SUBMISSION TO THE SPECIAL RAPPORTEUR ON EXTREME POVERTY AND HUMAN RIGHTS

UNPAID WORK, POVERTY AND WOMEN'S HUMAN RIGHTS

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Introduction

In South African society women have and continue to conduct work that does not usually yield financial benefit or recognition. This is often because the work conducted by women is under-valued and unrecognized as 'real work.' As a result of this perception, persistent images of women as 'supporters' rather than 'actors' continue to make women's work invisible. The impact of unrecognized work on women's ability to engage with the economy and provide and advance them financially can often have devastating consequences, and perpetuates women living in poverty.

We therefore welcome and are grateful for the opportunity to make contributions on unpaid work, poverty and women's human rights.

Organisations Making the Submission

- ### The Legal Resources Centre[1]

The **Legal Resources Centre (LRC),** established in 1979, is a South-African based human rights organisation with regional offices in Johannesburg, Durban, Grahamstown and Cape Town. The organisation uses the law as an instrument of justice for the vulnerable and marginalised, including poor, homeless, and landless people and communities who suffer discrimination by reason of race, class, gender, and disability or by reason of social, economic, and historical circumstances. The strategies employed to

[1] www.lrc.org.za

secure the protection and promotion of human rights include impact litigation, law reform, participation in partnerships and development processes, education, and networking within South Africa, the African continent and at the international level. The LRC through its Gender Rights Project ("the project") focuses on empowering women by providing: legal advice; legal representation and negotiation to victims of gender violence; and by participating in advocacy and law reform in the public space.

- **The Parent Centre**[2]

The Parent Centre is a primary prevention Non-Profit Organisation in based in Cape Town, South Africa that aims to prevent child abuse through the promotion of Positive Parenting. The organisation was established in 1983 and provides education and training workshops, home-visiting programmes, community talks, support groups as well as parental counselling. In the Western Cape the organisation works directly with parents and caregivers from the pregnancy stage till the early adulthood stage of parenting and professionals (e.g. teachers, social workers; psychologists) and community members who are concerned about the care of children. It also partners provincially and nationally with organisations which support and work with parents and caregivers. Some of the services offered include Parent-Infant Psychotherapy, Positive parenting skills training; Teen parenting skills training, Parent-infant Intervention Home visiting, Parent and caregiver support groups, Fatherhood Programme, Behaviour Management (in schools and daycare facilities), Training of (parenting skills training) facilitators – also known as the Train-the-Trainer Programme, Mentoring and support to

[2] www.theparentcentre.org.za

Train-the-Trainer Programme graduates, Online parenting information and support as well as a Parenting Library.

- **Wellness Foundation**[3]

The Wellness Foundation (previously AIDS Response) has been providing care and support to care-based organisations working in the HIV and AIDS and TB context across 4 provinces in South Africa since 2001. We provide direct psycho-social services (e.g. counselling, support groups, wellness sessions and self-care retreats) as well as capacity building (e.g. how to set up and run in-house care for the carer programmes). Our interventions are primarily aimed at grassroots based organisations across the prevention, treatment, care and support spectrum as part of health systems strengthening. Across Southern Africa, unpaid, voluntary, informal networks of care providers have emerged as a critical vanguard in the provision of care to sick people and are filing a health care gap left by governments. This kind of work is not yet sufficiently acknowledged as an essential service that forms the bedrock of our own response to HIV and AIDS and TB in South Africa. The work is stressful, not paid, inadequately resourced and done by poor women, many of whom are themselves living with HIV and AIDS. The advocacy aspects of our work focus on the recognition and formalization of care as work. Over the last few years we have also strengthened the capacity of a group of local CCWs to establish the CCW Forum, a platform for mobilising and organizing CCWs across various provinces around the call for recognition, decent work and a living wage.

