

**A NATIONAL AUDIT OF LOCAL-LEVEL  
DATABASES ON ORPHANS AND  
VULNERABLE CHILDREN IN SOUTH  
AFRICA**

**RESEARCHED FOR**

**UNITED NATIONS CHILDREN'S FUND  
(UNICEF)**

**BY THE**

**COMMUNITY AGENCY FOR SOCIAL ENQUIRY**

**FINAL REPORT JUNE 2006**



**social development**

Department:  
Social Development  
REPUBLIC OF SOUTH AFRICA



**Published by:** The Community Agency for Social Enquiry (C A S E)

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2017

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## ACRONYMS

|        |  |
|--------|--|
| ART    | Anti-retroviral treatment  |
| ARV    | Anti-retroviral drug   |
| CBO    | Community Based Organisation   |
| CCCC   | Cluster Child Care Coordinators  |
| CHoiCe | Comprehensive Health Care Trust  |
| CINDI  | Children In Distress   |
| CSG    | Child Support Grant  |
| DCI    | Development Cooperation Ireland  |
| DOE    | Department of Education  |
| DOH    | Department of Health   |
| DSD    | Department of Social Development   |
| FCG    | Foster Care Grant  |
| HCBC   | Home and Community Based Care  |
| HSRC   | Human Sciences and Research Council  |
| JEAPP  | Joint Economic AIDS and Poverty Programme  |
| IOC    | Ingwavuma Orphan Care  |
| IPS    | Izingolweni Primary School   |
| MIET   | Media in Education Trust   |
| MSF    | Medicins Sans Frontieres   |
| NACCA  | National Action and Coordination Committee for Children affected by HIV and AIDS   |
| NACCW  | National Association of Child Care Workers   |
| NDA    | National Development Agency  |
| NGO    | Non-governmental Organisation  |
| NHLS   | National Health Laboratory Service   |
| NMCF   | Nelson Mandela Children's Fund   |
| NPO    | Non-profit Organisation  |
| OVC    | Orphans and Vulnerable Children  |
| PACCA  | Provincial Action and Coordinating Committee for children affected by HIV and AIDS |
| PEPFAR | President's Emergency Plan For AIDS Relief   |
| PMTCT  | Prevention of Mother to Child Transmission   |
| RNE    | Royal Netherlands Embassy  |
| SANAC  | South African National AIDS Council  |
| SBC    | School Based Carers  |
| SDC    | Swiss Agency for Development Cooperation   |
| SST    | School Support Team  |
| UCT    | University of Cape Town  |
| UNICEF | United Nations Children's Fund   |
| VCT    | Voluntary Counselling and Testing  |

**WHO**      **World Health Organisation**



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# INTRODUCTION

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Reports on orphans and children made vulnerable by HIV and AIDS reveal that Sub-Saharan Africa has the greatest proportion of children orphaned in the world. Of the 16 million orphaned worldwide in 2003, 5.2 million were from sub-Saharan Africa. In 2003, an estimated 13% of all children between 0 and 17 years were orphans. Of all orphans, 48% were reported by UNAIDS to be HIV and AIDS orphans (UNAIDS, 2003). However, in South Africa, the Human Sciences and Research Council (HSRC) wrote about the difficulty in estimating the percentage of orphans who have lost parents to AIDS because information on the cause of death of parents is scarce (Brookes et al, 2004).

More recent reports from the AIDS Foundation South Africa note that in 2004, 2.2 million children were orphaned in South Africa. Over half of these orphans lost parents to AIDS-related illnesses (AIDS Foundation South Africa, 2005). In addition, the fathers of a significant number of South African children are unknown or have lost contact with the children and so are in effect orphaned when their mothers die. Despite the difficulty in estimating the proportion of AIDS orphans among all orphans, what is certain is that the number of children orphaned by HIV and AIDS will continue to rise for the next decade.

The Department of Social Development has taken note of the plight of children affected by HIV and AIDS. In response, they have developed guidelines for social services to children infected and affected by HIV and AIDS. These services include: early identification of children and families in need and linking families and caregivers to poverty alleviation programmes and services in the community. To do this, a method of maintaining data on orphans and other children made vulnerable by HIV and AIDS is needed.

National guidelines for social services to children infected and affected by HIV and AIDS indicate that making use of forms to capture necessary data is essential. Example formats of four forms are provided. The first intake form would have variables such as name of the client, family details that would reflect address, occupation of parent or caregiver, date of birth, date of death, and names of both parents. The second form would focus directly on the child, including variables such as name, date of birth, sex, school, grade and address of the child. Also captured in this form is information on relatives within the child's household namely: HIV-positive persons, family income and housing specifications. The third and fourth forms serve as referral forms. The third identifies placement options for children if necessary and the fourth referrals to other service providers (Department of Social Development). It is not clear whether the department has conducted any assessment of how widely these forms are used.

In the national action plan for orphans and other children made vulnerable by HIV and AIDS for 2006 to 2008, six strategic priorities are laid out. The rationale behind the plan was to identify the roles that various stakeholders would play in addressing the social impact of HIV and AIDS. The second strategy stresses the necessity to mobilise and strengthen community-based responses for the care, support and protection of orphans and vulnerable children. More importantly, the plan identifies the need to establish and maintain a database of services at local level. This would result in a comprehensive directory of services available to OVC at community level. It is hoped that the directory of services will lead to increased community knowledge and the use of available sources. The time frame set for the establishment of this database was November 2006 (Department of Social Development, 2005).

The third strategy includes developing and maintaining a coordinated national database that supports the implementation of policies, strategies and programmes for OVC. The plan states that a directory of OVCs at local level would be needed for this purpose. The action plan identifies partners that would implement this system as being the Departments of Social Development, Health, and Education. Also involved would be partners in the business sector, development agencies, Statistics South Africa and other partners (Department of Social Development, 2005). A number of organisations are presently working on this task in a task team known as the National Action and Coordination Team for children affected by HIV and AIDS. These include Joint Economic AIDS and Poverty Programme (JEAPP), Save the Children, Nelson Mandela Children's Fund and UNICEF.

About five years ago Save the Children (UK), on behalf of the National AIDS and Children Task Team, commissioned the Children's Institute at the University of Cape Town to compile a database of organisations providing HIV-related services. This was duly done. A publication was produced (Children's Institute, 2001) containing the details of close on 1 000 organisations and the computerised database was placed on a website ([www.childaidservices.org](http://www.childaidservices.org)).

In late 2005, the Community Agency for Social Enquiry (C A S E) was contracted by UNICEF to conduct a national data audit on orphans and vulnerable children (OVCs). The audit was intended to inform the process of developing a system to identify, record and track OVCs in the country. The specific objectives of the study were:

- To determine ways in which data are collected by a sample of local organisations and institutions, the type of data collected and the format in which it is collected;
- To make recommendations on how data can be used at local level to track children and ensure that they receive the essential care and support services;
- To make recommendations on how data collection and processing can be improved.

C A S E conducted this study between December 2005 and February 2006. The rest of the report describes the methodology, the individual case studies selected, overall trends and

learnings and recommendations for the improvement of data collection and management and use of data to enhance services provided to OVC.

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# METHODOLOGY

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C A S E approached the task in six phases detailed as follows:

The first phase involved developing a list of organisations/institutions that deal with orphans and vulnerable children across the country. To do this, C A S E contacted a broad range of stakeholders including representatives of the National Action and Coordination Committee for Children Affected by HIV and AIDS (NACCA), Soul City, National Association of Child Care Workers (NACCW), local municipalities, South African National AIDS Council (SANAC), Children's Sector Network, Children's Institute, Red Cross Children's Hospital and individuals knowledgeable about services in relation to children. Informants were asked to recommend organisations at the local level which were keeping databases of children affected by HIV and AIDS. To assist in the identification of such organisations, C A S E also referred to previous work done related to the subject, including a national study of home and community based care projects and a HCBC audit that is currently being conducted by Umhlaba Development Services.

The second phase involved developing a sample of organisations/institutions to be included as case studies. The information derived from the first phase was useful in identifying organisations and individuals working with OVC and particularly those that have established databases to record and monitor the children that they support. The suggested organisations were then followed up telephonically to establish (a) whether they had OVC databases and (b) whether they were interested in taking part in the study. The sampling strategy was purposive and, in line with the terms of reference (TORs) developed for the study, we ensured that the categories of health centres, municipalities, schools, NGO/CBOs, ECD centres and HCBC organisations were represented, and that there was at least one case study in each province. Further, we attempted to have some representation of rural sites. The following table reflects the final sample of organisations that took part in the study.

| Province      | Name of organisation              | Type of organisation | Rural/Urban |
|---------------|-----------------------------------|----------------------|-------------|
| Eastern Cape  | Isibindi                          | NGO                  | Rural       |
| Free State    | Dihlabeng Development Initiative  | NGO consortium       | Urban       |
| Gauteng       | Friends for Life                  | NGO                  | Urban       |
| KwaZulu-Natal | Ingwavuma Orphan Care             | NGO                  | Rural       |
| KwaZulu-Natal | Msunduzi                          | Local government     | Urban       |
| KwaZulu-Natal | Siyabona Trust                    | NGO                  | Rural       |
| KwaZulu-Natal | Media In Education Trust          | NGO                  | Rural       |
| Limpopo       | Choice Health Care Trust          | NGO                  | Rural       |
| Mpumalanga    | Amazing Grace                     | Shelter              | Urban       |
| Northern Cape | Age in Action                     | NGO                  | Urban       |
| North West    | Ntutubolle Creche                 | ECD                  | Rural       |
| Western Cape  | Western Cape Department of Health | Health centre        | Urban       |

#### Organisations sampled for the national OVC data audit

The third phase was the development of the audit tool. We developed a semi-structured instrument that broadly addressed background information about the organisation, history of the database, technical issues such as how information is stored and what variables are listed, maintenance issues, access to information including confidentiality issues and a general assessment of the database and its usefulness to the organisation. The instrument is attached as an appendix to this report.

The fourth phase of the study was the piloting of the tool. This phase took place in December 2005. It was originally intended to be conducted at two sites. However, this was not achieved mainly because of the difficulty of establishing contact with the relevant people during the festive season. Only one pilot was completed, with Friends for Life in Alexandra, Johannesburg. The aim of the pilot was to test the audit tool to see that it yielded the information required and that questions were understandable for informants. The pilot exercise was useful in that it confirmed the appropriateness of all the questions we were asking and brought out the need to identify the right people to speak to in the organisation beforehand to ensure that all the relevant information is provided during the interview. It also sensitised the researchers on the need to respect the organisation's policies around confidentiality of the information.

The fifth phase of the study was the data collection in the remaining sites. This took place in January and the beginning of February 2006. A researcher from C A S E visited each site and spent a few hours interviewing the relevant people in the organisation who are knowledgeable about their database. In most cases, these were the directors of the organisation and programme managers.

The sixth step involved writing up the interview and case study descriptions as well as analysing the data and drawing out overall trends and learnings and providing recommendations on how the data can be used at local level to monitor OVCs and for the improvement of data collection and maintenance in this regard.

The rest of the report presents this sixth phase in more detail. It provides a description of each of the 12 case studies and then discusses the overall trends and learnings achieved from the study. It ends off with some recommendations for future data collection and tracking of OVCs.

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# CASE STUDIES

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## EASTERN CAPE: ISIBINDI CREATING CIRCLES OF SUPPORT

### Background

The Isibindi Creating Circles of Support project of the National Association of Child Care Workers (NACCW) constituted the Eastern Cape case study in that the study focused on the King Williams Town-based site of the Isibindi project. Information was obtained from national staff of NACCW, as well as staff of the King Williams Town Child and Youth Care Centre through which NACCW works. The former included the staff responsible for data capture. The latter informants included 16 child care workers who were interviewed via speakerphone during a team review meeting.

NACCW is a national association with a presence in all nine provinces, and offices in Cape Town, Durban and Johannesburg. The Isibindi project is coordinated from Durban and operates in five provinces – Eastern Cape, KwaZulu-Natal, Limpopo, Northern Cape and Western Cape. The very first project was initiated in Umbumbulu in KwaZulu-Natal and in 2005 the Umbumbulu Isibindi Project won the Impumelelo Award which rewards innovation in government and public-private partnerships that reduce poverty and address key developmental issues of national concern. The Child and Youth Care Centre which was the focus of the case study operates in King Williams Town and surrounding villages, and does not have other branches. Both NACCW and the Child and Youth Care Centre are NGOs.

The Centre runs a number of programmes, including residential care, life skills training and awareness raising and care of orphans and vulnerable children (OVCs). Isibindi's staff includes 60 child and youth care workers at its residential facility, and five staff for the life skills centre. In addition, there are 16 child care workers, a project manager, a project coordinator and two child care worker supervisors working on the Isibindi project. NACCW has a nine-member team which manages the project from Durban. The project mentor is responsible for liaison with the King Williams Town centre.

The objectives of the Isibindi project are to deliver child and youth care services, promote the rights of children, and facilitate access to state benefits and services. Activities include visiting families, advocacy for children to access services such as grants and schooling, home and community based care for children, provision of psychosocial support, and emergency support. The focus is on vulnerable children, namely orphans, ill children, those whose parents have died, those living with elderly care givers, homeless or street children, young adults caring for children, and abused children.

NACCW receives funding from a wide range of sources – the US government’s Presidents Emergency Plan for AIDS Relief (PEPFAR), Nelson Mandela Children’s Fund, Royal Netherlands Embassy, Anglo American Chairman’s fund, De Beers Fund, First Rand Foundation, DG Murray Trust, Ernest Oppenheimer Trust, Swedish International Development Cooperation, and Momentum Fund.

