



Anti Retroviral Treatment Support Programme for HIV/AIDS Children in the Eastern Cape, South Africa



Annual Report Period May 2010 to April 2011

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1) Project Overview:

The impact of HIV/AIDS on children in the Eastern Cape is large. At present the HIV/AIDS prevalence rate in the province is more than 26 %. Young women and women of childbearing age are the most infected. Most of these women do not come for voluntary counselling and testing and many children born to HIV positive women are becoming infected. These HIV infected children are not getting treatment early in their lives and are suffering and dying without adequate care, usually before the age of five. The Eastern Cape Provincial Department of Health have recently accredited 48 sites to roll-out anti-retroviral therapy but does not have an integrated service that provides prevention, treatment, support and care for these children and their mothers/caregivers.

Since 2004, One to One Children's Fund has been supporting such a program at Dora Nginza Hospital in Port Elizabeth and at Uitenhage Provincial Hospital in the remote and challenging Eastern Cape Province, with the successful collaboration of Port Elizabeth Hospital Service, and a local NGO, Small Projects Foundation (SPF). Now the sites have expanded to include Kareedouw and Kirkwood in the rural hinterland, and the rural districts of Port St John's (Isilimela Hospital, Tombo Community Health Centre and Port St John's Community Health Centre) and the Queenstown area.

In the last year there has been an increase in the patients treated in our hospitals from 1100 to 2,252, all being helped through the programme in conjunction with the Provincial Department of Health.

A key area in prevention is the need to get young and pregnant women to attend voluntary counselling and testing. This service allows mothers and their children and young women to be tested and referred directly for treatment without the fear of stigma, disclosure or discrimination. In this period, 15,474 pregnant women were tested for HIV and 2,559 were identified as HIV positive. These women were helped to take measures to prevent transmission; 2540 were given AZT (an HIV prophylactic) before labour.

One to One Children's Fund is running the ART Support Programme through the provision of two project coordinators: Sister Nonkosi Ndalasi and Sister Hlubikazi Skaap, and a nurse/counsellor in each hospital, with outreach vehicles, to monitor the children and their families within their communities.

Sister Skaap has recently taken over for Cheeky Zinto, who retired this year. She is a retired professional nurse and works hand in hand with the social workers, traces defaulters, and counsels. She works in the community and does a great deal of testing, as well as follow up with defaulters and children who have transferred to other clinics.

Sister Nonkosi Ndalasi has been promoted to co-ordinator and paediatric mentor ARV support roll-out at Uitenhage, Dora Nginza and the newer sites. She overviews all of the sites and has become an indispensable element of the Port Elizabeth Hospital service, also mentoring medical staff at Uitenhage and Dora Nginza Hospitals. She also coordinates the outreach service, provides training to Expert Patient Volunteers (EPV's) and lay counsellors, oversees the gardening and nutrition initiatives and networks with other organisations.

Support groups are organised to follow up on ART patients, build patients' morale and ensure adherence to the ART pill-taking regimen. Defaulter tracing and support has resulted in a zero

percentage of patients lost to follow up and only an 8 percent mortality rate of children. Gardening and nutrition have been improved through provision of food for children and training children and caregivers in gardening.

Life-saving Anti Retroviral drugs are now funded by the provincial government of the Eastern Cape, but hospitals remain largely under-resourced and the shortage of medical staff represents a crucial challenge to provide essential care for HIV infected children and mothers in this rural area. To alleviate this shortage of professional staff, One to One Children's Fund took the initiative to recruit and train EPV's.

One to One Children's Fund, in collaboration with SPF, specifically decided to address the problem of malnutrition in the Eastern Cape Province. With this in mind, we included the provision of small plots of land, gardening kits and kits to help families grow their own food.

Our key focus is combating HIV/AIDS and developing skills, resources and systems of poor communities to do this in a sustainable manner. A key part of the programme is to mobilize and build competence of children, caregivers (mothers/grandmothers), community volunteers, health professionals and paediatric wellness clinic teams to effectively combat disease.

The programme developed a network of community based volunteers who carry out home visits, assist in PMTCT and refer patients to the clinics, as well as provide counselling and support. The programme is developing by reaching out into the communities on a larger scale to identify, refer and treat many more children.

The key elements of this programme are intrinsically linked. The work of the outreach nurse to the tracking and ongoing adherence counselling, training for Counsellors and EPVs in conjunction with the SPF as well as the provision of vegetable plots and seeds, food growing capability and nutrition training, and the provision of children's food supplements.