[3] www.wellnessfoundation.org.za

I. Introduction to South Africa

Since the end of apartheid in 1994 when South Africa celebrated its independence from apartheid, there has been notable social and political transformation which has, among other things, ushered in participatory democracy, refinement of democratic institutions and improvement in inclusive social services.[4] *'As the 20th largest economy in the world which contributes 38 percent of Sub-Saharan Africa's GDP, it has succeeded in transiting from an economy driven by the government to the one propelled by the private sector, and creating conducive investment climate and robust stock exchange. All these have contributed to:*

- *A steady growth of GDP which rose from an average of 3% during 1994-2003 to 5% during 2004-2007.*
- *Between 1999 and the first quarter of 2008, the real sector of the economy experienced uninterrupted expansion.*
- *Between 2002 and 2005, the Rand was rated the world's most actively traded emerging market currency (a la the Bloomberg's Currency Scorecard).*
- *Prudent macroeconomic policies and strong fiscal discipline (from a deficit of about 7% in 1993/94 to surplus about two years ago) has lead to low inflation (but*

[4] National Context relevant to UN/UNDP development dynamics at http://www.undp.org.za/the-country-programme/country-overview [Accessed 3 May 2013].

currently being affected by global increase in food prices and recent weakness in Rand) and increasing investor confidence.'[5]

However this is not to say that South Africa does not continue to battle with many challenges. Some of the main challenges that the country continues to face are:

- spatial poverty and accelerating inequality;
- high incidences of violence particularly against women and children;
- high incidence reported of child abuse and neglect;
- high unemployment with growth in labour force outstripping the growth of the economy;
- high HIV/AIDS which has assumed a serious development challenge to the country; and
- delayed or non-existent service deliver and increasing low skill content of the educational system reducing the employability rate of youth.

II. Introduction to Care Work in South Africa

Various descriptive words are used within a South African context to refer to those who do work in communities related to the provision of health care. These terms include community caregiver, community based worker, home-based carer, and ancillary health care workers among others. These community workers generally do not possess any

[5] Ibid.

formal, professional health care qualifications. An evaluation of care work in Southern Africa found that 91 percent of carers are women.[6] In many instances women had to forego income earning opportunities in order to provide care (especially in cases where care is provided to family members who cannot afford medical health care or who cannot access it), which pushes the family deep into poverty and increases financial dependence on social grants paid by the State.

In the South African context the majority of care workers are women, and fall into two categories[7] of care workers, namely voluntary care workers (who are not employed and fulfill the role of care worker to family and community members as the need for health care is great) and employed care workers (who are either employed by the Department of Health or Department of Social Development or who are paid a stipend or a salary[8] by a Civil Society Organisation). The increasingly high rates of unemployment in South Africa mean that in the instances where a stipend is received it is often very quickly spent given the need within the family. Very often stipends are spent on the very clients that are cared for as there is such high levels of poverty of those receiving home based care.

[6] Ibid 104.

[7] There is the possibility of sub-categories under the two

[8] It is worth noting that these salaries are by bo means a decent wage, and neither are the conditions of work. South Africa does not have a basic minimum wage to protect vulnerable workers against exploitation.

The care work sector is largely unrecognized, but even where care workers are gainfully employed or are paid a stipend women often have to live with a lack of job security due to the uncertainty of renewal of the funding[9] on which the programs that employ them rely. 'Many young girls are often forced to leave school to care for a sick family member, thus forfeiting the chance of an education and future prospects of employment.'[10] Essentially placing these girls in a perpetual state of poverty as they will not have any skills or education to obtain professional employment or otherwise once the need for their care seizes. The fact that the care work that they conducted is not recognized as real work they would also not be able to use it as experience within the recognized medical sector.

Though some Community Based Organisations received financial aid from the Department of Health or Social Development, a number of such organisations remains unfunded and provides care on a voluntary basis. As most of the care is provided to poor and marginalized community who would not be able to afford private health care or who are unable to access health care through a government clinic, the carers are unable to charge a fee for their services. Some organisations are able to provide care through private funding and donations, but this is also not very secure as it mostly dependent on the generosity of the funders and the continuation of funding for the specific program. In recent years the lack of funding as a result of the global economic crises has had a devastating impact on many programmes that provide care. We have

[9] Ibid 104/

[10] Ibid.

seen the mushrooming of private care providers where agencies act as labour brokers in providing community care workers with jobs in the private sector at exploitative rates and in unacceptable working conditions with very little, if any protection and recourse.

III. HIV/AIDS Context

The high impact of HIV/AIDS in South Africa has led to an increased number of people requiring care and support. Many HIV/AIDS patients who are discharged from hospitals usually do not have family members to care for them or they have to go to work for financial income to support their families. Sometime family members if available are often unskilled and ignorant about the treatment required to treat HIV/AIDS, many of them unwilling to provide care fearing that they themselves will get infected.[11] It is crucial to note that many community care workers themselves are living with HIV and AIDS and therefore face the same situation as those they are caring for. The stigma and prejudice experienced by those inflicted and affected by the pandemic means that people living with HIV/AIDS are often discriminated against and neglected by their families at a time when they are most in need of care and support.