### **History of the database**

The Isibindi project started in 2003 in KwaZulu-Natal and the King Williams Town project was launched in August 2005. The database was set up in 2003 after an external evaluation found that NACCW needed a more effective data management system to monitor progress and report to donors, for accountability and performance management of staff, and to ensure that children were being assisted. The records in the database represent children. A significant proportion, and specifically the orphans, children in child-headed households, and those living with aged caregivers, represent children affected by HIV and AIDS.

NACCW set up the paper database and formats in line with the database reporting system that is required for all PEPFAR-funded projects. PEPFAR provided training on monitoring and evaluation (M&E) and the use of the electronic system.

### **Technical issues**

Details of children are written onto paper forms given to child care workers. There is one composite summary form for each site recording details of children at that site. Summary statistical data on each site are then captured on the computer at the Durban office. Informants could not say which computer programme has been used for the computer database as it had been supplied by PEPFAR.

The paper forms record name, age, sex, presence of adults in home, identity details, HIV status of child and parents in respect of each child and also services provided and action taken by the child care workers. Informants felt that all variables were useful, but reported that information on the HIV and AIDS status and identity details of parents and children were often difficult to obtain. The forms have been modified over time as PEPFAR’s reporting requirements have become more stringent and the Fund has required additional information. At the time of the interview, the Isibindi database contained 1 090 records of children nationally, and 184 for the King Williams Town centre.

All NACCW courses include a component on confidentiality and ethics and a code of conduct for staff. Confidentiality is preserved in respect of the database by excluding all identifying details from the information provided to PEPFAR. Only the records kept by the child care workers have this level of detail.

The computer programme generates reports on a quarterly basis. It provides a breakdown per site of the number of children being serviced. The annual report is 23 pages long and includes sections for prevention work, treatment work, OVC care work, among others. The report is standard for all PEPFAR sites and not all the 23 pages have information in the case of NACCW as NACCW is not involved in all these areas. The care section, which is most relevant for NACCW, includes the number of OVCs receiving education, economic, food, health care, legal, and psycho-social report, as well as the number protected from abuse.

### **Maintenance of the database**

Child care workers collect the information for the database during weekly home and community visits. Information is collected both for first contact and for all subsequent contacts. The information for a particular child is updated on the database a quarterly basis. The relevant record is deleted if a child dies.

The Durban administrator is responsible for inputting the information into the electronic database. The task takes approximately three hours per month. Two other people in NACCW also know how to input the information. While there is no manual for the database, there is a M&E plan for capturing data that emerged out of PEPFAR training. The project manager and two other staff know how to extract information from the database. NACCW makes both paper and electronic backup of the database and they report quarterly to PEPFAR.

### **Access to information**

Within the King Williams Town centre there is strict control over the files. A child care worker cannot make an entry into the file unless the project coordinator gives her access and adds her own report. This is to ensure that no records get lost or get tampered with in any way. From outside the organisation, PEPFAR has access to the electronic information. NACCW also provides information generated by the database to other donors on a regular basis. It is only statistical data that are shared, rather than individual details, and there is therefore no issue about confidentiality.

NACCW would not be prepared to make the database available to others unless it was clear how it could benefit the child and why the information was required. NACCW does not get database information on children affected by HIV and AIDS from any other organisations or institutions.

### **General assessment**

In the interviews, different informants explained how the database was useful for their particular role. Child care workers said that it provided the basis for their performance assessment and helped them do their work. Supervisors said the database enabled them to follow up on progress made by the child care workers and review whether the actions taken were appropriate. NACCW said the database facilitated impact assessment and cost-benefit

analysis, helped them comply with donor reporting requirements, and informed their advocacy work.

On the negative side, child care workers said that they had a large numbers of forms to complete and narrative reports to submit. NACCW noted that donor expectations that the organisation would keep micro-level detail of interventions with children imposed a burden. For example, the forms required information not only on how many children were assisted through a particular type of intervention, but whether they were male or female.

In response to a question as to what advice they would offer to other organisations contemplating setting up a database, informants said that one needed to ensure that there was a good reporting format and a formal supervision system to monitor the quality of the work. Staff first need to be trained in M&E and develop a plan before implementing a database so that they are clear as to why they are recording the data.

## **FREE STATE: DIHLABENG DEVELOPMENT INITIATIVE**

### **Background**

Dihlabeng Development Initiative is a consortium of 15 organisations working in the HIV and AIDS fields in Bethlehem, Free State. The consortium oversees work done by member organisations in three clusters (home-based care, OVC and HIV and AIDS awareness). The consortium also coordinates funding by submitting applications on behalf of member organisations to the Departments of Health (DOH) and Social Development (DSD) and also receives and distributes funding to organisations. The consortium provides capacity building in terms of project management and offers training of trainers for its members.

Services provided by the OVC cluster involve care and support to orphans and vulnerable children. Orphans are defined as children who have lost both parents. If one parent is dead and the other parent is unknown, an affidavit is required from the police as proof of this to avoid false claims of orphanhood. Vulnerable children are considered to be those who are infected by AIDS, children whose parents are sick and children from poor backgrounds. The consortium was unable to approximate the proportion of services focused on children but the main focus of the consortium's activities is on HCBC. The consortium is funded by DOH (approximately 60%) and DSD (approximately 40%).

The consortium employs five full-time staff including three administrative staff, a coordinator and a director. A total of 90 volunteers work for the organisations in this consortium. They have an additional three volunteers known as liaison officers who head each the three clusters. The volunteers receive stipends from DSD and DOH.

## History of the database

The consortium has 3 databases – one for OVCs, another one for HCBC patients and a third one for volunteers. The OVC database was set up in 2003 while the HCBC one was set up in 2002. The first database was set up in 2002 in order to keep proper records and statistics of their beneficiaries. For the OVC database, the number of OVCs identified by the member organisations was growing but they realised that only a small proportion of them were receiving grants. The motivation for this database was to keep records of children who are not receiving grants and follow up with DSD on their behalf. The way the system operates is that the volunteers from the different organisations have to fill in forms for the OVCs and HCBC patients under their care and the consortium then keeps records of all the beneficiaries.

Each child receiving support from member organisations is listed on the database. There are 300 children on the consortium's database of OVCs at present. All member organisations have similar databases. The database covers the entire municipality. Computers and floppy disks were required for the database but the organisation already had these when they started. The consortium uses the database for reporting and evaluating what they have done at the end of the year, for example how many children have been assisted with grant applications in a given year. The consortium also uses it to push the DSD to give feedback to applicants on the status of their applications for grants. The consortium provides the records of all outstanding grant applications to the DSD from its database.

## Technical issues

The electronic database is stored in MS Word and only lists basic information such as surname of child, first name, date of birth and physical address. The forms that the volunteers use to collect the information have more information. Background information such as area, organisation, address, telephone and fax, caregiver's name, month of the report and submission date are listed at the top of the form. Variables linked to the specific child include: name and surname, address, name of guardian, ID number of guardian, name of school, clinic card, baptism, birth certificate, ID number of child, how each child was identified (school, clinic, home-based care, self referral). These forms are filled in monthly by the volunteers. The forms also have the following at the bottom which must be filled in every month: number of children receiving/not receiving grants, number of children without necessary documents such as birth certificates, number of children who have not registered/applied for grants. This information is disaggregated by age and sex.

All of the above information is useful for the follow-up of grant applications. The information on clinic card and baptism card is useful because these can be used to apply for birth certificates where these are missing.

## **Maintenance of the database**

Volunteers collect the information for the organisation during monthly home visits. When children are identified as OVCs, the volunteers visit them and record the information for the first time on the form. Records are deleted when children move away, when they get to the age of 18 or when they die. The consortium would in future like to have a separate database of the deleted entries for follow-up purposes where necessary.

Five people in the organisation know how to input information. These include three liaison officers, the director and a coordinator. The database is saved on stiffy disks each time it is updated. Very little time is spent specifically on the database because the electronic database is only updated when new beneficiaries are listed or when old entries are deleted.

## **Access to the information**

Within the organisation, everyone except the volunteers has access to the information. Outside the organisation, funders and auditors get reports that are compiled using the database. The organisation provides information from its database to the DOH and DSD and to member organisations. The organisation would be prepared to share the database with others provided that the information on HIV status is withheld. They feel that it would be helpful to share information with other organisations to avoid duplication of services which happens very frequently particularly with HCBC patients. Clinics and other organisations refer children but other than that no database information is received from any other organisation or institution.

In addition to its own database, Dihlabeng provides information to the Free State Provincial Department of Social Development using a form that the caregivers must fill in and send back to them reporting on child-headed households. The units in this form represent households. The background details of the children including names and sex of each child in the household, age of eldest child, age of youngest child and school information are required. The second section is the actual report which asks the following:

- How was the child-headed household identified?
- Are any services rendered to this household currently?
- If yes, which organisation is rendering the service and what is the nature of the service?
- Comments and observations regarding the family
- Name of person who lodged the report
- Organisation contact details (telephone, address)

## General assessment

Dihlabeng's database is useful in assessing progress with grant applications. The database statistics can be used as a performance indicator. The database also assists in the preparation of reports to funders as well as in the application for funds for member organisations. The consortium has not had problems specifically on the database but has encountered problems with organisations fighting over beneficiaries and with relatives of OVCs withholding documents or giving false information about receiving grants. The organisation also feels that the number of volunteers they currently have is insufficient to cope with the demand for HCBC and OVC support in the area.

The consortium recommends that any organisation wanting to implement a database must have proper back-ups and keep manual printouts to prevent any loss of data. In addition, the hard copies can be used when there is no electricity or when the computer crashes. They should try and categorise their data, for example, those who have applied but not received grants and those who have reached the age of 18 but still require support.

The director is keen to learn from other organisations that have databases on OVCs. He feels that children above 18 need further support and would like the database to follow up on them. The only concern is that most funders do not fund children above 18. The consortium would like to improve their paper-based database of volunteers further by giving them reference numbers instead of names and possibly do the same with the other databases in future. This will make filing and searching for information easier. The consortium would like to extend its database and its services to communities on the farms but is limited by shortage of funds.

## GAUTENG: FRIENDS FOR LIFE

### Background

Friends for Life is a non-governmental organisation situated in the Alexandra township in Johannesburg. The organisation was established in 1991 to provide care and support to people living with HIV and AIDS. Friends for Life runs several programmes which include counselling, home-based care and support groups for people living with AIDS. Other activities include an income-generating project, HIV and AIDS training and indigent burial assistance. The support of orphans and vulnerable children (OVC) is an integral component of the organisation's work.

Although it was not possible to establish what proportion of services is focused on children, OVC support together with home and community-based care (HCBC) is the main focus. OVC support includes assistance with food parcels and clothing, HIV testing, pre- and post-test counselling, life skills training, provision of school uniforms, negotiating fee exemptions and

assisting with access to social services such as social grants and medical assistance. They also run a toy library where children can borrow toys for a specific period at a minimum cost. Other than assistance with basic needs like food and clothing, the organisation has recently started offering help with social events. For example, they arrange for traditional ceremonies such as cleansing and circumcision and matric dances for the orphans. This is done in an effort to curb stigma and to try to ensure that the children they are supporting continue living the life they were accustomed to when their parent/s were alive.

The categories of children served include child-headed households, HIV-positive children, orphans and vulnerable children. Friends for Life currently have over 300 orphans and 15 child-headed households in its database. Orphans are defined as children who have lost both parents while vulnerable children are considered to be those whose parents are terminally ill.

Approximately half of the funding comes from Development Cooperation Ireland (DCI). The rest of the organisation's funding is obtained from the Departments of Health and Social Development and private donors. The organisation employs close to 40 staff members including 25 volunteers, 6 programme coordinators and 5 administrative and management staff. There are two branches in KwaZulu-Natal and there are plans to expand to the Eastern Cape.

### **History of the database**

The database for orphans and vulnerable children was set up in 2001 to keep track of orphans supported by the organisation. The database was set up to keep records of numbers as well as to record the needs of the children. Previously the organisation had a manual file on each child. The storage of files was not very systematic and searching for information/files was very cumbersome and time-consuming. The manual system was upgraded to OptiPlan and this together with the electronic system enhanced efficiency of record keeping and tracking. The director together with the City of Johannesburg Region 3 officials set up the database. The Irish Embassy funded the database including general capacity building, including IT support and training, by the British International Organisation for Development.

### **Technical issues**

The database is predominantly a paper-based OptiPlan recording and filing system. There is a hard copy file for each beneficiary. The filing is organised around colour schemes according to the different programmes (orphan care, counselling, home-based care and support groups). This makes it easy for storage and retrieval and for the programme coordinators and volunteers to identify their files from the cover.

The electronic database is stored in MS Word and Excel programmes. The electronic database is essentially a list of children served by the organisation. The units in the electronic database represent individual children. They are identified by name and grouped into numbered

categories representing the various groups of children that the organisation caters for. There are 6 categories which represent the following: child-headed households, HIV-positive children, occasional clients, children whose parents are alive but chronically ill, orphans with guardians, children whose fathers do not support them and whose mothers are either ill or have passed away. The occasional clients include children who are temporarily in the area but who live elsewhere and children who attend the life skills training but are not OVCs. Some children belong to more than one category, for example, HIV-positive children who are orphaned. Such children are listed under each of the appropriate categories.