2) Gardening project:

The gardening initiative encourages people to be self-sufficient, enabling families to generate an income by selling the vegetables they grow and boosting the intake of vitamins for children. Counsellors, nurses, EPVs and community health workers are actively involved in this project.

The project consists of growing community gardens, training children and their caregivers, and distributing seedlings and gardening kits to enable them to grow their own vegetables.

Roughly fifty bags of different seed crops are distributed per month (each bag carries about five hundred seedlings) to all caregivers of Paediatric ARV patients.

As part of the One to One Children's Fund ART Support Programme, SPF have previously trained 300 children and 20 adults to create and maintain their own gardens. A further 50 caregivers were trained as trainers to further promote this project. During this year in Port Elizabeth and Uitenhage, 152 new gardens have been created, and 138 already-established gardens were visited on follow-up.

Sister Nonkosi Ndalasi received gardening training from South African Institute for Entrepreneurship (SAIE) and now trains children, caregivers, and community volunteers in taking care of the community gardens. Already, children's square metre gardens in the community are expanding to others areas in the Nelson Mandela bay and adults have mobilised against poverty by growing their own gardens.

The gardening project has been instituted in hospitals: Dora Nginza Hospital & Uitenhage Hospital, the Orsmond TB Hospital in Uitenhage, and St Barnabas VCT community based center have established food gardens. In Kareedow and Kirkwood, 28 gardens have been established and 136 gardens became operational in the last 12 months.

Gardens are being added in other areas of the community also. There are, for example, gardens at Mzamomhle Special School, community gardens in Nelson Mandela Bay, and the gardens from the Siwa Street Gardening project. In this project, 25 children were trained to grow their own gardens in 2006 and continue through the present to engage themselves in gardening. They trained and are the mentors of 107 children in their communities and are making a positive impact in the lives of their communities. There are many other people that have asked to be trained in the development of small gardens, and Sister Nonkosi Ndalasi is organizing their training.

Food supplements are also being distributed to the more severely malnourished children of the region by dieticians in the hospitals and local charities are providing food parcels to some HIV infected children and their families.

It should be noted that the roll-out of the garden project, although going well, is hindered by the water restrictions that are in effect across the Eastern Cape.

3) Expert Patient Volunteers

Expert Patient Volunteers are HIV positive mothers trained to provide improved care and support to children in clinics and to teach and support peer caregivers in the community to meet the medical, physical, emotional and psychosocial needs of the children.

There are nine Expert Patient Volunteers in total. Three at Dora Nginza Hospital, and three at Uitenhage Hospital, and three in the Port St John's area.

The third EPV at Uitenhage was recruited in this period to lighten the load, as one of the EPV's was doing double the work- working in the community and in the clinic. The new Expert Patient has attended a training in East London with a group of counsellors and says that she now feels able to educate her clients on disclosure, both in and out of the clinic.

EPV's receive a salary of 500 ZAR per month (GBP 32) for their service to children and their families, which represents a valuable income for families in this impoverished province of South Africa.

Also, a new reporting template has recently been introduced to the Expert Patient Programme, which is much less challenging for the Nursing Sisters who act as Expert Patient Supervisors.

Their work:

The EPV's assist with various activities including routine tasks (such as weighing and scaling the child, counting pills, child care and play therapy), health talks, adherence counseling, tracking defaulters, home visits and door to door campaigns. The role also includes encouraging Voluntary Counselling and Testing to care givers, and marketing the ART Clinics in the community.

Their training:

The EPVs have been trained in the following courses:

- Training Adherence Counselling (5 days)
- HIV/AIDS management (5 days)

- TB Management (5 days)

In the current year, they will be trained in the following courses:

- Voluntary counseling and testing (10 days)
- Prevention of Mother to Child Transmission (5 days)
- Square meter gardening and nutrition

Training workshops are organized with our local partner SPF, in collaboration with the Foundation for Professional Development (FPD). Training seminars are organized on a regular basis for new recruits and more experienced volunteers. The EPV's were also involved in all the In-service trainings in the Paediatric Wellness clinic such as the gardening training received from Sister Nonkosi.

Three of the the former EPVs have been promoted to Lay Counsellors and have been replaced by new EPV's. This demonstrates that the One to One Children's Fund programme is contributing to building capacity of hospitals in the Eastern Cape by training EPV's who are capable of becoming competent non-medical staff to care for HIV infected children in the region.

4) Training and mentorship of Volunteers and Community Health Workers :

Volunteers:

57 Community Health Workers in the Port St Johns Area have been trained in a variety of areas, including:

- VCT (10 days)
- PMTCT (5 days)
- TB (3 days) Participatory learning and action workshops (2 days x 10)
- Place survey – dealing with community mobilisation, peer education and advocacy (12 days)

As well as this, the 9 Expert Patient Volunteers and the Community Health Workers were also given HIV training with an emphasis on STI's.