Many people who are HIV positive present late to the primary health care clinics which increases the pressure on home care organisations. There are many instances where these patients are left alone at home, community care givers have become the primary carers. Some of the functions include household chores, sometimes spending their own money for food and transport to the clinics.[12] The role of a carer is therefore not

[11] Cameron, S etl *Community Caregivers* in [find] at 100.

[12] Ibid 101.

restricted to medical support by often extends into areas of counseling and advisor. The function of carer also extends to children orphaned and also children infected with HIV/AIDS. The function of the carers here would include 'facilitation of placement, helping to secure relevant grants and seeking programmes providing paediatric care.'[13] In various parts of the country there is an increasing breakdown in primary health care services, most notably in rural parts of the Eastern Care where community care workers have to deal with the growing incidence of drug resistance and other issues around adherence. Other consequences such as unwanted pregnancies due to interrupted family planning services, increased vulnerability to MTCT and increases in child and maternal mortality rates also confront the community care workers on a day to day basis.

General Activities of Care Givers

The main function of a community care givers generally include physical care which includes bed bathing, wound dressing and 'cleaning those patients with frequent bouts of a diarrhea, assisting with securing relevant grants; limited financial support; training family members on home based care; emotional support; administering medicines; and referrals to clinics and hospitals, among other functions. These functions are often performed after hours usually exceeding their skills and ability to cope thereby affecting

[13] Ibid.

their own families negatively.[14] When financial support is required, these carers usually sacrifice their own limited financial resources to assist.

Because of the nature of the work they are often called upon to assist in bereavement, counseling and helping to make funeral arrangements. This is a heavy burden to place and bear by people who receive little to no support either financially or in respect of their own wellness.

CASE STUDY: Wellness Foundation Care Work

Public health systems across the Southern African region face a number of critical challenges that impact adversely on service provision to vulnerable communities. These include under capitalisation, competing national priorities, on-going brain drain of health care workers, and an overwhelm of diseases such as malaria, TB, HIV and AIDS. South Africa's own AIDS response rely heavily on community based caregivers to meet the prevention, treatment, care and support needs of over 90% of the population of 50 million people unable to afford private health care. Numbering between 60 000 and 70 000, this predominantly female cadre of health foot soldier has been providing a range of services (palliative care, community education on STIs, adherence support, referral of clients to health centres, psycho-social support to clients and family, nursing care, to name a few) providing a credible reach in rural and poor communities in particular. Yet their work is not seen as "real" work with a proper working conditions, remuneration or protection under labour laws. Our own research has shown that they are at risk of burn-

[14] Ibid 102

out and carer-fatigue due to the stress full nature of working in resource-poor settings, the lack of recognition for their work, the fear of contracting illness due to the unregulated nature of their work and being faced with the rising cost of living and lack of food security.

With the South African government's recent announcement of its plan to revitalize the primary health care system through amongst others, the large scale deployment of community care workers as part of community health teams, there is cause for celebration and cause for concern. As a sector we have been advocating hard for the recognition of care work and care workers to be formalised as part of the health care system. This has been achieved on paper as part of the revitalization model. However, the battle is not yet over. Not enough is being done to get the voices of community care workers into the debates and decision-making. Decent work for community care workers is not on the agenda, nor is the gendered nature of care. Experience has taught us that the interests of a group is best looked after by representative members of that group. In the absence of an appropriate movement or organisation that champions the interests of care workers, work needs to get done to ensure the formation and strengthening of such a representative group for care workers. Wellness Foundation's interventions are aimed at the individual, organizational and sector levels to strengthen individual and collective capacity to advocate for such a representative movement of community care workers.

Our target groups (community care workers and care-based organisations) are essential to realise the intention and scope of the National Strategic Plan (NSP)[15] across all 4 strategic objectives. Localised responses to HIV and community care worker are an integral part of the National Health Insurance (NHI) designed to close the gap between private and public healthcare, and address some fundamental service delivery challenges.

