norms and expectations around kin support and reciprocity in African communities (Button et al, 2017; Kimuna and Makiwane, 2007; Madhavan and Schatz, 2011; Mosoetsa, 2011). The CSG has also been shown to influence family dynamics, power structures and movement between households, and promote the independence of women (Dubbeld, 2013; Patel, 2015).

Comparatively little has been written about the influence of disability-related social grants on family practices (Morgan, 2011), family configurations (Widmer, 2016) or care arrangements in South Africa. There has also been very limited study of these concepts in relation to welfare provision for disability internationally. While there is some research on caregiving for the sick and orphaned children in the context of the AIDS epidemic (Evans and Atim, 2011; Knight et al., 2016), social constructions of family and caring in disability-affected households in African countries are understudied (Livingston, 2005; Manderson and Warren 2013; Manderson et al., 2016 are exceptions).

This paper focuses on family dynamics in relation to social grants paid on the basis of disability. More specifically, it explores the interaction between state provision, economic conditions, social and cultural attitudes towards disability, expectations and obligations around kin support and family practices and configurations. Family practices can be understood as everyday activities that construct and affirm relationships between family members, which at the same time give these social actions meaning (Morgan, 2011; Cheal, 2002: 12). Family configurations, on the other hand, refer to the evolving patterns of practical, emotional and cognitive interdependencies and conflicts that emerge among family members out of these interdependencies, which adapt to life events, household circumstances and transitions (Widmer 2016: 5).

These frameworks help move beyond normative ideas about caregiving and the nature of family relationships and focus on actual practices of giving and receiving care. The emphasis here is instead on the control and use of resources, as well as on how this is mediated by the roles, identities and relative power of household members and external structural factors.

Methodology and context

This paper draws on data from two qualitative research studies on disability grants in the Western Cape. The first is an ethnographic study of the Blikkiesdorp community in Delft, Cape Town, and their perceptions and use of social grants. The second is a larger study of the interactions between medical professionals, applicants for disability related grants and their families in the Western Cape. The methods used for each of these studies are briefly outlined below.

The Blikkiesdorp study was conducted over eight months in 2012. Blikkiesdorp, otherwise known as the Symphony Way Temporary Relocation area, is a formal relocation settlement of 1,800 metal structures on the outskirts of Delft, which is estimated to be occupied by between 4,000 to 12,000 people. It has a reputation for being a ‘dumping ground’ for Cape Town’s homeless and dispossessed, and with its big fence, rows of bleak zinc corrugated iron structures and police presence, has frequently been compared to a concentration camp by the local and international media.

Data was collected using a combination of participant observation, unstructured interviews, focus groups and ‘participation action research activities’. As an able-bodied and privileged person, it took time to build trusting and equitable relationships with community members and participatory research practices were important in overcoming barriers of race, language and class. I provided participants with information, advice, transport and other resources to assist them in accessing health and social services. In doing so, I also learned from their experiences of navigating the social grant and other government systems.

Although 32 people were formally involved in the study, research activities centered primarily on the stories and experiences of a group of ten people accessing or seeking access to DGs in the community. These participants formed an informal support group as a result of their involvement in the study. The majority of the 32 participants identified as ‘coloured’, reflecting the broader demographic makeup of Delft. The remainder were black African (3) or white (5). The support group included people living in a variety of household structures: a cohabiting couple living with two children; two cohabiting couples with no children; a married woman living with her husband and her paternal family; a widowed woman living with two of her three children; one single woman living alone; two single women living with their grown children; and a young man living with his parents.

A significant majority of participants were receiving the DG because of chronic illnesses such as HIV/AIDS or mental illness or temporary illnesses such as tuberculosis, rather than permanent sensory, physical or intellectual disabilities. While people living with HIV or other chronic illnesses are not necessarily disabled, or do not identify as disabled, the provision of disability grants to some chronically-ill people, particularly at the peak of the AIDS epidemic in the early 2000s, has blurred these lines. DG beneficiaries qualifying on the basis of chronic illness typically only received temporary grants for periods of six to twelve months and many were stuck in a constant cycle of losing their grants and reapplying.

Data for the study on healthcare interactions were gathered via interviews with healthcare workers and observations of doctor-patient interactions in twelve clinics and three hospitals in the Western Cape province between October 2013 and August 2014. Twenty-four doctors were interviewed, of whom 17 were observed conducting a total of 216 consultations with patients.