The list of files stored electronically includes lists of food parcel distribution, wish lists for Christmas, home visit records, referrals, life skills training attendance. There are no unique identifiers used but the name and age of the child is included in all the files.

On the manual forms, an intake register is filled in by the volunteer when a child is identified. This form records the child's full names, home address, date of birth, parent's names, guardian's full names, guardian's address and date of assessment. The volunteer then records descriptive information about the child's background and family situation such as with whom the child is living, whether they are in receipt of any grants, information about the parents and what sort of assistance they need from the Department of Social Development. Caregivers also have to record information regarding the child's health status by asking whether they are currently suffering from any illnesses and whether they attend clinics. The caregiver then provides recommendations or comments with respect to what needs to be done by the organisation to help the child. Some of this information is later captured electronically on a monthly basis. The form is stored in the child's file.

The collection of information is done by the caregivers during home visits. The information is updated during subsequent home visits or when the child visits the centre. The organisation has not encountered any particular difficulties with the collection of information. However, it notes that the collection of information about documents such as birth certificates is often difficult because the children or guardians do not know where the deceased parents have kept these documents. Also, some relatives refuse to present the documents in order to be able to state that they are a foster parent and so access a social grant. Children are removed from the electronic database when they reach the age of 20 or when they move away from the area but their manual files are stored and archived.

Confidentiality of information is very important for the organisation mainly because some of the files have information about HIV status. The organisation restricts access to the database to management and coordinators only. Files that record HIV status are only saved on diskettes. Outside of the organisation, donors who visit the database are allowed to look at the database but otherwise do not have access to the entire database. The organisation ensures that any lists sent to funders do not have names of children for confidentiality purposes.

The database does not generate any reports. However, management refer to database records for monthly and quarterly reports to funders. The database has not changed significantly since it was established. However, information about referrals which was previously only manually kept is now also captured electronically. The organisation revisits its entire systems and operations every five years.

### **Maintenance of the database**

The collection of information is done by the caregivers during home visits. The information is updated during home visits or when the child visits the centre. The updating of electronic information is done monthly. Children are removed from the electronic database when they reach the age of 20 or when they move away from the area but the manual files are stored and archived.

The inputting of data electronically is done by programme coordinators. HCBC records are updated weekly while OVC data are updated monthly. All managers and coordinators are able to extract information from the database. However, the manual files are used more often for reference and updating purposes while the electronic database tends to be used as a back-up system.

### **Access to the information**

Access to the electronic database is restricted to management and the coordinators. The volunteers only have access to the manual registers. Information from the database is provided to donors and the local AIDS coordination committee. This committee consists of local HIV and AIDS NGOs as well as faith-based organisations. The database information is useful particularly where beneficiaries belong or have access to multiple organisations to avoid duplication of services.

Local NGOs and clinics often refer OVCs to Friends for Life. The organisation has encountered difficulties with referrals in the past. Organisations doing the same work sometimes “dump” children with them when they can not provide for them any more. This has led to problems because the organisation would intervene and support the affected children only for the organisation that “dumped” the children to later claim that those children belong to them. To avoid this, Friends for Life has now instituted a formal referral system. Organisations/individuals who wish to refer children have to write letters to which Friends for Life provides a formal response on whatever action they are taking in respect of the referred child/children.

### **General assessment**

Friends for Life strongly recommends the OptiPlan System for any organisation wishing to establish a sound recording and filing system although it is expensive to install as it comes with huge metal filing cabinets. The OptiPlan has made it easier for the organisation to track

children in the programme. In this case, the electronic system mainly acts as a back-up for the manual system. The organisation admitted to having lost electronic data on several occasions in the past. This could be attributed to the lack of a proper back-up system. The organisation also recommends proper research on the needs of the children as well as the categorisation of these needs before the database is established. The OptiPlan system is useful not only for databases but also for general management and accounting purposes.

## **KWAZULU-NATAL: INGWAVUMA ORPHAN CARE**

### **Background**

Ingwavuma Orphan Care (IOC) was established in June 2000 and is registered both as a non-profit organisation and as a hospice. It was established in response to the needs of orphans in Ingwavuma. Ingwavuma is in the Lebombo Mountains in the northern region of KwaZulu-Natal, close to the Mozambican and Swazi borders. The IOC provides a number of services to communities in the surrounding three traditional authority areas. These communities are spread over 2100 square kms. The number of people served amounts to approximately 110 000.

The services that IOC provides include short-term provision of food parcels, social grants and ID advocacy, and assistance in applying for foster care grants. In addition to this it facilitates orphan clubs in 20 schools that provide structured psycho-social support to 400 orphans. It also facilitates holiday orphan clubs. IOC provides home community-based care and community-based health services to the community. It is registered as a hospice but is not running one at present. The community- and home-based services ensure that children need not be the only ones looking after AIDS ill parents. Community-based carers are trained to assist dying parents to create memory boxes which contain mementos and historical information of their family for their children. IOC facilitates support groups for HIV-positive children and their carers and involves carers in income-generating projects. In order to raise awareness of the plight of orphans within the communities, yearly Christmas parties are organised for 300 orphans.

IOC serves children who are orphans, those whose parents are dying, abandoned children and children that are sick. They do not specifically target children affected or infected by HIV and AIDS. This is to avoid any stigma in the community that may arise as a result of such classifications.

IOC is run by professional staff: the medical director and founder, Dr Dean, a treasurer, a social worker and a nurse. There are six development workers that include a life skills trainer, two paralegal officers, a business trainer, a psycho-social support person and a food gardens trainer. 22 staff including a trainer are home and community-based care (HCBC) workers. There are three administrative staff that include two British volunteers. Four general workers

are cleaners or security guards. Almost all staff have been recruited from the community as IOC maintains a strong commitment to skills development and claim to be the largest employer in Ingwavuma. The British volunteers have been with IOC for several years working on critical areas such as financial management and fundraising.

IOC obtains its income from a number of funders. Last year their total income was just under R2,2 million. Its website has a strong marketing approach and invites people to donate funds. Funders of IOC include the AIDS Foundation of South Africa, Johnnic Communications, the Elton John AIDS foundation, the European Union, Friends of the Children of Southern Africa, Community Care Centres (previously KwaZulu-Natal Lotto), the Global Fund for HIV and AIDS, TB and Malaria (through South Coast hospice), the Isle of Man development agency, iThemba, and the Ingwavuma Orphan Trust Fund of New Zealand.

### **History of the database**

Dr Dean felt it was necessary to make an assessment of the scale of the problem of orphans after her previous work at Mosveld hospital had indicated the enormity of the problem. She therefore initiated a research project. She developed a form and recruited people to find out information on the numbers of vulnerable children in the community. The paper database was set up from this in 1999/2000. Her intention behind gathering such information was to alert the government to the problem of orphans in the area, hoping they would address the issue. IOC was established in 2000 and an electronic database was established in 2003 by a visiting German national, Mr von Belino.

Mr von Belino found that IOC had over 1 500 hand written files containing information on orphans from 400 households. He advised them to computerise their database. He offered to develop a more efficient system to manage and process the information they had. He reported that it took him four months and over 1 500 hours to develop the home care database for IOC. All of his work for IOC was voluntary. He used computers that IOC had, and trained the receptionist in IT skills so that he could capture and produce reports. After Mr von Belino gave a presentation to the CINDI (Children in Distress) network on his databases, five further organisations besides Ingwavuma started using the home care database. He still visits South Africa three times a year and, where necessary, provides assistance during these visits.

The database focuses on any children identified as vulnerable, and not explicitly on HIV and AIDS affected children. Records in the database represent both children and households. The database covers all the communities that IOC serves, which are as already stated the three surrounding tribal areas. The database is used mainly for fundraising.

### **Technical issues**

The database is stored on computer using the Microsoft Access programme for managing data, Microsoft Word for the manual and Microsoft Excel for the entry of forms. The database

has two forms, the child initial assessment form and the family initial assessment form. The child initial assessment form includes the following variables: name, age (date of birth), sex, address, whether they have an ID or not, attendance at school, school details, grade at school, whether exempted from school fees or not, access to grants, whether a foster care application is being processed, nature of support needed, details of biological parents (including whereabouts and ID) and details of caregiver.

Under variables concerning school the form also asks whether there are any problems with schooling and has some options to tick such as school fees, poor performance, etc. The family initial assessment form includes the following variables: surname of the head of the household, number of adults in household, number of children, number of orphans, dwelling type, access to basic services (water), access to grants by household, household income and food growing activities of household.

IOC reported that the household information on the family assessment form has now become obsolete. IOC does not use the information on type of household such as whether they have toilets or water, in any meaningful way. Information on this form pertaining to orphans is useful, but can be obtained from the child assessment form. It is difficult to obtain ID details of parents and of the children for both forms.

Initially the database focussed on information on the child that would inform service delivery and advocacy. Subsequently Dr Dean extended the information categories to find out about the socio-economic context within which the children lived. This was done as part of her masters study. In 2004 a social worker was appointed to work with 45 families per month, assisting with processing foster care applications. The social worker found that the existing system was unhelpful and developed a separate database for managing services to families that she works with. However, she does refer to the existing database when interviewing a new family so as not to duplicate information that is already known about a specific family.

The database has over 3 000 records. The September to December 2005 quarterly report indicated that there were 1 010 children aged 0-8 years, 1 019 aged 9-13 years, and 1 637 aged 14-18 on the database. It is, however, not clear how many of these children are currently being serviced as the database records all children in the communities, regardless of whether they are being serviced or not. The quarterly report for September to December 2005 indicated the following services to children: 600 OVCs participated in Christmas parties, 30 OVCs participated in the camp project, 400 OVCs were participating in orphan clubs at 20 schools and children in 45 vulnerable households were assisted with food parcels monthly.

The database can provide reports on numbers of orphans, lists of children attending per school and per grade, problems experienced in school lists of children who are in need of foster grant applications, lists of those children exempt from school fees, lists of children per household

under 18 years old and a list of sick adults in a household. The reports are printed out when the information is needed for fundraising.

### **Maintenance of the database**

Up until the end of 2005 information on new families for the database was collected by three home-based carers. Any new information to update the database is collected by other HCBCs. Special forms are used to collect this data. Information is collected during home visits. In December 2005 the three home-based carers stopped collecting new information. IOC is unable to service all the families and so it did not make sense to carry on collecting information on new families. Records are deleted from the database if a child dies or has left the area.

Information is input into the database on a monthly basis. This is done by the receptionist who is in charge of IT and takes about three days every month. Only the receptionist, the treasurer and another staff member know how to input information into the database.

An extensive manual has been developed that explains how information is placed in each form, how to access each form and how to manage records being captured, analysed and printed. In 2005 Mr von Belino sent IOC an updated version of the manual. He does this each time he updates the system. Only the receptionist, the treasurer and the director know how to extract information from the database. No backups of the database exist.

### **Access to the information**

Within IOC, only staff who need the information stored on the database have access to it. Social workers from the Department of Social Development have access to information in the database as well. They are unable to look directly at the database, the information that they need is extracted for them by the IOC social worker. Statistical trends obtained from the database are provided in the IOC's annual and quarterly reports available on their website ([www.orphancare.org.za](http://www.orphancare.org.za)). Information on children regarding foster care applications is made available to the Department of Social Development. IOC assumes that the social worker involved will be committed to ensuring confidentiality by virtue of her training.

In other instances when providing information on children in reports to the public and donors confidentiality is ensured. On their website, IOC clearly states that pictures of children will not be provided for confidentiality reasons. Regulations are enforced for visitors wanting to interact with children. For example no pictures can be taken and an IOC employee must be present.

The organisation is willing to make the database available to others if the purpose and value of the information is clearly stated. The organisation does not obtain information for its database from any other organisation.

## **General assessment**

The database has assisted IOC with fundraising initiatives and has been used for advocacy purposes. For example, IOC managed to get the Department of Social development to send a team to Ingwavuma to address backlogs in foster care applications. The database has been of use in terms of quick retrieval of information needed in foster care applications.

A difficulty encountered with the database is the amount of information collected and the relevance of that information. There is a lot of information that is not of value for the organisation's service delivery. IOC advises any organisation setting up a similar database to be clear about what they want to use the information for so as not to complicate the system with unnecessary data.

An unintended outcome of developing an electronic system is that through the training the receptionist has become well skilled in IT and has provided IT training for community members.

## **KWAZULU-NATAL: MSUNDUZI MUNICIPALITY**

### **Background**

Msunduzi Municipality's Aids Information Centre within the municipality's HIV and AIDS and Social Services Unit was the case study chosen to represent a local government initiative. The municipality's work, including the database, is supported by Aberdare Cables, a national corporation with its head office in Edenvale, as part of its corporate social responsibility programme. This case study thus represents an example of public-private partnership. Information for the case study was obtained from both sides of the partnership.

Msunduzi comprises 37 wards, but the Aberdare-supported activities and database cover only one ward, Namaxlala Village. From the municipality's side, the HIV and AIDS and Social Services Unit employs 18 service delivery staff, four administrative and support, and three volunteers to staff provide voluntary counselling and testing, education and training, HCBC outreach services and support to vulnerable children. From the side of Aberdare Cables, the five staff members who constitute the Transformation Action Team are involved. Their activities are part of the company's "Making a Difference" project, which focuses on vulnerable children.

The primary category of vulnerable children served is those who are orphaned, but services are also provided for infected children, those living in child-headed households, those who are chronically ill, and those who are living with chronically ill adults.