Providing care to those with HIV/AIDS remains a challenging priority to the state. As an incurable condition, HIV and AIDS cause considerable stress on a psychological, behavioural and physical level, not only for those infected, but also for those responsible for their care. Community care workers suffer from burnout, compassion fatigue and secondary traumatic stress, amongst other conditions. Their performance is further negatively impacted by poverty (particularly the lack of food) and by personal risks faced by carers in the routine delivery of their service. Most Community Based Organisations/NGOs working in the HIV field often operate with a small core complement of professional staff whose primary responsibilities are the recruitment, training and support of carers, and often the lack of a conducive organisational environment - poor communication, inadequate or no supervision and counselling, limited resources and weak community support systems – exacerbates the burden on carers. Their contribution is not seen as “work” and then therefore do not have the necessary protection under the labour laws nor do they earn a decent living given that

[15] National Strategic Plan for HIV< STIs and TB 2012-2016

they provide an essential service that is the responsibility of the state to provide to its people as set out in Section 27 of the South African Constitution.

The average ratio of CCWs to clients is about 1:10 and this means that about 600 000 people get cared for by this cadre of health care worker.

Transformation is best effected by the people who will benefit most by the change. In this case, CCWs are best placed to articulate and champion their cause for recognition, decent work and a living wage. The Wellness Foundation Changemaker course aims to strengthen a 1st and 2nd tier leadership structure of the Community Care Worker's Forum to mobilise and organise a critical mass of community care workers to advocate for change. At present there exist only one other structure in South Africa that has a similar agenda and they operate primarily in parts to the North of the country in Gauteng Province, North-West Province and Kwa-Zulu Natal. We are working on a co-operative agreement with this group so as to strengthen the voice of community care workers nationally. Community care workers are largely "invisible" and un-organised. Organised labour has failed to date to bring volunteer or stipend workers into the fold. Once the Community Care Workers Forum, through the Changemakers mobilising and organising efforts, reach critical mass they may well mobilise for sectorial determination to get the necessary protection under South African labour laws and join and existing union or form their own. Not only will such a move bring much-needed formal recognition, but it will also enable Community care workers to realise the various demands enshrined in the CCW Charter, the document encapsulates their mandate.

Organised labour has consistently failed to bring this cadre of worker into their fold. This reflects society's general de-valuing of care work and by implication, care workers.

IV. Maternal Health Context

The current context of maternal health in South Africa has seen the increase of home based care geared directly for women pre and post birth. Already in 2002, reports were denouncing the improper health care given to pregnant and women in labour within government hospitals and clinics.[16] Women are turned away from clinics while in labour, ignored by nurses when called for help, and even refused admittance to health facilities; they are not given adequate pain relief; they are discharged inappropriately, sent home without pain medication or antibiotics, sometimes after Caesarean births; they are left unobserved for long periods of time, subjected to physical and verbal abuse, and even forced to give "gifts" to some health workers in exchange for maternity services to not be delayed or withheld altogether.[17] The list of abuses continues and the Parent Centre has documented a number of abuses suffered by women during the maternity period.

[16] "A study that audited pain relief provided in the labour ward at Mowbray Hospital (Level 2) in the Western Cape found that 35.4 % of women received no pain relief in labour, and of these 65.5% did not ask for a method of pain control and 34.5 did asked but did not receive it. When interviewed all stated that they "would have liked help". This was in an environment with a high percentage of women having complicated labours and extra analgesic requirements. The study also found that 60.2% had no birth companion despite the fact that it has been shown that birth companions improve the quality of the birthing experience for women and the practice is officially encouraged in the institution (Fawcus 2002)." See also Penn-Kekana, Loveday and Blaauw, Duane, Final Report: A Rapid Appraisal of Maternal Health Services in South Africa, a Health Systems Approach, Centre for Health Policy, 2002, p. 21 and p. 22 respectively.

[17] *"Stop Making Excuses": Accountability for Maternal Health Care in South Africa*. Human Rights Watch, 2011. Pages 21–30, 33.

General Activities of Care Work

In addition to monitoring and referring women who have faced problems as described above to legal, psycho-social and medical services, carers could potentially also provide much needed support to mothers. The Department of Health has accepted that "the early post-natal period is important for mothers and their infants not only do many maternal and neonatal deaths occur in this period, but mothers require support in caring for and breastfeeding their babies."[18] The Department further recognised that "post-natal visits should ideally be home-based, although facility visits may be practical in some settings. These are all services provided by carers as nurses from clinics and hospitals do not attend to homes to provide the care identified. Community Health Workers (CHWs) have a key role to play in improving coverage through conducting structured home visits during this period and the ward-based primary health care outreach teams will play a significant role in ensuring that all mother-baby pairs are visited."[19]

CASE STUDY: The Parent Centre's The Parent-Infant Intervention Home Visiting Programme as a First Line of Defense against Many Social Problems

Overview of Programme

[18] Strategic Plan for Maternal, Newborn, Child and Women's Health (MNCWH) and Nutrition in South Africa 2012 – 2016 at http://www.doh.gov.za/docs/stratdocs/2012/MNCWHstratplan.pdf

[19] Ibid.