A number of illustrative examples have been drawn from these studies to show how families negotiate spending of the grant and care arrangements, both within and between households. These cases provide insight into household experiences, but are limited in their generalisability, particularly outside of urban contexts, where kinship norms and relationships may differ. Both studies focused specifically on grant beneficiaries and the data therefore largely reflects their experiences rather than those of other household members.

The policy context

People with disabilities and households with a disabled member often face significant financial constraints brought about by loss of work income and additional costs such as assistive devices, healthcare costs or travel expenses. Households may also face challenges related to caregiving or experience stigmatisation, social exclusion and reduced social capital (Gona et al, 2011; van der Mark et al, 2017; Gooding and Marriot, 2009). In recognition of the vulnerability of individuals and households with disabilities, the South African government pays an equivalent amount (R1600 or $136) to disabled adults and the caregivers of disabled children in the form of the Disability Grant (DG) and Care Dependency Grant (CDG), as well as a small additional Grant-in-Aid (R380) to DG and OAG beneficiaries who are in need of permanent care. In the case of the DG, the grant is often temporary; paid to beneficiaries for six to twelve months before reapplication is required.

In 2017, over one million people received the DG. Demand for and receipt of the CDG and Grant-in-Aid are significantly lower, with only 146,666 caregivers receiving the CDG and 184,696 disabled or elderly persons receiving the Grant-in-Aid (SASSA, 2017). This is likely because of relatively low awareness of these grants and bureaucratic obstacles, which were reported by healthcare staff involved in this study. Salojee et al (2007) found that, in their study sample, only 45% of children eligible for the CDG were receiving it.

South Africa spends around 3% of its GDP on social grants (Budget Review, 2017/2018) and 7.2% on poverty programmes alleviation more generally. The White Paper on the Rights of Persons with Disabilities and several legislative measures are in place to promote the independence, employment, self-representation and inclusion of disabled individuals, they are poorly implemented. The state also provides subsidised or free health care, rehabilitation services and assistive devices to people with disabilities. However, policy implementation is weak, and the quality and availability of services is poor. People with disabilities therefore remain less likely to be employed and more likely to be low-wage earners, may struggle to access education, health or rehabilitation services and face significant discrimination at all levels of society (Grut et al, 2012). As a result, many people with disabilities are exclusively dependent on grants for an income. Disability rights activists have argued that the government's spending on DGs comes at the expense of making more meaningful efforts to include disabled people in the labour force (Gooding & Marriot, 2009).

The possibilities for care support for people with disabilities and their families in South Africa are provided by a combination of kin and community, the state, the non-profit sector and the market (Razavi, 2007). The state emphasises family or community-based support for people with disabilities via social grants. Social grant spending comprised 94% of the 2016/2017 budget allocated to the Department of Social Development, which is responsible for the welfare of persons with disabilities (Portfolio Committee on Social Development, 2016). This leaves little budget available for other state-funded services and programming, and households unable to pay for care in the market are left dependent on underfunded Disability Service Organisations for access to services or support. As a result, costs and responsibilities for care fall largely on relatives (Manderson and Block, 2016).

Although relatively generous compared to cash transfers for disability in other low and middle-income countries, both the CDG and DG comprise less than the minimum wage and the GIA provides only very minimal compensation for a caregiver. However, in the context of high unemployment and limited social protection for the able-bodied unemployed, these grants are highly valued, may in fact be shared with other family members and have been shown to reduce poverty and improve well-being in beneficiary households (Booysen and Van der Berg, 2005; Knight et al., 2013). Like older persons eligible for OAGs, people with disabilities may in fact have more 'earning' potential or ability to mobilise an income than many unskilled able-bodied people. Survey data has demonstrated that DG beneficiary households have high rates of unemployment and are more likely to be multi-generational or skip-generational (Mitra, 2010). DG beneficiaries are also likely to be older (Mitra, 2010) and the DG is reportedly used as an unofficial OAG amongst older people who are not yet of pensionable age (60) and who have been detached from the labour market for some time (Kelly, 2017). This makes it probable that, much like the OAG, the DG is used by older adults to support grandchildren and unemployed adults in the household.

While many DG beneficiaries are functionally independent and may in fact provide care to others, people with more severe disabilities may need care or support from either family or other informal or formal caregivers. South African disability policy makes no provision for a personal assistance service system and, in most households, care is provided by female family members (see Reddy et al, 2014; Gouws and Van Zyl, 2014; Manderson and Block, 2016). The majority of care providers for persons with disabilities are single mothers of children with disabilities (Statistics SA, 2014) who may receive little support from fathers and are highly vulnerable to poverty (Salojee et al., 2007).