Furthermore, training in paediatric care treatment and psychosocial support training were given. The Treatment teams who were trained, comprised of:

- Isilimela – Dr Goudswaard, Sister Gilbert, Mr Nkwalase (pharmacist), Ms N Madywadi (lay counsellor)
- Tombo CHC – Dr Ajayi, Sister Sodo, Ms Makhente (pharmacist assistant), Ms K Mngqolo (lay counsellor)
- Port St Johns CHC – Dr Mahlakhata, Sister Luhadi, Mrs C Macmimm (pharmacist), Ms V Stokisi (lay counsellor) (is this too much information?)

Co-ordinator: Mrs Xinwa – SPF coordinator

These treatment teams were trained over two days to treat and care for Paediatric HIV/AIDS.

In Uitenhage, the team trained in paediatric care and psychosocial support consists of:

- Sister Elm Zyatye,
- Ms C Davis (pharmacist)
- Ms N Cholani (EPV)
- Ms N Qongo (coordinator SPF)
- Mrs N Ndalasi (regional coordinator SPF). (is this too much information?)

In Dora Nginza, the team trained in paediatric care and psychosocial support consists of:

- Dr Mabandla
- Sister N Tyoba
- Mr M Maqungo
- Ms P Zantsi (EPV)
- Mrs H Skaap (coordinator SPF) (is this too much information?)

In Uitenhage, 30 community health workers carried out 6 months of training earning 51 credits towards ancillary health care level 1. This training was also carried out in Dora Nginza for 25 community health workers. Furthermore, the EPV's in both areas were given training on VCT, PMTCT and ART and nutrition.

Each training module (1-2 weeks) is followed by practical application of new skills in the community under supervision of clinic medical staff.

The Small Projects Foundation (SPF) trains and mentors them as part of the One to One ART support programme in the townships surrounding Port Elizabeth. The One to One programme includes 24 volunteers under the direct supervision of Sister Nonkosi Ndalasi, Head of the One to One ART support programme at Dora Nginza Hospital. Volunteers are trained in a number of accredited modules which are then applied directly in their work in the community. SPF also provides training to their community based organization in management, administration, and operating.

Volunteers will over time accumulate enough credits (from these assessed skills training modules) to qualify for a nationally recognized qualification as Ancillary Health Care Worker Level 1.

Community Health Workers:

A total of 120 community health workers have been intensively trained in accredited courses to provide outreach support and care in the communities served.

The training incorporates the following courses:

- Gardening and nutrition
- VCT and PMTCT
- Home-based care
- TB/DOTS
- Adherence, counseling and tracing
- Peer Education
- Expert Patient and support group training

These care workers now provide a continuum of care for families living with HIV and TB in three townships in Port Elizabeth and one township in Uitenhage.

5) Monitoring of activities and outcomes

It is the policy of One to One Children's Fund to closely monitor and evaluate all its projects, and SPF and coordinator Sister Nonkosi Ndalasi sends monthly reports to update One to One Children's Fund in the UK. Project partners are in regular contact to discuss the progress made and next steps to be taken by the project team. A representative of One to One Children's Fund UK visits the project at least twice a year.

6) Development of an Adolescent Centre

It was discovered that when children are moved from the paediatric ward to the adult ward they feel misplaced due to the environment change and become withdrawn. In December 2010, David Altschuler, Jenny Altschuler and Mr Mpilo Fata, met to discuss the development of an adolescent programme. This programme is currently being established by the management at Dora Nginza Hospital and some adolescents have already been transferred out of the paediatric clinic. In the last meeting that we had it was suggested that the unused former VCT centre situated at St Barnabas Kwazakhele, which would help reach out to the adolescents who are already in local facilities.

The Community Liaison Officer employed by the Department of Health is wholly involved in the creation of this programme. Ora Nel, a psychologist working with the Smile Madiba Bay Centre where psychological and spiritual services are offered, is willing to render her services gratis . This centre is not far from Port Elizabeth Provincial Hospital, so it is easily accessible to adolescents.

This roll-out programme will further develop the capacity of the Department of Health to undertake the care of HIV infected children and their families in all hospitals across the Eastern Cape Province within the next few years. Sustainability will be achieved through the training and support of hospital staff and volunteers, the information provided to children, adolescents and adults on HIV/AIDS related issues and interventions of community volunteers- all of which contribute to reducing the stigma around infected patients and to improving patients' morale.