The Parent-Infant Intervention Home Visiting Programme is one of the Parent Centre's Programmes and is an early intervention programme which aims to enable parents to create a nurturing environment for the healthy long term development of their children. The programme operates within a systems approach impacting on the family as a whole as well as the broader community and could easily be located in an ecological approach.

This programme is implemented through 5 ante natal visits and 15 post natal visits in the comfort of a parent's home until the baby is 6 months. Home Visits are conducted by 14 home based visitors in 11 communities in the broader Cape Town communities. The focus is on supporting vulnerable pregnant women living in non-conducive circumstances/poverty stricken areas and who are at risk of developing postnatal depression which could be detrimental to the healthy long term development of their children. When home visitors enter the home of each parent (single mothers in most instances); they do not only provide emotional support, counseling as well as information and skills pertaining to a mother's pregnancy and the development of the baby, but they act as so much more.

The home based visitor plays a pivotal role in ensuring that mothers form a healthy bond/attachment with their baby. *"According to the U.S. Department of Health and Human Services, attachment theory was introduced in the 1950s by psychoanalyst John Bowlby. "Attachment" refers to an emotional bond between an infant and caregiver where the infant seeks the caregiver for closeness and support, especially when feeling upset. In most cultures, infants are primarily attached to the mother. Attachment theory*

speaks to the emotional bond formed between all human infants and caregivers, the role of the caregiver in nurturing the bond, the anxiety in the separation of the bond, grieving the loss of the attachment, and how either a secure or anxious bond contributes to later relationships in the life of the infant."[20]

Further Objectives of the Programme include:

- To detect antenatal and postnatal depression and provide the mother with appropriate intervention.
- To detect mothers who are suicidal and provide them with appropriate intervention.
- To encourage exclusive breastfeeding during the first 6 months through dissemination of information about the benefits of breastfeeding and providing practical and emotional support to the mother.
- To enhance parent's self-esteem and a sense of agency, particularly with regard to their infants and children.
- To promote the parents' use of available resources which strengthen their ability to care for their children, such as the community health clinic, local government office, drug rehabilitation centres, food projects; etc.

[20] The Development of an Infant-Mother Attachment at http://www.ehow.com/about_6699853_development-infant_mother-attachment.html, [Accessed 3 May 2013].

- To provide support to parents infected with HIV/AIDS through giving them a safe space to talk about their illness and linking them with appropriate resources.
- To encourage treatment compliance with parents who are infected with HIV/AIDS and who have children who are infected as well.
- To improve the parents' awareness of, and ability to respond to, the needs of their older children.
- Where mothers have returned to work, to home visit the caregiver and promote sensitive and attuned infant care.
- To network with all relevant parties involved in the community in order to continue to provide a viable and appropriate service.

"The most important factor in a child's healthy development is at least one strong relationship (attachment) with a caring adult who values the well-being of the child." (Engle et al, 1997).

Areas of Operation

The Parent-Infant Intervention Home Visiting Programme is implemented in the following 11 communities in the broader Cape Town: Khayelitsha; Phillipi; Heideveld; Hanover Park; Retreat; Imizamo Yethu; Hangberg; Mitchell's Plain; Gugulethu; Bonteheuwel and Nyanga. These indigent communities (all programmes of the Parent Centre's operate in indigent communities), are riddled with crime, high levels of abuse; neglect and abandonment of children; gender based violence, poverty and generally are

neglected communities. Cape Town is known as a city where gang violence is quite rife holding residents in communities often hostage in their own homes during these violent outbreaks. This type of violence often occurs unexpectedly, but quite regularly. Despite these challenges including the long wet; windy and very cold winter months, the home based visitors continue to conduct their work with passion, commitment and dedication wanting to make a difference in their client's lives.