Social grants provide opportunities for unemployed household members to be compensated for their caregiving work. However, neither the CDG nor the GIA are sufficient to cover the additional costs of care and disability, nor can they act as a substitute for an income for a caregiver (Hanass-Hancock et al., 2017a, 2017b; Sandy et al., 2013). While the means test for the CDG is relatively generous and should allow caregivers to earn an income, doctors involved in this study would often refuse to recommend the grant to caregivers who were employed. This was based on their understanding that it was the responsibility of the beneficiary of a CDG to provide full-time care. This effectively limited access to care support, forcing caregivers to choose between employment and a grant.

South African social policy around care for the disabled, sick and elderly is strongly rooted in normative ideas about the extended African family and community. There is an ongoing emphasis of the role of informal and traditional ethics of care, mainly by kinship networks and communities (Lorenzo et al., 2015). The White Paper on Families (2012) proposes that family support should reduce the burden of care on society, with the role of the state being to support families to provide that care (Button et al, 2017; Manderson et al., 2016). In practice, family policy focuses on family structure rather than functioning and there is little focus on the actual capacity of families to provide care and financial support (Morison et al., 2016) or guidance on how to support caregivers in the current White Paper. Caregiving work is generally undervalued in South Africa and the resources required to provide care are not acknowledged or provided for (Gouws and Van Zyl 2014; Reddy et al., 2014).

The White Paper on the Rights of Persons for Disabilities (2015) adopts the same framework of care provision as the White Paper on Families. It does propose the development of an inter-sectoral plan to provide support to families caring for persons with disabilities, but no such plan yet exists. As a result, the struggles of families with disabled people are left largely invisible and unattended to by government programming (Manderson et al., 2016).

Manderson et al. (2016) argue that policymakers' romantic notions of families do not reflect actual arrangements. In reality, the radius of responsibility within families in SA has shrunk over time, making it harder to spread the care work load, resulting in insufficient care or support from kin (Button et al, 2017: 2).

Sharing and spending money from disability grants

In households involved in the Blikkiesdorp study, grant beneficiaries were expected to share their income with other family members. Given the extent of unemployment in the community, the DG and CSGs were, in many cases, the only sources of household income.

Being considered the 'breadwinner' created opportunities for people with disabilities to have decisional autonomy, exercise agency within households and be seen as valuable household members, despite requiring assistance from others. In a few cases, the grant allowed beneficiaries to create more sustainable livelihoods or at least stretch the grant to the end of the month through micro-business activity. However, being the 'breadwinner' also placed significant stress on beneficiaries who expressed experiencing significant pressure from other family members in terms of how the 'pot' of money would be divided within the household.

Most people interviewed were supporting non-disabled unemployed family members and their children, as well as their own immediate families, with their grants. Jessica, who has received a permanent DG her whole adult life (as a result of severe back problems after being hit by a car as a child), complained that she has never had the opportunity to live alone with her husband because her one-roomed structure was inundated with family members who relied on her grant for food. Although her husband worked as a day labourer in the construction industry, her income was seen as more reliable because his work was unstable and irregular.

Another participant, Mary, was supporting her two children, as well as her boyfriend, Samuel, on her disability grant and two CSGs. The CSG is insufficient to fully cover the needs of a child and therefore much of her DG went into the cost of school uniform, clothing and stationery for the children, as well as food and electricity for the house. Although the government has stated that school-fee exemptions should be available to all parents unable to afford fees, there appears to be very low awareness and implementation of this policy in the area and many participants struggled with the cost of fees.

> For ten seconds you've got your own money! …The disability is not enough. It's more stress when you get the money than it is without it because your whole family depends. When it's payday they've already worked out what they want. Your house is full! (Mary*)*

Mary also experienced pressure outside of her household from her adult daughter, as well as other people in the community who knew that she received a grant. She was initially hesitant to reveal that she received a DG to me because of fear of people other people finding out and asking to borrow money from her.

Division of the grant and care of children within families could lead to fighting or even violence within families, especially where drugs or alcohol were involved. Jessica frequently fought with her sister-in-law, who refused to contribute her CSG to the household but benefitted from Jessica's grant. Often parents receiving the DG were extorted or robbed by their children for drug money. Every time Mary went to collect her grant at the SASSA office she faced the threat of physical violence from her drug-using 26-year old daughter, who lived in another part of the township with her young child and demanded a share of the grant.