## **History of the database**

The database was set up in 2003 after Msunduzi received reports from home-based carers (HBCs) that there were large numbers of children who were vulnerable and needing assistance, but was unable to estimate the extent of the problem. Msunduzi therefore requested the HBCs to go back to the ward and assess the scale of the problem. One part of this assessment involved compiling a list to assist with tracking grant applications.

At about the time that the assessment was happening, Msunduzi was contacted by Aberdare Cables seeking information on vulnerable children whom they could assist. Aberdare Cables had been referred to Msunduzi by the Pietermaritzburg-based CINDI Network of which Msunduzi is a key partner. Aberdare indicated that they wished to provide food parcels and other forms of support to vulnerable children on a quarterly basis.

Msunduzi put Aberdare Cables in contact with the HBCs. Aberdare soon discovered that the HBCs had no system for managing information besides paper lists of children. The company therefore offered to assist with capturing this information in an electronic database. Msunduzi accepted the offer. The database was developed by Aberdare's human resources manager specifically for the project. The company's existing computers, software, printing resources and personnel were used.

The database covers both children in need of support and those currently being serviced. The records include information on the households containing vulnerable children as well as the individual children. It is used by Msunduzi to track the children who need grants, and by Aberdare to identify vulnerable children so that they can provide them with food and other material support.

## **Technical issues**

The database is stored in an Excel file. Variables recorded include the name of the HBC, name of head of household, number of children in the household, name of the child, age of the child, sex. Informants did not provide a full list of variables, but said that all the information captured was useful. They noted, however, that date of birth was difficult to collect as many births were not registered. At the time of the interviews the database contained details of approximately 90 households and 500 children. Of these, all were households or children the organisation was servicing as at December 2005. The system generates standard quarterly printouts which record food distribution and visits completed for the past quarter.

## **Maintenance of the database**

The information for the database is collected by the HBCs during their home visits and when doing the quarterly distribution of food parcels. The information is passed on to Aberdare Cables at monthly meetings for updating of the electronic database. Data input is done on a quarterly basis by the human resources manager or the Aberdare shopsteward who is part of

the Transformation Action Team. Updating includes removing records of children who are no longer in need of services, for example because they have died or moved from the area. The process takes a maximum of two hours per quarter.

All members of the Transformation Action Team know how to input the information into the database and extract information from it. There is, however, no manual that explains how to input data or use the database. The IT department makes backup of all Aberdare's records on a weekly basis and the OVC database is backed up during this process.

### **Access to the information**

From Msunduzi's side, the manager, social worker and HBCs have access to the information, while from Aberdare Cables' side, it is the Transformation Action Team. No other organisation or institution has access to the information. The municipality and Aberdare would not be prepared to make the database available to others as they do not see what use they could make of it. They also do not get database information from other organisations or institutions. Perhaps as a result, they have not they have not considered ethical issues in setting up and using the database.

### **General assessment**

The database has provided Msunduzi with a structured and updated list on a quarterly basis which helps the HBCs track progress with grant applications and target support. For Aberdare Cables, the database helps that those in need get support from them and that they can monitor the value of their work.

The main difficulty encountered has been that Msunduzi municipality has not been able to maintain the database on its own due to lack of capacity and resources to manage this information. For similar reasons, they have not been able to implement the database in other wards, despite the fact that HBCs work in all wards.

In terms of advice to others contemplating setting up a database, Msunduzi advises that the private sector be drawn into partnership. Aberdare Cables advises that the database be simple and that it focus only on information that will be used.

## **KWAZULU-NATAL: MIET IZINGOLWENI PRIMARY SCHOOL**

### **Background**

The Media in Education Trust (MIET) operates nationally. It provides educator in-service training, material development for education enhancement and through schools provides care

and support to vulnerable children. In respect of its Centre of Care and Support project it serves three provinces namely, the Eastern Cape, KwaZulu-Natal and the North West. From its branch office in Durban, the project facilitates the Izingolweni Primary School (IPS). The school is in the South Coast of KwaZulu-Natal, approximately 60 km from Port Shepstone. The children served at IPS live in the Izingolweni ward. Other branch offices that MIET have are in Richards Bay and in Gauteng. MIET is a registered NGO while IPS is a state-run education institution.

MIET employs three regional coordinators, a training coordinator, four Cluster Child Care Coordinators (CCCCs) for KwaZulu-Natal and 28 school-based carers (SBCs). In addition to this, MIET has a large component of staff who are not directly involved in the project. The staff component of IPS consists of 34 educators, the principal, and an administrator. They cater for children from grade R (over 5 years old) to grade 7 (between 13-15 years old). MIET's focus is on vulnerable children that attend school. These are children without parents, children with ill parents or caregivers, abandoned children, sick children, those not attending school on a regular basis and those without any physical means of support or shelter. MIET is largely funded by donors. Its funders are the Swiss Agency for Development Cooperation (SDC), Royal Netherlands Embassy (RNE), the National Development Agency, Rockefeller Brothers Fund and DG Murray Trust. IPS is funded by school fees and the state.

### **History of the database**

The database was set up in April 2004 by the MIET Systems Coordinator. The need for the database arose at the time of implementation of the project. MIET was paying stipends and salaries to a large number of people and needed a system to monitor how many children were being serviced by the organisation. This information would inform services provided to the children and also monitor the work done by the SBCs.

The focus of the database is on children identified as vulnerable and those serviced. Most of these children have lost their parents or have parents or caregivers who are too ill to care for them. While it has not been explicitly stated, there is a common understanding that the high death rates are caused by HIV and AIDS. The units in the database represent children. The children are learners at IPS.

The database format used at IPS is being used by all MIET's SBCs. In KwaZulu-Natal it is used in 28 schools. The Systems Based Coordinator developed the format of the database and provided training for the CCCCs and SBCs on using the formats. They were also provided with forms, files and pens. The training programme was funded as part of the training provided to CCCC and SBC that is funded by donors mentioned previously.

The database has been used to keep track of the number of children serviced by each SBC and to determine the scale and extent of needs of vulnerable children.

## Technical Issues

The database is manual rather than electronic, and is stored in files that are kept with the SBC. No changes have been made to the database since it was developed.

The database consists of three forms that are filled in by SBCs. The first form focuses on categories of children at risk. Variables in the form include: name of the child, sex, age, category, urgent action, comments, and action taken. The urgent action variable indicates to the SBC if urgent action is needed. The comments variable is for if there is any information that the teacher wants to convey to the SBC regarding the child. The action variable indicates what has been done. All the forms reviewed had 'referred to SBC' under this variable. A child is identified as one of the six categories that the form makes provision for. These categories are: (a) orphan (both parents deceased); (b) child with ill parent(s); (c) child in a child headed household; (d) child living in extreme poverty and neglect; (e) child suspected of being abused; and child mentally or physically disabled. Space is provided for indicating the name of the school, name of the teacher, and grade of child on the list.

The second form covers a particular grade. Variables on this form are: date, name and surname of child, age, sex, grade, comments on counselling session and action. Under the action column, the SBC can record whether identification numbers or birth registration need to be addressed. Space is provided on the form for listing the educator's name and the school's name. This form appears to serve multiple purposes although all were not necessarily originally intended. Firstly, it helps the SBC to list all the children in the grade who need to be interviewed and assisted. Secondly, it is handed to the form teacher on the morning of the interview day and the form teacher sends learners for their appointments as per the list. Thirdly, the list serves as a record of children currently being serviced.

The third form consists of a list of vulnerable children in need of care and support and children who are being supported. This form is shared with MIET and the Department of Education and Welfare. Variables on this form are: name of the child, academic performance, age, sex, nature of vulnerability, date, action taken, and follow up action. For the variable vulnerability the categories are: (a) persistent absenteeism; (b) death of learner or family member; (c) evidence of poor nutrition or starvation; (d) behavioural change; (e) abuse; and (f) persistent illness or poor health

All of the variables in the three forms are useful. Finding out information about abuse is difficult. This is because it is not easily disclosed and the SBC often find out about it much later.

With regards to ethical issues, all SBCs and CCCCs have been trained by the NACCW on issues of confidentiality. These issues were covered in a training module for SBCs and CCCCs. SBCs are clear that they will not provide information to just anyone. The main criteria used when considering sharing information is need. For instance, the Department of

Health will need the information to deliver services. In contrast, an educator not teaching a particular grade will not need to review records of learners in that grade.

In terms of size of the database, there were 150 records on the forms for grades 1, 2, 3, 4, 6, and 7 at the time of the interview. The SBC interviewed was unable to find records for the grade R and grade 5 but indicated that there were a further 8 or 9 records. The data was current for January 2006 for all grades except grade R. The grade R class consists of newly registered children.

Hand-written reports from the SBCs and the CCCCs are given to the regional coordinator and the training coordinator. These data are included in the reports submitted by MIET to donors.

## **Maintenance**

SBCs collect the data for the database at the beginning of the year. The form teacher is given a form to complete and submit to the SBC. The SBC receives information on an ongoing basis from form teachers who raise concerns about absentee children or children whose performance in class has dropped or who appear to be unhappy or disturbed. Children are also able to ask for help from the SBC, though this rarely happens. Often a community or family member will alert the SBC to some concern about a child. This is then followed up. Updates on the information are done on an ad hoc basis, for example, if a child is interviewed by the SBC and support is provided by the SBC. An educator may indicate on forms in the new year if anything has changed in relation to the child's circumstances from the previous year. On rare occasions records are deleted from the database. For example, a record may be deleted if a child no longer requires support.

All completed forms from educators are filed by the SBC at the beginning of the year. Forms are filed whenever a child has an interview with the SBC. CCCCs and the School Support Team know how to input information in the database. There is no manual explaining how to input data and use the database. Files are available for review by the CCCC and the School Support Team (SST) (formerly the Health Promoting Team). This team is comprised of some educators, the SBC and some community members. Often these community members are drawn from the school governing board structure.

No backups are made of the database, but copies of the third form are sent to MIET.

## **Access to the information**

Within the school, the principal, the child's educator, SST, CCCC, SBC and the MIET regional and training coordinators have access to information in the database. Outside of the project, the Department of Education and Social Development officials have access to information in the database if they request it. The SBC provides a monthly summary report to MIET. MIET reports to donors quarterly or every six months. Confidentiality is not ensured

in these reports. MIET is not willing to share the format of the database with others. No other organisation provides MIET with data on orphans or vulnerable children.

### **General assessment**

Some advantages of the database for MIET include that they are able to check the performance of the CCCCs and the SBC. They are also able to identify trends in the issues affecting vulnerable children. These issues can be addressed through advocacy at provincial level. For example the trend of low levels of birth registration prompted MIET to engage the Department of Home Affairs on providing mobile services to the area. IPS finds the database advantageous in that they know how many children need assistance, and for how many they need to provide food parcels. The database also acts as a way for IPS to monitor the work of the SBC.

Some difficulties with the database are that writing of narrative reports by the SBC is time-consuming. Previously reports were received timeously as submission of reports was linked to payment. This is no longer the case as payment is now directly into bank accounts. As a result there is little incentive for carers to complete a number of forms and reports. Another problem concerns the accuracy of data. Initially the information about vulnerable children was collected by educators to ensure that more children received food parcels (which the school provides). In the past the information about children's needs was sometimes doctored by educators who wanted to make sure a child received the food parcel. Now with the SBC present at school and investigating all cases, including through home visits, they have removed from the list those children who "did not meet their criteria for being in need".

Advice that MIET would give another organisation developing a database is that planning should be done carefully. They should rationalise the number of forms they have and the way that information is captured so that too much time is not taken up with making reports.

From April 2006, MIET hopes to have all records in an electronic database. MIET has received funding from the Royal Netherlands Embassy for computerising and updating the data collection system. This is because managing project information from three provinces has become unwieldy and cumbersome. The new system will ensure less writing by the SBC as relevant columns will be ticked. In addition it will allow for quarterly progress reviews on whether birth certificates applied for have been received or not, school attendance levels, age, height, and weight data to be collected to assess the impact of feeding schemes and to identify whether or not a child is receiving a grant. The new system is still to be developed.

## KWAZULU-NATAL: SIYABONA TRUST

### Background

Siyabona Trust is an NGO situated in the Ugu region of KwaZulu-Natal and serves Umzinto, Ixopo and Braemar villages. The director is Gordon Bailey and the projects manager is Molly Bailey. The organisation has facilitated the establishment of the Dumisa Wellness Centre which caters for HIV/AIDS and TB infected people, addresses care of orphans and other vulnerable children and targets youth through a programme known as youth purposeful living which involves establishing youth forums and providing life skills education for youth. Sixteen community volunteers known as “abasizi” or family helpers provide community services in health and HIV/AIDS, TB support and care for orphans and vulnerable children.

A core focus of the organisation’s activities are focused on children and support to their families. Although the organisation does not keep HIV/AIDS statistics, they estimate that 30% of the children they service are affected by AIDS. Vulnerable children are broadly defined as those with absent parents, children in child-headed households, children who are HIV positive, children in households with a dying parent or caregiver and children in households which are without any income or material support. At present, only one child-headed household is served by the organisation.

Siyabona is funded by two organisations - Feed the Babies and the Methodist Church. The income from these two sources goes directly towards support for children by way of food parcels and other support (school fees etc). Molly Bailey and her husband undertake consultancy work and the income from this gets utilised to run the office and cover the salary of the administrative support worker. The University of KwaZulu-Natal Medical School’s Department of Community Health conducts research on a number of health issues in the district working with Siyabona and the abasizi. The abasizi are paid monthly stipends of R120. In previous years Siyabona was able to pay them up to R300 but the level is now dependent on what funds are generated.