Importance of Home Visiting

Research has shown that the importance of home visits acting as a preventative measure against issues such as violence prevention, child abuse and neglect and the healthy development of children cannot be overemphasized. Entering a parent's home enables the home based visitor to observe the family in their natural environment which is a great opportunity to impact on the family as a whole (e.g. interaction between mother and baby; mother and other siblings; mother and partner/spouse; mother and extended family; mother and neighbourhood and mother and broader community). The home visitors is therefore able to act as frontline workers in the fight to keep families together by imparting skills and knowledge to parents regarding their parenting style; relationship issues; linking the family to much needed poverty alleviation resources in the community and importantly acting as an advocate for the rights of women and children.

Each session comprises of a time to check in with the mother (how she is doing and baby and what is currently happening in her life – mothers usually share quite a lot with the home based visitor during this time; this is followed by an opportunity by the home

visitor to provide some specialist input regarding the stage of mother's pregnancy or the development of the baby, if baby is already born). The session is concluded by making a follow-up appointment and planning for the next visit.

Home Based Visitor

Who is the Home Based Visitor?

The home based visitors that implement the programme are women living in the same community where home visits are being conducted. The home based visitor has generally experienced poverty, was unemployed and does not have post school qualifications, before joining the Parent Centre. The home based visitor possess the aptitude, passion and commitment to make a difference in her community and who has a special interest in the attachment and bonding between a mother and infant for the better of the community she lives in.

Training

The home based visitor has received 39 weeks of specialised training from the Parent Centre. This 39 week training programme equips these women with the skills they need as home based visitor. Each 4 hour session includes: Practical self-awareness exercises; Positive parenting skills; Counselling skills; Skills to assess infant behavior and Observation skills. Specialised workshops during the 39 weeks include : infant massage; antenatal and postnatal depression; child abuse; grief work; infant nutrition; HIV/AIDS; foetal alcohol spectrum disorder (FASD); pregnancy, labour and birth;

trauma counseling and sexuality. It also include a continuous and rigorous screening process before, during and after the training programme, ensuring that only the best candidates make it onto the programme.

The goal to provide high a quality intervention programme to vulnerable pregnant women in at marginalized communities is further enhanced through regular inservice training sessions as well as group supervision (once a week for 3 weeks of the month) and individual supervision, once a month. Home based visitors are being supervised by experienced infant-mental health practitioners comprising of both social workers and psychologists.

Payment

As this program is run by a non-governmental organisation, the home based visitor is paid a monthly stipend which is paid from funding raised from private donors. This programme is not funded by the Government. As with any private funding, the security and continuation of the program linked with the fund is based entirely on the availability and provision of these funds. The funding that was secured for this programme comes to an end at the end of December 2013 and no substitute funding has been secured as to date.

Fundraising proposals have been sent to various funders and there has not been any clear commitment at the moment. This creates a real danger and likelihood of closing this programme. The closure of the programme would terminate an important early intervention service to families in 11 communities in the greater Cape Town. Closing

this programme will leave vulnerable pregnant women and their babies once born, at risk of various problems and with no social and emotional support which is so crucial during the first few months of a new baby's life.

The programme aims to impact permanently on "at risk" parents through developing within them mindfulness about their children's wellbeing, an attachment and commitment to their children and a sensitivity and attunement to their children's needs and responses. And in so doing, has ensured that their children will grow up in environments that are nurturing and allows them to develop into resilient, caring, creative members of society.

This hope was affirmed by one of the participants of the programme. *"The programme changed my lifestyle. I feel the programme must never end in Hanover Park. I think if everyone here is on the progamme, it will make a huge difference in Hanover Park, because parents will learn to give their children love and support. There would be less gangsterism. Many young people are only looking for love and comfort and their parents don't know how to give it to them. Please help everybody in Hanover Park; we will be able to have less crime in our community".*

More significantly is the financial impact the closure of the program will have on the 14 home based visitors. These women have acquired skills and training that they have positively utilized for a number of years. Additionally with the little stipend that they have earned they have been able to financially contribute to their families and to the upbringing of their children. Coming from indigent and marginalized communities, this stipend, though very small, has enabled these home based visitors to increase their

financial standing and afford everyday necessities that they would ordinarily not be able to afford with this payment.

As this is an area of interest for these home based visitors, because it positively advances their own communities and it is something that lies close to them as women, some of these women may continue doing this work without any form of stipend or support. As these women have made some strides both financially and socially, the closure of this program therefore renders them vulnerable and financially dependent on either their spouses or the government (social grants) which further pushes them into poverty.