> Every month she is waiting for me at the AllPay [payment point], shouting at me. She beat me last year. She told her friends 'naai her up'. They kept my hands and she pulled out my hair - the blood was running in front of my tooth. Every month she waits there at the AllPay: 'Ah ha, I'm here. Come, the money.' (Mary)

Household care arrangements

Livingstone (2005) and Manderson et al (2016) have shown that care arrangements for people with disabilities are often negotiated and dependent on multiple planes, including the emotional, social, economic and moral, as well as kinship ties.

In Blikkiesdorp, care arrangements in households were fluid and pragmatic, with care of people with functional limitations and children strongly (but not exclusively) driven by the availability of resources. Few Blikkiesdorp residents were able to access private care services and community health and development workers in the area provided little concrete support. Most caregiving work was therefore performed by kin with little external assistance.

Care relationships and activities are often informed by life circumstances and the attitudes of ‘give and take’ that inform other aspects of family relationships (Manderson and Warren, 2013). While grants can help families to stay intact (Manderson and Block, 2016), they can also drive movement of kin between households, particularly when an individual is in need of care.

These dynamics are illustrated by the case of Nomakhwezi, one of the few Black African participants in the study. She had been receiving a temporary DG because she was was suffering from an HIV/AIDS-related illness, but had recently lost her grant as her health had improved. She was struggling to find work because her English was poor – a common challenge faced by those migrating to Cape Town from rural areas. She had two young children and an adult daughter and had been widowed by AIDS. She had used the money from her DG to live independently of her husband’s family, moving in with her eldest daughter who was employed in a local supermarket. Nomakhwezi sent her son to live with her mother in Khayelitsha to save on groceries and provide him with what she considered better educational opportunities. Her mother received an OAG and could therefore take on the responsibility for his care, while Nomakhwezi could use her DG and the two CSGs she received to support herself and her young daughter.

This arrangement faltered when her mother was diagnosed with multi-drug resistant tuberculosis and admitted to a specialised hospital for an extended period of time. In the grandmother’s absence, other family members in Khayelitsha began to demand a share of his CSG in return for caring for Nomakhwezi’s son. Left with only her daughter’s CSG to live off of, she could not afford to pay anyone to look after her three-year old daughter whilst she sought work, making it very difficult for her to exit the poverty she had found herself in.

In cases where household members were severely disabled, grants shaped household care arrangements in other ways. In low-income households, sick and disabled children and people can be seen as burdensome, both in terms of their care needs and the affordability, availability and accessibility of services for disabled people in the context of poverty (van der Mark et al., 2017). Care work is difficult and stressful, and caregivers may suffer from burnout and depression. In higher income settings, people may feel hesitant about being remunerated for caregiving (Manderson and Warren, 2013), but in low-income contexts, disability-related grants can provide important support, as well as incentive to poor families to care for disabled household members.

This was demonstrated by the case of Mary and Samuel, who were in a relationship and living in Mary's house, together with Mary's two children. Mary was HIV positive and, according to her, so was Samuel, but he refused to admit it. Although I couldn't confirm it, it seemed that he also suffered from some form of drug resistant tuberculosis as health workers had attempted numerous times to move him from his home into a facility; presumably to isolate him. Mary was receiving a temporary DG, but Samuel, although very ill, did not receive the grant and was dependent on Mary for support. Although he and Mary had a volatile relationship, he was estranged from his family, who refused to provide any financial support or care and Mary felt responsible for him.

During the time of fieldwork, Samuel's condition deteriorated, and he became bedridden. He was nursed by Mary, who would carry him to the local clinic. Knowing that her own temporary DG was coming to an end, Mary became extremely stressed as this grant and the two CSGs she received were the only household income and she was heavily indebted. Losing her grant would re-start what for her had been a cycle of constant stress around losing the grant, falling into extreme poverty, getting sick again and then re-applying for the grant. Mary responded to this looming crisis by urgently trying to get a DG and Grant-in-Aid for Samuel. The process of applying for a DG is confusing, bureaucratically burdensome and requires waiting in multiple long queues, exacerbating the exclusion of people like Samuel with limited mobility and means. It was only when he was finally hospitalised and a doctor completed a disability assessment at his bedside, and once I had arranged for a SASSA official to visit his home to complete his application, that he was finally awarded a DG.

Only a few hours after the visit from SASSA, Samuel called his family to fetch him from Mary's home. His family were prepared to welcome him back into their household based on the understanding that he would soon have a monthly income to contribute. This devastated Mary emotionally and financially, as by this point she had lost her own grant. Eventually, Samuel did begin sending Mary R20 to R30 a month to help her buy electricity, but this case ultimately shows both the limitations of reciprocity in relationships and the lack of kinship obligations that exist outside of marriage.