### History of the database

The database was set up five years ago. The main purpose was to identify and address needs of vulnerable children. In her interactions with the family helpers who provide support to vulnerable children and their households, Ms Bailey received feedback about the dire hunger needs of children. However, there were no data on the size and complexity of the problem and hence she developed a form for the family helpers to complete so that an assessment could be made regarding the number of children needing help.

The other motivation was that there would be no guarantee that these resources would be sustainable and hence it was important to find out if children were accessing the child support grant (CSG). This was necessary because it was often reported by the family helpers that

children were not getting grants because of a lack of documents. Hence, this list was to assist in identifying children who needed urgent assistance with accessing grants.

The database is mainly used for identifying children who need to receive food from Siyabona on a monthly basis. To do this it needs to identify the most vulnerable children as almost all children living in these communities are poor and need help but there aren't sufficient resources to cover them all. Hence the database serves as an important screening tool. Information such as household income and number of children in the household is useful for screening purposes. The database is also used to track children served by the abasizi, to identify children who receive grants and track progress with advocacy efforts with the Departments of Social Development and Home Affairs as well as reporting to donors.

The units in the database represent children in a household. The database covers the Vulamehlo South District between Umzinto, Braemar and Highflats. The database was set up by Gordon Bailey. Siyabona made use of an existing computer to store the database. They trained the abasizi in filling in the forms and provided stationery including note books, pens and forms on a monthly basis to the abasizi. No external resources were received for this.

### **Technical issues**

Part of the database is stored in the computer on MS Excel and part of the information is on paper in files and in notebooks.

The computer database stores minimal records. It lists variables such as name of family helper, name and surname of child, sex and date of birth. In some records the date of birth is given as a year, in others an age is given, while in others the record provides the actual date of birth. The variation is because for those children whose births are not registered the only information available is how old the child is or which year the child was born. All this information is useful but the most useful information for the organisation is the date of birth as it indicates whether a child possesses a birth certificate. This would be one indicator of whether the child is able to be assisted in applying for a grant since an unregistered child cannot access the CSG.

The hand-written form captures the name of the child, date of birth, sex, whether the child receives a grant or not, physical address, who cares for the child, father's identity details, mother's identity details, presence or absence of father or mother in the household, whether there are ID documents and death certificates in the case of deceased parents and the household's income. Only the mother's and father's identity details are noted even though the grandmother or someone else might be the real caregiver particularly when dealing with a significant percentage of orphans.

Records are also kept of the child's needs, for example, which child needs hospital care or which child needs school uniforms. This information is compiled by Molly Bailey based on

the monthly meetings with the abasizi where verbal reports are presented. They refer to their note-books and provide Ms Bailey with information on which children need help beyond what they can offer. She records this information in her own note-book so as to have a record of action that she has to take or to guide the abasizi to take. This additional information is focused on providing other support to the vulnerable children such as dealing with abuse or violence, ensuring that the child receives appropriate health care treatment or dealing with a schooling problem. One specific example of action taken based on the information collected was cited where some adults collected the grant and used it for themselves. Molly Bailey used the information received from the abasizi to investigate the matter.

Some information is difficult to collect, for example on income. People do not want to disclose this information for fear that they will not be assisted. Accessing identity details is also difficult. Often the parents are not present and the grandmother or caregiver does not know whether such documents exist or not although this information would assist them in applying for a birth certificate for the child.

No changes have been made to the database since it was established. The organisation currently has about 240 children listed on their database. All the records are current.

### **Maintenance of the database**

The abasizi collect the information for the database during home visits or when the child visits the abasizi to receive a meal. The information is first collected at intake when the child or family becomes known to the abasizi. The information is updated during home visits or when the child visits the umszizi. This occurs at least once a week but usually more often. This information is captured on the computer by the coordinator whenever she has time and at least once every month. This task takes about 3-4 hours. The only other person who knows how to input data electronically is Gordon Bailey.

Records are deleted from the database when a child moves away from the area, when a child dies or when they no longer need support. Once a child's caregiver has been assisted with securing a grant they are removed from the system unless there were other matters being attended to.

For back-up purposes the database is stored on a disc once every few months. New lists of the records are printed and stored physically every month.

### **Access to the information**

The hand-written records are available to all the abasizi. The abasizi refer to their note book when they need information and hand over notebooks to Molly Bailey when they are filled. The information they collect is for their use only. Outside the organisation, the two donors have access to the database. They receive print-outs of the database periodically.

All abasizi have been trained in confidentiality especially in the context of HIV/AIDS and access to treatment. No other ethical issues were considered in setting up the database. For confidentiality purposes, the list provided to others outside the organisation does not contain the physical address of the children. Siyabona would be willing to share their database with others provided that they knew what the information was needed for.

### **General assessment**

Siyabona feels that their database is useful in tracking what is happening to children and to screen for resource allocation. “It feels good to be able to target our support to those most in need and the information we have collected has been generally accurate.”

The difficulties they have experienced with the database are mainly around capacity. They do not have staff to do the data capturing hence a lot of information is not yet included in the computer database but still sitting on the paper records. As a result of lack of capacity of staff, the coordinator has to do the capturing herself on a monthly basis.

Siyabona’s advice to organisations wanting to set up a database is to work closely with the community volunteers in order to get a good system for regular data collection. Siyabona had to secure commitment and trust from abasizi as the work is largely voluntary, with abasizi receiving only a small stipend.

## **LIMPOPO: CHOICE TRUST**

### **Background**

Comprehensive Health Care Trust (CHoiCe) is a registered non-profit organisation operating in the Greater Tzaneen Municipality in Limpopo province. The organisation was started in 1997 by four professional nurses to meet the needs of people in the area for HIV prevention, care and support. CHoiCe has a full-time staff complement of 14 and over 200 volunteers, about half of whom receive a stipend from the Department of Health while 9 volunteer coordinators receive a stipend from the organisation. They also have a Peace Corps volunteer from the United States who has been with the organisation since December 2005 until 2007. The office is based in Tzaneen with outreach projects in all 5 local areas as well as through the mentorship program in rural areas of Bohlabela and Mopani. CHoiCe has received several accolades for its leadership and role in community service. The organisation is on the executive committee for the Tzaneen AIDS Council as an NGO representative and chairs the home-based care sub-committee for the area.

CHoiCE also runs a range of outreach projects. These projects focus on providing care and support to vulnerable groups including children, the elderly and people living with HIV and

AIDS. These include support groups for people living with AIDS and home-based care. Volunteers conduct home visits to identify vulnerable children as well as to provide home-based care to people infected and affected by HIV and AIDS. They also do door-to-door HIV and AIDS campaigns. To address the needs of OVC, support groups in the form of Cubs and Scouts have been initiated. The programme is open to all children, both boys and girls and is intended to shape them to become responsible and caring adults in future. Forty-eight volunteers have been trained as leaders and have specific child counselling and skills training. In July 2005, over 800 children attended 21 groups per week with groups planned for each village in the future.

CHoiCe provides training to caregivers, trainers, private organisations, CBOs and individuals on a range of health issues including HCBC, first aid, HIV and AIDS and wellness, TB/DOTS, CBO Capacity building and mentorship. CHoiCe is an accredited training provider with the Health and Welfare SETA. Food security issues related to health, water and sanitation, women's empowerment and clinic committee capacity building are smaller projects which are carried out in partnership with other local organisations.

CHoiCe Trust has a range of funders including both international and local agencies. The local funding comes from the National Department of Health, the National Development Agency (NDA), Nelson Mandela Children's Fund (NMCF), and the lottery fund. International sources include Development Cooperation Ireland (DCI), AusAid, CARE South Africa and Oxfam. The director could not approximate the exact percentages for each source but indicated that the biggest share comes from the National Department of Health who give core funding as well as funding for volunteer stipends.

The organisation defines orphans as children who have lost both parents and those who have lost one parent and the other parent is unknown. The definition of vulnerable is very broad. It includes "potential orphans" i.e. children whose parent/parents are terminally ill as well as children living in poverty. The main focus of the work is on HCBC but the focus on OVC is growing. The organisation has in the past not differentiated between orphans and vulnerable children but would now like to use the database to do this.

### **History of the database**

The database for orphans and vulnerable children was set up in 2003. The organisation started operations in 1997 without any baseline information to inform their work. The organisation then decided to set up the database to record and track information about beneficiaries so as to be able to inform the organisation's evaluation of their impact. The organisation has not done this evaluation yet but is thinking of doing it soon. Another reason for the database was to improve record keeping and management. One of the donors, the NMCF, suggested the database would be helpful although they did not provide any resources or capacity building for it.

The units in the database represent a household but information on all the children in the household is captured. The database covers Greater Tzaneen which consists of 119 villages. The NMCF uses a similar format and CHoiCe suspect that other organisations could be using a similar database.

The main use of the database at present is to provide data for donor reports. The director feels that the organisation is not using the database optimally mainly due to the lack of capacity in the organisation. In future, the organisation would like to use the database for research, monitoring and evaluation and also for lobbying for funds.

### **Technical issues**

The database is stored on the MS Access programme. Initially, the database was on Excel but the organisation decided to upgrade to Access which has better functions such as for generating reports. The only problem is that fewer people are conversant with Access than with Excel within and outside the organisation. No reports have been generated using the programme as a result.

The most important variables were said to be those reflecting the level of social support including receipt of grants. Information about income, birth certificates and IDs is difficult to collect. The major problem, however, is not with beneficiaries providing information but with the volunteer's collecting and recording the information properly.

The Peace Corps volunteer is currently doing a lot of work on the database. She has recently made the distinction between orphans and vulnerable children in the forms and in the database and has added a comments box where any information that does not fall under the other variables can be recorded. Other minor changes that have been made are the use of tick boxes to simplify data capturing and including a column to list children on anti-retrovirals (ARVs).

There are 1 560 records on the database at present. It is difficult to tell how many of these records are current because children who move away or reach 18 are not deleted. One would need to go to the comments column and physically check for those who are no longer current.

The variables on the initial contact form for orphans include the following:

- Volunteer's details such as name, and name of volunteer coordinator
- Area details including name of village and area, block number and stand number
- Carer's details such as name, sex and age, relationship to orphaned children and whether carer lives with the children
- Household details: whether the household is orphan-headed, number of children in the household under 18, number of children at school

- Foster care grant information: number received, number applied for, when applied, where applied, where applicable reasons for not applying, name of social worker's name and contact number
- Information on individual children: names, ages, whether they have birth certificates, grade
- Parent information: mothers death certificate, father's death certificate and history
- Socio-economic information: approximate family income per month, food parcels received, number of food parcels received in a month, church involvement, contact details of church, other involvement, contact details of other involvement
- Needs identified
- Vegetable garden at home (not started, in process, producing)

The variables on the initial contact form for vulnerable children are mostly the same as those listed above. However, the form for vulnerable children asks for the reason for vulnerability and for information on child support grants. The electronic database has the same variables but also includes a comments box where any changes regarding the status of the children can be listed.

### **Maintenance of the database**

Volunteers collect the information for the organisation. An initial contact form is filled on the first visit. The information is then updated during home visits. This information is then transferred to the electronic database which is less frequently updated due to lack of capacity. The Peace Corps volunteer is currently working on improvements to the database more or less on a full-time basis. Once the re-organisation is complete, an administrative assistant will be required to update it at least once a month. Everyone in management knows how to input data but only the Peace Corp volunteer can extract information from it and generate reports. There are plans to develop capacity among other staff through training in the future.

### **Access to the information**

In theory everyone in the organisation has access to the electronic database but it is mainly used by the director to prepare reports for donors. Outside of the organisation, the Tzaneen municipality often asks for numbers but do not otherwise have access to the database. CHoiCe would be keen to share the database with other organisations provided that they were informed what the database would be used for by the other organisations. CHoiCe does not receive database information from anywhere else except from their volunteers.

### **General assessment**

According to the director, it is "credible and fashionable" to have a database. She feels that this adds a plus to the organisational profile particularly when soliciting funds from new

donors. While the organisation has not utilised the database to its full potential so far, they hope to be able to use it in future to conduct monitoring and evaluation. The organisation would welcome the opportunity to learn from best practice models but wishes that the government would have a closer relationship with NGOs and support the implementation of such systems. They ideally would have liked the government to assist in designing their database and in discussing the purpose of the database.

Another issue raised in relation to the database is the fact that different donors have different formats and requirements for reporting and this makes the process very laborious for the donor recipient. CHoiCe feels that it would be useful if a standard format for reporting was to be developed. CHoiCe's advice to other organisations is to shop around for best practices and if possible to consult with database experts before establishing their databases.

## **MPUMALANGA: AMAZING GRACE**

### **Background**

The Amazing Grace Children's Centre was started in 1999 as a feeding scheme for street children. The centre is based in the Malelane region in Mpumalanga. The organisation recently established a branch in Lenasia, Johannesburg. The organisation employs 14 full-time staff and 16 volunteers. The centre provides shelter, food, clothing, education and psycho-social support to orphans, homeless children, abandoned children and children who have encountered physical, emotional or sexual abuse. The centre provides short-term shelter (6 months) for the children while attempting to locate their parents or relatives. Ideally, the children should not stay there permanently but often the parents or relatives cannot be traced and so the centre has to keep the children longer than 6 months. The centre supports homeless children, orphans, children who are abused physically, sexually or emotionally, trafficked children and children affected by AIDS. The organisation's activities are entirely focused on children.