Impact of the Work of The Parent Centre

*"*Jacky* is a 15 year old mother living on the Cape Flats, Cape Town. The family planning sister at her local Maternity Obstetrics Unit just told her that she is four months pregnant and is worried about her because she is on Tik (Crystal Meth). Jacky is asked if she would like to be visited by the Parent Centre home based visitor, Jacky agrees. She is worried about how she is going to care for her baby. She and her boyfriend have no money, they are living with her boyfriend's parents who cannot work because they are both sick. They also care for two other grandchildren. She does not have a good relationship with her own parents whom she feels have never wanted her. She wants to be a better mother to her baby. Jacky is happy to hear that the Parent Centre home based visitor will be visiting her at home 20 times – five times during her pregnancy and 15 times after her baby is born. She is a bit scared in the beginning as she does not*

know what the home based visitor will think of her. Perhaps the home based visitor will not like her because she is so young and will think that she will be a bad Mother.

She is surprised to find that the home based visitor is kind, listens to all her worries, makes her feel good about herself and helps her believe that she can be a good mother. The home based visitor gives her information and teaches her new things that make it easier for her to take good care of her baby. When her baby was crying a lot, sometimes she got angry when she didn't know what to do and wanted to hurt her baby. She told the home based visitor who showed her how to calm her baby when she cries. The home based visitor also introduced her to another mother who lives close by and was home visited a year ago. Now, on days when she needs a hand with her baby, she can go to her new friend. The home based visitor also helped to get into a drug rehabilitation programme. She has stopped taking drugs, it was very hard but thinking about her baby has kept her going. She is very happy that she had the home visits. Her baby is happy and growing well and she is proud of herself as a mother. She wishes all pregnant women can be home visited." (The Parent Centre 2012 Annual Report, p. 5) (*Name has been changed.)

Jacky's story is characteristic of the 745 parents and infants living in Hanover Park; Khayelitsha; Gugulethu; Nyanga; Phillipi; Mitchell's Plain; Imizamo Yethu; Hangberg; Retreat; Heideveld and Bonteheuwel who participated in the home visiting programme. Each home based visitor works with an average of 20 mother-infant dyads during a six month period. A total of 9012 home visits were conducted by the 14 home based

visitors and Approximately 11 155 parents and caregivers attended Early Parenting talks at the Community Health Clinics given by the home based visitors, during the 2011-2012 periods. Sadly, 26 % of the mothers home visited were younger than 19 years old.

It is evident from the above that Home Visitors reach a high number of parents/caregivers annually in the comfort of their homes amidst very trying circumstances in local communities, making it a very important service which will put vulnerable women (especially teenage mothers) at higher risk, should the programme be terminated due to funding.

V. Impact of Recognition of Care Work

The South African government has made some attempts, though minor and unsatisfactory, to provide some form of payment and support to home-based care workers. This was done in 2004 through the integration of careers into the government's Comprehensive Care, Management and Treatment Programme guiding ARV rollout. This is obviously only limited to home-based care workers providing care to HIV/AIDS patients. Further attempts can also be noted through the inclusion of home-based HIV caregivers and early childhood development practitioners in its Extended Public Works Programme as a bridge to formal employment for informal or unpaid workers in 2004.

This is superficial 'recognition' as it is only geared towards ensuring payment of stipends to these workers. From these policies community health workers receive a stipend but do not become government employees but rather are employed through mostly civil society initiatives as explained above. Government in this model provides grants to CSOs who employ the care workers. It is therefore evident that the state has deliberately avoided absorbing caregivers into the civil service by choosing CSO led support system for caregivers. "*The result, however, is that NGOs are seen as little more than disbursers of stipends and the caregivers attached to them do not have the same employment rights as other health workers. The stipends paid to home-based caregivers under the Extended Public Work Programme are lower than those paid to men engaged in infrastructure development, essentially formalising the gendered stigmatisation of care work in the context of a government programme*."[21]

Numerous research studies confirm that the burden of care is borne on a voluntary basis by women and girls in private household and community settings, placing considerable added strain on already resource-limited and poor households. It is estimated that a staggering 90% of people with HIV/AIDS are cared for at home and 80% of HIV-related deaths occur in the home. Additional statistics from the most recent National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa, 2009 paint a devastating picture.