Social workers and nurses from two hospitals also shared anecdotes that indicated that kinship support of sick and disabled people was strongly tied to the potential for grant income. Health workers indicated that grant applications were often initiated by the family, who sometimes applied enormous pressure on healthcare staff or social workers to recommend a grant for a patient. In one instance a nurse noted, ‘We had an incident when the patient's mother came to hit the social worker. Truly, because of the grant’ (Nurse, Psychiatric Facility).

The state promotes a model of community-based care for people with psychiatric and intellectual disabilities, but policy is poorly implemented and there is limited support or services provided to families who take on such responsibilities. Knowing the value of grant income to households, health and social workers would use grants to incentivise families to take responsibility for mentally-ill and intellectually-disabled people so that they could be discharged and live at home.

> So sometimes the patient...actually we blackmail the families into taking the patients if you know what I mean: ‘you will get the grant if the patient stays at home.’ (Nurse, Psychiatric Facility)

According to the regulations specified in the Social Assistance Act of 2004, social grants should lapse six months after a patient has been admitted to a state institution. In some cases where patients were admitted long-term, social workers in psychiatric facilities avoided reporting the length of stay to SASSA to reduce pressure on household dependents in return for making regular visits and taking patients home for weekend ‘leave’. Tuberculosis hospitals have struggled to keep patients with drug-resistant and multidrug-resistant tuberculosis in extended periods of confinement because of the potential lapsing of the grants on which patients’ households depend[1].

There were also concerns amongst nurses that people with intellectual and psychiatric disabilities were vulnerable to neglect or abuse by households that spent little of the grant money on the beneficiary.

> Nurse 1: There is lots of room for abuse. Patients get abused. For their patients [Referring to nurse dealing with intellectual disabilities] they can't talk properly or ...so there's a lot of people that exploit the grants - give a good picture but behind closed doors it’s another story.
> Nurse 2: Because they want to make money
> Nurse 1: Oh of course you get this issue where the social worker is so pressured to place the patient that if somebody comes they are so grateful that somebody is actually willing to take the patient so... (Focus Group discussion with nurses, Psychiatric facility)

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[1] See Minister of Health of the Province of the Western Cape v Goliath and Others (13741/07) [2008] ZAWCHC 41; 2009 (2) SA 248 (C) (28 July 2008)

Most people with mental illness are only given temporary grants and mental health workers reported that relapse was common before the end of the grant period, which was suspected to be the result of patients not taking medication or families withholding medication from patients to avoid recovery and thus potentially lose the grant.

> Sometimes what they do is they don't take grant medicine because they need to...even the families don't give the tablets because he must stay sick or she must stay sick so that they can get the grant. (Nurse, Psychiatric Facility)

Reports of patient nonadherence to medication by people with various chronic illnesses were made by several other health professionals working in high poverty areas, where recovery rarely resulted in an ability to find employment. In the mid-2000s, a number of studies also highlighted the pressures faced by HIV-positive DG beneficiaries acting as household breadwinners and related incentives towards ill-health (de Paoli et al, 2012; Nattrass, 2006). While this trade-off between health and income has not been demonstrated beyond anecdotal reports from health care professionals and communities, these studies do highlight gaps in the social grant system that makes no provision for the able-bodied, long-term unemployed.

Conclusion

This paper has shown how the strength and characteristics of household relationships, as well as the macro-level environment, influence practices and patterns of kin support, as well as the capacity of households to provide care. It also reveals fault lines in social policy to address poverty and inequality and integrate disabled people into society. High levels of structural unemployment leave many households dependent on the grants of disabled people and weak policy and programming around care provision for people with disabilities or chronic illnesses places a significant burden on caregivers.

Social grants targeted at people with disability play a vital role in reducing this burden by compensating people, particularly women for the care work they perform in households.

Grants also promote interdependency within households, allowing people with disabilities to support households financially while receiving care in return. However, these arrangements may not benefit disabled people or caregivers in the long-term. When households are reliant on the incapacity of an individual, it reconfigures the value attached to health and disablement and has negative consequences for the health, well-being and social and economic inclusion of people with disabilities and chronic illness. In the context of unemployment, kinship norms of sharing grant money result in little of these grants being used on the beneficiaries themselves, placing an unfair burden on a category of people that the state has explicitly defined as vulnerable.

The income provided by grants is nowhere near sufficient to both alleviate household poverty and compensate for poor access to services and greater investment in community-level support for households, as well as supply-side efforts to empower and create opportunities for people to engage in meaningful livelihood activities are urgently needed.

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