Funding sources include the Department of Social Development (DSD), a German organisation based in Mozambique, local businesses, the national lottery fund and individuals in the community. The organisation was previously registered as a shelter but according to regulations, shelters should not have more than 35 children in their custody. DSD therefore advised the organisation to change its registration to a place of safety. The process of registration was very long and not without some negative consequences. For example, the social workers are no longer paid by the department because the funding is now computed per child. The centre thus had to look for alternative sources of funding for the social workers.

## **History of the database**

The database of children was set up in 1989 by a staff member when the centre was established. A key motivation was to provide donors with adequate information. The centre also wanted to enhance its record keeping and tracking. All the children staying at the centre are listed on the database. Each unit in the database represents a child staying at the centre. Some of the children are affected by AIDS but it is often difficult to get children to speak about their backgrounds particularly because most of them are from difficult circumstances. Some of the children at the shelter are HIV-positive but this information is kept strictly confidential. The Lenasia branch which began operations in December 2005 has also established a similar database. The director and some of the programme staff spent some time there helping them with the database and other operations.

The centre does not know of other organisations with similar databases although they know of organisations with databases for business services and home-based care. Computers and staff who are computer-literate were required to establish the database. These had already been acquired by the centre for financial and administrative purposes.

The main purpose of the database is to provide accurate data and information to donors regarding the children served by the centre. Other secondary uses are for programme planning and information sharing.

## **Technical issues**

The electronic database is stored in MS Excel format. This database is essentially an intake register of children at the centre. The variables listed on this database are: name, age, person who referred the child to the centre, date of admission and case description (explaining the history and circumstances surrounding the child). The case description is qualitative information but has sub-variables such as physically, emotionally or sexually abused, ran away from home, trafficked and abandoned. The case explanation is the most useful information for the centre. This information helps to establish the child's background and assess their needs. Getting the child to divulge information is the most difficult aspect in collecting this information. Most children, and particularly those from abusive environments, are reluctant to give any information concerning their background at the first contact. No major changes have been made to this database since it was established.

Each child has a paper file which contains any reports written by the social worker such as home visit reports, school reports, counselling sessions as well as copies of documents such as birth certificates, if available. The social worker visits the child's school twice a month to discuss their progress with the teachers and writes a short report on each visit. This report is also kept in the child's file.

Information on HIV status is kept strictly confidential. Additionally, all staff sign a document stating that confidentiality concerning any personal information about the children will be maintained. This is important because the centre deals with children from difficult circumstances who often encounter stigma and therefore the centre has to be sensitive in dealing with such information. Amazing Grace currently provides shelter for 46 children. Two children are above 18 but are still staying at the centre because they have nowhere else to go. In such cases, the centre strives to help them continue with their education and if possible find employment. As the electronic database is essentially a register, no reports are generated.

### **Maintenance of the database**

Social workers and volunteers collect the information about the child's background for the centre. The information is gathered from the police, clinics, the children themselves and the person who referred the child to the centre. The information is collected during intake. A manual tick sheet is filled out daily. This is done to check that all the children are present every day because children frequently abscond. They either go back to their families or back to the streets. These sheets are not captured electronically.

The electronic database is updated by a social worker and a programme manager. This is done on an ad-hoc basis. Others in the organisation who know how to operate the electronic database are the director and her personal assistant. The programme manager and director compile reports using this data. No formal training has been provided to any staff on this. The database does not have any back-ups but hard copies are printed out and filed every time the list is updated. Names are deleted from the list when children are reintegrated back into their families or when they move to other centres.

### **Access to information**

Within the organisation, the social worker, personal assistant, programme manager and director have access to the database. No one from outside the organisation has access. The centre provides reports to donors and information for Form 25 and 26 required in terms of the Child Care Act to the Department of Social Development.

Form 25 is for the notification of ill-treatment or deliberate injury to children. This form asks for basic demographic information about the child (name, sex and date of birth), particulars of the alleged incident, nature and extent of the ill-treatment or injury, details of the alleged perpetrator(s) and details of the informant. The second form (form 26) is for the notification of children suffering from a nutritional deficiency disease. This is similar to the previous form but asks for the nature and extent of the suspected disease in addition to the child's information. Both forms are sent to the Director General's office and regular follow-ups are then conducted by the department concerning the welfare of these children. The department has a national child protection register for children who have been injured or ill-treated

deliberately. Surprisingly, copies of the forms are not kept by the organisation and the information on the forms is not recorded on the database.

### **General assessment**

The advantages of the database for the organisation are being able to summarise its achievements and failures. The database enhances the compilation of reports. However, incomplete information makes it difficult to compile reports. Meeting deadlines for reports can also be quite pressurising. The centre would advise other organisations providing similar services to establish a database because they feel that it is a good way to manage information. If an organisation wanted to start another project, the database would help to show where the pitfalls are and to advance programmes.

## **NORTHERN CAPE: AGE IN ACTION**

### **Background**

Age in Action was launched in November 2001 in Cape Town. It was formerly known as the South African Council for the Aged. They claim to represent more than 2,7 million elderly across the country. In their mission statement they state that their aims for the elderly are to ‘... provide health care services to poor, needy and abused older persons, including the provision of preventative and educational programmes relating to HIV and AIDS and support to their families’. They not only endeavour to assist the aged but families of the aged as well. The HIV and AIDS pandemic has resulted in an increase in the number of OVCs. Some of these children are left to fend for themselves. Some others, if fortunate, find themselves in the care of grandparents or other relatives. Organisations serving the aged are thus faced with an increasing number of children to serve as well.

As a registered NGO, Age in Action has 11 offices nationwide. One or more offices serve a particular province in the country. For the purposes of this study, staff members from the Northern Cape regional office in Kimberley were interviewed. The staff interviewed were, the regional director, Ms Van den Berg, and the administrator of the database, Ms Hoffman. Any references made to ‘Age in Action’ below refer to their branch in Kimberley.

The Kimberley office is run by eight staff members, two of whom play an administrative role. The other staff members include the regional director and co-ordinators. Assisting them are 86 trained home-based caregivers from the community. These home-based caregivers are spread across the entire Northern Cape. In addition, the organisation is assisted by volunteers. However, volunteers assisting the Kimberley office are scarce, and when available, stay for one or two days, making only a small contribution to the services the organisation provides.

About half of Age in Action's funding comes from the national lottery, approximately 45% is from the Department of Social Development and the remainder is equally spread among donations and their own fundraising initiatives.

Although the need for services clearly directed towards children has been recognised by Age in Action, such services are not in place yet. At present, they are only keeping records of children who they know of who are being looked after by grandparents in the Northern Cape communities. They suspect that others, of whom they are not aware, are also being looked after by the elderly. These are the elderly that they are not yet serving. If when collecting data, they find that certain children are in need of something, referrals are made to the DSD in cases where the latter might be able to help.

The children recorded in the database are between the ages of 5 and 12 years old or are between grades 1 and 5. This age group is being recorded because plans are in process to create what has been called a 'Children's Forum'. The need for such a group arose because of the large number of children that the elderly in the Northern Cape had reported they were looking after. These children were either orphans, or were looked after by grandparents because of ill parents. Some of the children are HIV-positive themselves. The forum would act as an after-school care programme. Children would meet at a community or school hall, and would be engaged in a number of activities in the afternoons after school. The forum would be run by home-based caregivers or volunteers. It would be open to all children between grades 1 and 5. A pilot group is to be started in Postmasberg. This is because the majority of children in their database live in Postmasberg.

The idea for a forum might have been inspired by similar developments in other provinces, but this was not mentioned by Age in Action. Furthermore, no other such group exists in any of the other Age in Action branches across the country.

### **History of the database**

The electronic databases that Age in Action has were set up in 2004. This was after the DSD prompted them to set up a database, stating that it was the organisation's responsibility to create one. The main purpose of the database was to collect information on specific needs of the elderly that were being served by Age in Action. A staff member at Age in Action proceeded to create the format of the databases using Microsoft Excel, basing the chosen variables on interaction with the home-based caregivers. These databases are used concurrently with a paper-based database system.

The database was created using the basic computer skills that the staff member already had. Fortunately the organisation had two computers at its disposal. No outside assistance was given in the setting up of the databases. The format of the databases has been slightly changed

since it was created. Reasons for this include the fact that another organisation in the town had copied their format, and they wanted to make the databases easier to understand.

The database on children is one of the three electronic databases that the organisation keeps. The other two focus on the home-based caregivers, who serve the elderly, and the elderly themselves. Age in Action estimates that 40% of the elderly in their records are looking after children. All source data for the database are acquired by the home-based caregivers in the communities in which they work. The caregivers fill out paper forms that are sent to the Kimberley office where the information contained is entered into the electronic database.

Monthly reports for the DSD and the DOH are produced from the electronic database. Age in Action's head office also receives these reports. Numbers or statistics generated from the database have also been used in fundraising initiatives.

### **Technical issues**

The electronic database is stored using the Microsoft Excel programme. Back-up copies are made on floppy disks each month. The paper database that works concurrently with the electronic database is filed in Kimberley.

Variables in the children's database include: name of the orphan, identification number, name of foster parent, foster parent's identification number, and whether a foster grant is received or not. Included in the database for clients or elderly are the following variables: male or female, bedridden, disability, HIV, TB, orphans, foster care, families, hypertension, ARV treatment, epileptic, asthma and diabetic. Variables in the caregiver database include; name of caregiver, sex, ID number, age, contacts, area or town located, level of education, training received, and stipend being received from DOH/DSD.

All the variables were identified as being useful. The need for considering any ethical questions was not seen. Difficulties were reported to arise when trying to get ID numbers of some of the orphans. In such instances, home-based caregivers would go to the schools where these children were enrolled to try and get these numbers. Currently, approximately 600 children are recorded in the database.

### **Maintenance**

Data on children are collected while home-based caregivers are visiting their clients, the elderly. New entries into the database are made every month. Up until now the information in the database has not been updated. No entries have been removed.

Depending on how much data is collected, inputting into the electronic version may take 2 or 3 days. Three of the staff at the Kimberley office are responsible for this. These three staff and

the secretary have access to and are able to retrieve information from the database. No formal training was given. The staff concerned, all have basic computer skills.

### **Access to the information**

Within the organisation, the director, the secretary and two other staff have unlimited access to the database. The Age in Action head office and the Departments of Health and Social Development also have access to the database. Confidentiality is not taken into consideration when giving access to the database. The reason for this is that when either of the government departments receives donations, they can distribute them to specific individuals from the databases who are in need. With this in mind the organisation says that they feel free to give information from the database to others, provided it is for the benefit of the individuals in the database.

Age in Action does not receive any other information on children affected by HIV and AIDS for its database from other organisations.

### **General assessment**

The existence of the databases has assisted the organisation in generally providing a better service to its clients quicker. Future activities can be planned in advance once a certain need is identified. For instance, the organisation realised the need to serve children merely by counting the number of children that the elderly were looking after. Age in Action relates that they can now legitimately use the figures they have in their database for fundraising initiatives.

Advice given to other organisations in a similar situation is that firstly, having a method of collecting data on those they serve is a necessity, and that secondly, once this is done it saves time, and will assist them in providing a better service to their clients.

## **NORTH WEST: NTUTUBOLLE**

### **Background**

The Ntutubolle (open your eyes) crèche and aftercare facility in Seweding Village, Mafikeng represented the case study in the North West province. A family within the community donated the three-roomed brick house that has been transformed into the crèche. The crèche is run by Ms Malerato the owner, with the assistance of two teachers, a cook and two unpaid volunteers from the community.

The crèche serves children between the ages of 9 months and 5½ years old during the week. These children are from Seweding village and the surrounding villages of Patsima and Macoseng. This year, Ms Malerato is not aware of any of the children being HIV-positive.

Last year three of the enrolled children were HIV-positive. These children have not returned to the crèche this year. Presently, four of the 32 children in the crèche are orphans who are looked after by guardians in the community. It is suspected that these children are AIDS orphans. In some cases these guardians had not applied for the child support grant and could not afford the monthly crèche fee. Ms Malerato has assisted these guardians in applying for this grant.

Every Saturday Ms Malerato holds HIV and AIDS and drugs awareness workshops at the crèche for teenagers in the community. Between 10 and 15 teenagers are involved in these workshops. At times counsellors from the Department of Health come to address the group on HIV and AIDS related matters. The group has formed a, Teenagers Against Drug Abuse (TADA) club.

Ntutubolle is a private creche that is partly subsidised by the Department of Education (DOE). Over 80% of its funding is from fees. Guardians and parents sending their children to the crèche pay a monthly fee of R80 for children between 4 and 5½ years old, and R120 for those younger than 4 years old. The DOE provides the remaining 20% of their funding. The Department gives a ‘conditional’ grant of R1000 per month that is paid out to the crèche quarterly. This grant is conditional because it is reviewed every year. It is dependant on the number of children that are enrolled that year. To obtain the grant more than 25 children have to be enrolled in the crèche. Ms Malerato was unable to obtain funding elsewhere because she did not have a non-profit organisation (NPO) certificate. She has recently obtained this certificate and is in the process of applying for funding with agencies such as the national lottery.

### **History of the database**

Ms Malerato maintains a simple paper database, which focuses on keeping records of the children in the crèche and their particulars. She started this database in 2005. The impetus to create a database came from an Educare programme at NQF level 4 that Ms Malerato completed. During the programme, the child care workers were encouraged to create and maintain a database. The current format for the Ntutubolle crèche and aftercare database was adapted from one given during the Educare programme.