[21] Past due: Remuneration and social protection for caregivers in the context of HIV/AIDS – UK Consortium on AIDS and International development Policy Briefing March 2012 at http://aidsconsortium.org.uk/wp-content/uploads/2011/11/UK-AIDS-Consoritum-policy-briefing-remuneration-of-caregivers.pdf [Accessed 13 May 2013] page 11.

The severity of the situation cannot be overstated, and raises a range of complex questions such as:

- Who provides the care for the multitudes of children, women and men behind the statistics?

- How are these caregivers equipped to provide what is an essential service to poor communities where people cannot access private health care and, in many cases, are unable to access even the primary health care services provided by the State?

- What are care and support needs for the carers themselves?

- How are such caregiver needs being provided to such a marginalised and frequently “invisible” group?

- As many of these caregivers are community-based and working on a voluntary basis, how is their wellbeing ensured and how are their voices heard in the policy development process and political decision-making processes that affect them in the absence of a representative structure?

Here are some of the benefits of formal recognition of home –based care to the rights of women:

1. Recognition of the right to work of women

This right to work is entrenched in the Universal Declaration of Human Rights, Article 23 which states that *"everyone has the right to work."* Further Article 6(1) of the International Covenant on Economic, Social and Cultural Rights (ICESCR) states that State parties must "*recognize the right to work which includes the right of everyone to the opportunity to gain his living by work which he freely chooses or accepts."* South Africa has yet to ratify the ICESCR but this right to work has been entrenched in Section 22 of the Constitution which states that "*every citizen has the right to choose their trade, occupation or profession freely. The practice of a trade, occupation or profession may be regulated by law."*

The recognition and regulation of home based care effectively promotes the rights of women who provide this care without recognition. it emphasizes the right to choose their own occupation/profession. Further protects and respects their ability to make this choice thereby protects their dignity and equality as a profession and as women whose work is generally marginalized and undermined. Caregivers experience their work as a source of pride and personal satisfaction, an expression of their faith, their love of and commitment to their families, and their commitment to developing their communities. Therefore formal recognition of the contribution and the work done by caregivers is an important recognition of personal, social, and political value.

2. Financial Independence of women

As stated above most carers perform their function either on a voluntary basis or receive a stipend for the work they do. As mostly women perform this work essentially means that most women are therefore left with either a very limited source of income or none at all which places them in a state of perpetual poverty. Additionally, a number of carers also spend some money towards assistance they provide. These include transport to visit clients and buying supplies to aid their clients.[22]

The recognition of care work could among other things include regulation of minimum wages which ensures that women doing provide home based care are remunerated adequately and fairly. Additionally this would also support a development and sustainability of the livelihoods of women. Being remunerated would enable these women to live in dignity not only because their much needed contribution is recognized and supported, but also that they are given the recognition that enables them to access other rights.

3. Treatment of carers

Carers often report that they face discrimination and negative treatment from hospitals and clinics. Though there are other factors for this treatment, it is attributed to the fact that “many caregivers are very poor, often living with HIV

[22] Past due: Remuneration and social protection for caregivers in the context of HIV/AIDS – UK Consortium on AIDS and International development Policy Briefing March 2012 at http://aidsconsortium.org.uk/wp-content/uploads/2011/11/UK-AIDS-Consoritum-policy-briefing-remuneration-of-caregivers.pdf [Accessed 13 May 2013] page 6.

themselves, and representing key affected populations. Further, the low valuation of caregiving work by formal healthcare workers, and caregivers' constant exposure to illness, death, dying, and HIVstigma, leads to high levels of isolation, burnout, fatigue and a general decline in their health and wellbeing."[23]

With recognition comes a clear definition and elaboration of the roles that home-based carers can perform which could potentially improve the treatment and attitude towards this works by other health professionals.

VI. Conclusion

The participating organisations welcome the decision by the Special Rapporteur to submit a report on the issue of community care workers and the unpaid work that they do. As is clear from our submissions care workers in South Africa play a critical role in service delivery and in ensuring that the right to health care is enjoyed by the most marginalized in our communities. Theirs is a selfless profession that receives very little to no attention and as a result they frequently have their rights ignored while they are ensuring that others receive treatment and care in a dignified manner.

[23] Ibid page 6.

For further comments or queries please contact:

- For the Legal Resources Centre: Mandi Mudarikwa – mandy@lrc.org.za or Charlene May – charlene@lrc.org.za
- The Parent Centre: Milly Pekeur - milly@theparentcentre.org.za
- Wellness Foundation: Bernice Roeland - director@wellnessfoundation.org.za