The database covers all children enrolled in the crèche. With the assistance of a parent the format for the database was typed out on computer and printed out. Ms Malerato has basic computer skills but does not have a computer or typewriter for the crèche. For additional copies of the database format, one of the parents assists with photocopying. A separate paper-based register is kept each week to record the number of teenagers that attend Saturday HIV and AIDS and drug awareness workshops. The register has the date of the meeting and the name of the teenager. No backups exist of either the database or this register are made. The database is filed away and stored in a filing cabinet.

The variables in the crèche database are; ID number, name and surname, sex, ID number, race, address, name of mother, name of father, admission date, place and reason. The variable 'place' identifies the village the child comes from. Under the variable 'reason', parents or guardians explain why they are sending the child to the crèche. Some of the reasons include that there is no one to look after the child because the child is an orphan, parents want the children to be better prepared for school or the parents and guardians are unemployed and cannot afford to feed the children. (The latter is a relevant reason as the children at the crèche are fed twice a day.)

Ms Malerato maintains that with such a limited set of variables, all the variables are important. Difficulties arise when obtaining the identification numbers of children. Some of the children do not have birth certificates and so do not have identification numbers.

The database had a total of 32 records in it at the time of the interview. The records represent children. Regular reports are not made from the database, though the number of records in the database is reported to the DOE for grant purposes.

### **Database maintenance**

Information from an enrolment contract, a fees contract and indemnity form that parents fill in and sign at enrolment, together with photocopies of birth certificates and the child's clinic card, inform the database. Information is filled in on the database format whenever a child is enrolled. Ms Malerato is the only one who transfers this information to the database. The other staff members only assist with the enrolment procedure, including collection of the various forms. The main reason for Ms Malerato being the only one to transfer information is to maintain some confidentiality with regards to the 'reason' variable that is in the database. Only Ms Malerato has access to the database. With regards to access to the database from the outside, Ms Malerato maintains that she is unwilling to share the information with any other organisation.

### **General assessment**

The database has assisted in looking up information quickly. For instance looking for the name of a parent can be done without having to search for it amongst the contracts the parents signed when enrolling their child. The database is not, however, of great relevance for monitoring of OVCs in that, firstly, only a small number of the children at the crèche appear to be directly affected at any time and, secondly, the database does not explicitly record information about this aspect of the children. A register is kept for all HIV and AIDS and drug awareness workshops, but this cannot really be considered a database.

## WESTERN CAPE: KHAYELITSHA CLINICS

### Background

Three HIV/AIDS clinics in Khayelitsha, Cape Town represented the case study in respect of Western Cape and health services. The three clinic sites – Michael Mapongwana, Nolungile Community Health Centre and Site B Day Hospital – all currently offer a range of services, including ART, education, counselling and support groups, a hospice, prevention of mother to child transmission (PMTCT) and voluntary counselling and testing (VCT). The international NGO Médecins Sans Frontières (MSF) began providing clinical services, and ART in particular, in respect of HIV/AIDS to adults and children at the three clinics in 2000. It did so in collaboration with the Department of Public Health and Family Medicine at the University of Cape Town (UCT). Today the service falls under the provincial Department of Health's HIV/AIDS/TB directorate. UCT and MSF continue to play a role although the latter will in future be much less involved in day to day service delivery. At this point, probably 80% of the funding comes from government which, in turn, sources the funds through the Global Fund. The remaining 20% is from MSF.

Information about the database was obtained from Andrew Boule of UCT, who, in addition to his role in maintaining the database, has in the past provided clinical services at the clinics, and, with his colleague, continues to attend clinical meetings.

The data system described in this case study is being rolled out throughout the Western Cape, although not always in electronic form. At this stage, most of the 43 ARV sites in the province are using the paper-based register. Only Gugulethu and Khayelitsha clinics and Red Cross, Victoria and Tygerberg Hospitals are using electronic patient information systems. The paper-based register, which has one line per person, is based on the TB register system used in the country which is, in turn, based on an international prototype. Beyond the province, the ART system is being used in an MSF site in Lusikisiki in the Eastern Cape and will also be used in a newly established MSF site in Lesotho. The system is one of the country examples of the WHO recommendations for monitoring ART. (<http://www.who.int/3by5/publications/art/en/>).

The three Khayelitsha clinics between them employ 10 doctors, six nurses and twelve counsellors as direct service providers, two research nurses who do data enhancement resolving queries and filling gaps, and seven clerical staff who do data capture, filing, etc. There is also one cleaner per clinic. The research capacity is supplemented by UCT researchers off-site. At this stage the MSF office in Khayelitsha also provides some logistical support.

The three clinics provide comprehensive HIV care, from testing, through treatment for opportunistic diseases, to ARV. Counselling is provided to adults, including the caregivers of infected children. The majority of the children on ARV treatment at these clinics are older

than at nearby hospitals (average 4 years of age on starting), as they are easier for primary care clinicians to manage. The remaining children are generally cared for at local hospitals. This pattern is a result of the generally good paediatric services in the hospitals in the province, but there are plans to shift the locus of care to the clinics by transferring cases to clinics on an outpatient basis. This is seen as lessening the burden on the caregivers in terms of transport, needing to go to different places for themselves and their children, etc.

All children served by the clinics are HIV-infected. Approximately one in ten of patients on ARV are children. This relatively low percentage is a partially the result of the effectiveness of the prevention of mother to child transmission (PMTCT) programme in the province.

### **History of the database**

The original database was set up in 2000, when clinical services were first established. The main motivation was to conduct operational research on the new, and very visible and political, project to provide ART in the Western Cape. The main focus of the database was therefore programme monitoring, rather than clinical use in patient treatment. The variables thus cover epidemiological variables as well as the diagnoses and adverse events which are the main data needed by clinicians.

The database consists of multiple tables, with the basic unit being a record for every visit. Children (and adults) are entered in the system when they enter care, even if they are not given ART at that point. This is done to enable monitoring of programme quality before ART is necessary. The database was set up by staff of MSF and UCT, both of whom have continued to play a role. Although similar models, which capture data after every visit, are used around the world, this particular version is not at this point used anywhere else.

UCT provided the assistance as part of the service delivery responsibility which the UCT Department has to the province. In addition to considerations of financial costs, the advantage of this approach was that the system was designed by people who had an intimate knowledge of the clinical programme. The initial computers were supplied by MSF, but purchase of further computers and supplies as well as maintenance costs are now covered by the province.

While the database was designed primarily for programme monitoring, its utility in respect of clerical functions has encouraged buy-in among staff responsible for maintaining the data. Thus the system allow for printing stickers (for example, for blood specimens), searching on names, finding folders, helping with filing. It automatically generates the routine reports, such as numbers seen, numbers in care, and longitudinal cohort outcomes, required on a monthly and quarterly basis by the province. In terms of the operational research, it provides the basis or in-depth sentinel surveillance, providing information, for example, on the toxicity of different drugs, types of infections, etc.

One challenge is that the clerks and clinicians have very little incentive to ensure that all the clinical data are correct. This has necessitated the hiring of the data enhancers, who follow up on test results and patient details, and generally ensure completeness and validity.

### **Technical issues**

The current version of the database is written in Microsoft Access, but the province has arranged for it to be rewritten in Oracle and VB.Net so that it can be used at scale across the province.

The database consists of about 20 tables. A limited number of basic demographic data are stored in respect of each patient, including sex and age, as well as contact details. ID numbers are requested, but not always available. There is also a unique identifier for each person which the province is hoping to use in public facilities across the province.

For each visit, there are a significant number of clinical variables. These include WHO stage, weight, height, blood results, referrals, TB symptoms, and medication.

On a monthly basis, the standard reports generated by the database focus on outputs such as the total number in care, and total new patients. There is also a prescription report on drugs used over the last month. Quarterly the focus is on outcomes, such as retention in care, survival, and virological suppression. This is reported in terms of ‘cohorts’, i.e. a group of patients who begin treatment in a given month or quarter. In addition to these requirements from the province, staff on-site use the data to benchmark themselves against other facilities.

For the clerical staff, the most important variables relate to names, ID numbers and addresses which assist with scheduling appointments, following up on defaulters, retrieving folders if patients do not bring their cards, and printing labels. The system can generate a daily report on missed appointments. It also provides for ad hoc reports, such as a clinical summary if a patient is being referred.

Addresses and phone numbers are among the most difficult data to collect because of the mobility of the population served. Problems in relation to collecting laboratory results are largely the result of weaknesses in clinical recordkeeping.

The database has been improved over the years, as the ARV intervention itself has developed, or when there has been a change in practice or procedures. Some unessential clinical variables have been dropped because of the generally poor quality. A TB module has recently been added to the application.

There are concerns about ethics to the extent that name and status (all those recorded on the system are infected) are recorded on the same system. The UCT team applied to the university’s Ethics Committee to endorse the data enhancement process on the basis that the

exercise is clinical rather than research and does not collect any data that is additional to routine clinical care. This obviates the need for signed patient consent. Users of the database have individual usernames and passwords, which provides some degree of protection. Initially names were not recorded on the system, but this made it useless in terms of clerical functions on-site so they were added. At the time of the interview the system had about 150 000 visits and 15 000 patients since inception. Of these, an estimated 6-7 000 (adults and children) are active at any one time. Approximately 4-500 kids seek care at any time, of whom about 250 are on ARV.

### **Maintenance of the database**

The information is collected during each visit by the clinicians (doctors and nurses). They do this using a structured form which is stored in the patient folder. The form provides a vertical column for each visit, making it easier for the clinician to see what has happened in previous visits.

The visit information is captured the same day, but in a separate process. All clerical staff know how to input data, but one at each site has been designated as the main data capturer. These staff members probably spend 30-40% of their time on data capture and the rest on related tasks such as filing. The team estimates that one person is needed for clerical functions in a facility serving up to 300 patients, two people for 3001-1 000 patients, and three people thereafter. One problem with low volumes is what to do when the one person is on leave or otherwise unavailable.

All those who know how to do data capture are also able to generate standard reports and export data. It is only UCT and MSF staff who are able to do custom queries. Currently, all records since inception are retained in the database. This enables tracking of the history of a particular patient or cohort and also facilitates referrals. There is no 'how-to' manual on operating the electronic database. There is, however, a manual explaining all the data items and definitions. There is also a detailed manual ('Routine Monitoring of Antiretroviral Treatment') explaining, among other things, the use of the paper-based system which mimics the electronic system.

At present, there is no formal system of backing up data as the same database is replicated on seven or eight computers across the three Khayelitsha clinics, and the databases are synchronised on a weekly basis. If data capturers fail to capture a particular visit, it will be picked up at the time of the next visit because of the column-based way in which records are kept.

### **Access to the information**

All clerical staff and the two data enhancers have usernames and thus have access to the system. The clinicians do not have usernames and are meant to access the system through the

clerical staff. UCT and MSF staff who work on the system have access for data management purposes.

The clinics provide regular reports generated by the database to government, as described above. The raw data are also being used in a cohort collaboration called ART-LINC (Lower Income Countries). MSF previously contributed the data to an MSF combined analysis but is not doing so at present.

The standard reports consist of aggregated information so present no problems in terms of confidentiality. The names are removed and clinic folder numbers and exact date of birth scrambled when data are provided for the cohort programme so as to prevent identification of individuals. The team has previously provided a sample of the database to other programmes to 'play' with, but has not recommended people using the database because the team does not have the capacity to support them.

The clinics would like to get information as to which children benefited from the PMTCT programme so as to enrich possible analysis. Although the laboratory results are available from the National Health Laboratory Service (NHLS), at present this linkage is not possible, among others because of weaknesses in identifiers.

### **General assessment**

The team does not advocate an electronic system for facilities with relatively few patients. It argues that in many respects a paper-based system is more empowering for staff, and an electronic system tends to distance the clinicians. However, the team feels that the electronic system is more efficient than a paper-based one for larger facilities on condition that the resources are well managed. The resources in question include data capturers and data enhancers.

The main advice offered in the interview to others planning to set up a database was to try to find a source of unbiased technical support and advice, i.e. a source that was not motivated by commercial or other interests. From the description given of the application, it was also clear that the team had investigated carefully a range of systems being used in other clinical settings, both within South Africa and beyond, when initially designing the system, and continues to keep up-to-date on developments elsewhere.

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## OVERALL TRENDS AND LEARNINGS

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This section summarises the findings and describes the key trends identified in respect of OVC database development, maintenance and sharing information and draws out the key learning points observed from the case studies involved in this project.

### ORGANISATIONAL BACKGROUND

The organisations that were included as case studies in this project are fairly recent. Nine of them were established after 2000. Three were established in the 1990s. This pattern is not surprising given that it is during recent years that there has been widespread acknowledgement in South Africa that the HIV and AIDS pandemic has become acute, and the number of OVCs, in particular, has become significant.

Most of the organisations established their OVC databases either the same year they began operations or a few years later. The exception to this was Friends for Life who started in 1991 but only established a database ten years later. In one case the database was established before the organisation, as the research findings reflected in the database revealed the need for an intervention. Four organisations (Age in Action, Amazing Grace, Isibindi and MIET) had a presence in other provinces besides the one in which they are based. In three of these cases, the other sites had similar databases.

Eight of the 12 organisations were NGOs providing a range of services related to HIV and AIDS including care and support of orphans and vulnerable children. The type of services provided to orphans and vulnerable children was very diverse. Several organisations offered material support in the form of food parcels, school fees, clothing and school uniforms. Almost all of them provided psycho-social support in the form of counselling, group therapy and sports and recreational activities. A key element of the OVC support involved assisting and following up on grant applications. Virtually all the NGOs in the study were providing this service.

The definition of orphans and vulnerable children differed to some degree. The main definition appeared to be a child who has lost both parents. This is surprising in a situation such as that in South Africa where slightly more children are living with only their mother than are living with both parents as, in reality, many children become orphaned when their mother dies. Presumably in recognition of this, in some cases children who had lost one parent and the second parent was unknown were considered as vulnerable. Other cases of vulnerability included children from poor socio-economic background and children whose parents were terminally ill. While organisations were generally flexible about these definitions, one organisation (Dihlabeng Consortium) appeared to be quite strict in its definition arguing that some people would falsely present children as orphans in order to

access the foster care grant. This organisation would require an affidavit from the police as proof to avoid false claims of orphanhood.

Definitions on what constitutes orphanhood also vary according to the age limit for children. Orphans, as defined by UNICEF and UNAIDS are children between the ages of 0 and 18 years whose mother (maternal orphan), father (paternal orphan) or both parents (double orphan) are dead. Vulnerable children are those whose survival, well-being or development is threatened by HIV and AIDS (UNAIDS, 2004). The World Bank considers children to be persons between the ages of 0 and 14. The Health Systems Trust defines children as persons below the age of 16. Most of our case studies however seemed to concur with the constitution's definition of children as persons between the ages of 0 and 18.

Several organisations were serving other children besides OVCs. The most extreme case was the organisation in the Northern Cape, which provided crèche services to children in the community, and almost certainly included some children among these who were affected by HIV. However, this was not a particular focus of the organisation's services. In cases where databases included children who were not OVCs, the databases did not always include variables which would allow one to distinguish between OVCs and others.

## **HISTORY OF THE DATABASE**

While a few organisations such as Dihlabeng AIDS Consortium and the Khayelitsha clinics were funded predominantly by government departments, most organisations received funding from a range of local and international sources. Donor funding appeared to be closely linked to the motivation for setting up the database. For three of the NGOs, the key aim of having the database was to be able to provide accurate statistics and reports on their work to donors. Where funding was provided by government, for example for stipends for volunteers, this was also usually accompanied by the requirement that the organisation submit records, and thus prompted the setting up of a database.

For all the other organisations, having an efficient system for record keeping and tracking and for monitoring, research and evaluation were the reasons for implementing the database. Some organisations had been collecting paper-based records for several years prior to the establishment of the electronic database. An example is Ingwavuma Orphan Care who had over 1500 hand written files containing information on 400 children and needed an efficient system to manage this information. In most cases, staff members usually the director or other senior staff, were responsible for setting up the database. Further, in some cases volunteers, for example at Dihlabeng Development Initiative, were also part of designing the database. However, in several cases an outside 'expert' was brought in to help in setting up the database. Two of the case studies (Msunduzi and Ingwavuma) relied solely on external assistance for the development of their electronic databases.

The focus of the database was generally orphans and other vulnerable children identified as being in need of some support. The Western Cape clinics' database is focused on children receiving treatment and records each clinic visit. Two organisations combined household level data with data on individual children in the household defined as vulnerable. A third organisation collected information on child-headed households for the Provincial Department of Social Services but did not keep records of this information. The information on households is useful particularly for the identification and support for child-headed households. However, one of the organisations has discontinued the use of the household assessment form since data collected in the past has not been put to any use. Further, to be useful and reliable, information on child-headed households would need to be updated at short intervals as the children in these households are often absorbed into other households.

## TECHNICAL ISSUES

The storage of the OVC database usually involved a combination of paper-based and electronic methods although two organisations (MIET and Ntutubolle) exclusively used manual records. In many cases, the paper-based system recorded more detailed information than the electronic one. In one or two cases, the electronic system was little more than a list of names or a record of summary totals.

Microsoft Excel was the most common software used for storage of the database. Several organisations had simple lists or registers stored in MS Word. The latter provides less opportunity for analysis than Excel. Khayelitsha and CHoiCe Trust in Limpopo had databases on MS Access. Khayelitsha is in future looking to rewrite the database in Oracle and VB.Net. The Access programme allows for standard reports to be generated. The Khayelitsha clinics generate such reports on a monthly basis focusing on outputs such as total number of new patients. CHoiCe has not as yet been able to optimise their database to generate such reports mainly due to lack of capacity.

For organisations that used a dual method of record keeping, the paper form was generally used mainly by social workers or volunteers to collect data during home visits or at intake. This information would then be stored in files. Some of the organisations such as Siyabona attempted to capture this information electronically depending on time and capacity. Others like Friends for Life keep manual files of each beneficiary. The information from each file is not captured electronically. However, an electronic register of all children is kept as well as other files such as food parcel distribution lists and training attendance.

The variables listed on databases range broadly from basic demographic information about the child and their household and carer's details to family background including parent's details, detailed explanations about their circumstances and to data on grants applied for and received. Information on identity documents as well as social grant information is reported to be very useful for organisations that are providing assistance with grant applications and

follow-up. The quantity of information varies greatly depending on the uses of the data. Khayelitsha for example, collects a huge amount of clinical data for each patient visit. While most organisations said that all the information they collected was useful, some like IOC and CHoiCe admitted to being unable to put all the information to proper use. IOC for example collects a wealth of household level data which it is unable to process. The IOC system provides for collection of information on all children in the community, rather than only those who are served as in other organisations. The reason for this is its origins in a research project which later formed the basis for a master's thesis. The complexity of the IOC system has resulted in a social worker implementing an alternative system which is simpler and more focused on the organisation's work.

A few organisations had other databases in addition to the OVC database. Age in Action, for example, has a database of the elderly and a database of caregivers, in addition to the database of children looked after by the elderly. Interestingly, the database of the elderly and the one on children did not appear to be linked in any way except through the name of the beneficiary. This form of linking would be unreliable where, as is often the case, there is more than one person with the same or similar name. The alternative of linking on the basis of identity numbers would also be difficult, as identity numbers were the variable most often singled out as being difficult to collect. One reason for this is that not everyone has an identity document.

Few organisations knew of others utilising similar databases. Dihlabeng was keen to learn more about databases from organisations with similar or more advanced systems but did not know of any organisations with such systems in the area. Others like CHoiCe Trust felt that this was an area where government could play a bigger role in facilitating networking and learning and also in supporting organisations to develop databases. Several organisations noted that while donors and government had urged them to establish a database, in most cases they had not provided support to the organisation to assist them in doing so.

## **DATABASE MAINTENANCE**

Database information was mainly collected by social workers and volunteers. The exception to this was the Khayelitsha clinics where the clinicians collect the information at each clinic visit. In some cases, information for the database is collected from other sources, for example schools, police and clinics but generally the data are sourced from the beneficiaries themselves. Several organisations raised as a concern the issue of volunteers collecting reliable and accurate information. They felt that the challenge did not necessarily lie with the collection of information itself but rather with ensuring that volunteers and other staff responsible for collecting data asked the right questions and filled out the forms as required. The Khayelitsha clinics employ staff to validate the data and collect missing information.

While the collection of the information tends to happen on a regular basis, the capturing and updating of electronic data in several cases was ad hoc and subject to the availability and

capacity of staff. Data capturing was often limited to a few staff, usually administrative staff and data capturers or the executive director. Two organisations (Siyabona and CHoiCe) had accumulated back-logs as a result while MSF also mentioned it as a potential cause of concern if the designated staff member/s in a small clinic with limited staff were to leave or be absent. Ingwavuma in KwaZulu-Natal had also experienced similar problems in the past mainly due to the collection of a huge amount of unnecessary information.

Most organisations delete records of children who move away from the area, die or reach adulthood (usually age 18). While this practice is good for the management of the database, it would also be useful for the deleted entries to be stored elsewhere for follow-up purposes and/or to allow for trend analysis. Dihlabeng, in particular, would like to follow up the children who are deleted after they reach 18 because they feel that their vulnerability is often extended into adulthood but feel constrained by the fact that their donors do not have any provision for the support of children beyond 18.

## ACCESS TO INFORMATION

Within the organisation, access to information was generally restricted to managerial and administrative staff. In a few cases, other staff such as volunteers, coordinators and educators also had access. Several organisations provided database information to donors but this was usually limited to statistics and reports generated rather than the database itself. MIET did however provide their actual database to the Departments of Education and Social Development.

Confidentiality of information should be crucial in maintaining such databases. While most organisations did in theory have sensitivity to keeping information confidential, some appeared to be more open to sharing their databases with other organisations than one would expect. Some organisations like Amazing Grace ask their staff to sign a declaration of confidentiality to ensure that personal information about the children in their care is protected. This is particularly useful for organisations like these that deal with children in difficult circumstances. Khayelitsha have access controlled through user-names provided to the clerical staff and data capturers. The clinicians would only be able to access information through the clerical staff. This is important considering that the name, address and HIV status are recorded on this database. Some organisations felt that confidentiality was not a real issue as the database did not record any information in relation to HIV and AIDS. This raises a question as to whether there are not confidentiality concerns beyond HIV and AIDS.

Another related issue was the fact that none of the organisations except Khayelitsha made use of unique identifiers. This poses concerns for confidentiality in that the identifiers could be used instead of names when passing on information, and the link between names, addresses and other identifying information kept confidentially. However, most organisations seemed to be comfortable with listing names and addresses as long as the information was retained

internally. For example, Friends for Life would take out the names when sharing the lists with others externally while Siyabona would remove the physical address.

None of the organisations said that they provided their database to others besides their parent organisations, donors or government. None said that they received database information from other organisations except Amazing Grace who receive case history information from the police, social workers and clinics. None of the other organisations expressed a need for either of these types of sharing.

The Friends for Life case study brought out an interesting issue with respect to “ownership” of OVC and other beneficiaries. The organisation has had a negative experience where other organisations doing similar work refer children to them only to lay claim of the children later. To avoid this, formal referral systems have been instituted by the organisation. This serves as a useful lesson and points to the possible use of information sharing to avoid duplication of services which was said to be a very common occurrence especially with HIV and AIDS patients. This problem was not reported by any other organisation.

## GENERAL ASSESSMENT

Organisations were asked to comment on the advantages and challenges experienced with their databases and to say what advice they would give to organisations wanting to establish similar databases.

All the organisations felt that their databases had improved their efficiency in compiling reports, tracking progress, and analysing trends with regard to their beneficiaries or patients. ChoiCe Health Trust felt that having a database was “credible and fashionable” and a plus point when soliciting funds from donors. One of the other organisations also seemed to see the main function of the database as providing information for fund-raising purposes. Several organisations said they were able to assess their achievements and failures and assess progress in their programmes using their databases. Khayelitsha additionally said their database allowed them to benchmark themselves against other facilities in the province. However, it was not clear how some of the organisations were able to do this given the limited nature of the data collected.

The Khayelitsha clinics feel strongly about the utility of having a paper-based system especially in cases where limited information is collected. They feel that this system is more empowering to staff than an electronic system which is usually operated by specialised staff. The clinics have found that data collection is also improved when, as in this case, staff collecting the information can see how the information is useful in carrying out their own tasks. Friends for Life shared this sentiment. They strongly recommend the manual OptiPlan filing system with electronic data serving mainly as a back-up system. The only shortcoming

with using an exclusive paper-based system is that generating any type of report becomes very laborious and time-consuming.

A useful lesson to be learnt emerged in a comment from CHoiCe Trust with regard to donor's requirements for reporting. They felt that donors often had very different requirements for reporting and that it would be useful if the donor requisites were similar as this would make it easier for the collection of information and for the reporting process.

The importance of public-private partnerships in database development was stressed by Msunduzi municipality who have received assistance not only in the design and development of their database but in the actual maintenance of it. However, it would be useful for the municipality to develop capacity to run the database on its own in future.

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## RECOMMENDATIONS

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- Paper-based vs electronic system: A combination of the two seems to work well but for organisations with few entries or limited capacity the paper-based system is recommended.
- Training and capacity building in data collection for volunteers and other staff in capturing data and generating reports. The training would need to cover the rationale for the forms and questions asked to help the data collectors understand what the information they are collecting will be used for and, in particular, its utility for their own functions.
- Uses of data: Improving use of data for example by generating reports and going beyond providing statistics to using the data as a monitoring and evaluation tool is encouraged.
- Support in database development (technical as much as material). Where donors or government require databases of those they assist, they should be prepared to provide the assistance. Where possible, this could involve employing someone to provide such assistance and to promote standardisation across similar organisations/initiatives. This would help address the current worrying reliance on individual ‘experts’ inside or outside the organisation who might not always be available.
- Identifying needs and categories before system is established. It is recommended that organisations developing OVC databases should start small and grow from there, rather than starting big and not being able to cope and becoming discouraged about the potential of database.
- The use of reliable backup systems should be promoted.
- The development of simple manuals which explain the database and how it works should be encouraged to avoid problems when those responsible and knowledgeable about the database move on.
- Discussions should be encouraged as to what the confidentiality issues are in relation to databases, and what steps can be taken to ensure the necessary confidentiality.
- The databases reviewed in this audit should not be seen as forming the basis for the planned single national database of OVCs being served, or needing to be served, at local level. The case studies reveal the diversity of the type of information needing to be collected by organisations which offer sometimes very different services and serve different groupings of types of children. This results in different optimal database designs, including variables to be included, for different organisations. Further complicating any attempt to use these databases as the basis for a single national database is the varying mix of use of paper and electronic systems.

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