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# The state of our children's homes: a descriptive study of conditions and resources within childrens homes in the greater Johannesburg area with special reference to the impact of the HIV/AIDS epidemic on these facilities and the training/expertise of caregivers working in these homes

**Meiring, Michelle Adrienne**

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# THE STATE OF OUR CHILDREN'S HOMES:

## A descriptive study of conditions and resources within children's homes in the greater Johannesburg area with special reference to the impact of the HIV/AIDS epidemic on these facilities and the training/expertise of caregivers working in these homes.

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Submitted for the degree of

**MASTER OF MEDICINE**

**Department of Paediatrics**

**University of the Witwatersrand**

**Supervisor: Prof Gayle Sherman**

**Co-supervisor: Dr Tamara Meyers**

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**DECLARATION**

I, Michelle Adrienne Meiring declare that this research report is my own work. It is being submitted for the degree of Master of Medicine in Paediatrics in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

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_____ day of _____ 2008

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**DEDICATION**

DEDICATED TO MY DAUGHTER

Kerry Jean Porrill

who was born during this study

27/05/2003

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## PUBLICATIONS AND PRESENTATIONS ARISING FROM THIS STUDY

No part of this research dissertation has been submitted for publication as yet, but several presentations have been made to various audiences as tabulated below:

*Table 1 Presentations arising from this study*

| Forum | Date (s) | Purpose of presentation |
|---|---|---|
| Representatives from the National Institute for Communicable Diseases (NICD) and Department of Community Paediatrics | 13/05/2004 | Overview of infectious disease outbreaks in the children's homes |
| Provincial Expanded Programme of Immunisations | 25/08/2004 | Overview of measles outbreaks in the children's homes |
| Department of Environmental Health (Johannesburg Metro Council) | 26/08/2004 | Overview of infectious disease outbreaks in the children's homes |
| Gauteng Plan of Action for Children (GPAC) | 23/02/2005 | Health concerns in children's homes and the impact of HIV |
| The Department of Environmental health (Johannesburg Metro Council) | 19/05/2005 | Health concerns in children's homes |
| National Association of Child Care Workers (NACCW):<br>National Conference<br>Cape Town | 05/07/2005 – 07/07/2005 | Summary of research findings with emphasis on caregivers working in the children's homes |
| Paediatric Research Day<br>University of the Witwatersrand | 20/08/2005 | Summary of research findings on the state of our children's homes |

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**Posters relating to this research dissertation were presented at three AIDS conferences:**

1. J Perold, GG Sherman, MA Meiring, SA Jones: Children's Homes Outreach Medical programme (CHOMP): 1st South African AIDS conference, Durban: 3 – 6 August 2003

2. MA Meiring, GG Sherman, SA Jones: The impact of HIV PCR testing of HIV exposed infants under 18 months of age in children's homes on the AIDS orphan crisis: XV International AIDS conference, Bangkok: 11- 16 July 2004

3. MA Meiring, GG Sherman, TM Meyers: Children's Homes and The HIV epidemic: what is their role? International AIDS conference, Toronto: 13 – 18 August 2006

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**ABSTRACT**

**INTRODUCTION**

The HIV epidemic in South Africa has increased not only the number of ill children but also the number of orphans. Although the establishment of orphanages is not sustainable, the number of residential care facilities continues to increase. Many persons working in South African children's homes can testify to the impact HIV has had on this sector, but no studies have actually measured it.

**AIMS**

The primary aim of this research was to determine the impact of HIV on the Johannesburg children's homes. The secondary aims were to make recommendations informed by this research to assist children's homes to mitigate the impact and to inform the activities of the Children's Homes Outreach Medical Programme (CHOMP).

**METHODS**

A rapid appraisal of all children's homes in the greater Johannesburg was done by means of a telephonic survey. This was followed by an in depth analysis of 24 children's homes through the use of questionnaires, data collection forms, a pop quiz for residential child care workers and the inspection of facilities.

**RESULTS**

A total of 115 residential care facilities with a population (excluding the special needs homes) of 5 934 were identified. In a sample of 24 homes, 31,7% of the children were HIV affected and 20% HIV infected. The morbidity rate in the homes was 10%, and 99% of this morbidity was attributable to HIV/AIDS. Over a 6 month period 57 children died in the children's homes, 93% from HIV related conditions.

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## CONCLUSIONS AND RECOMMENDATIONS

The HIV epidemic has changed the face of the Johannesburg children's homes and several new unregistered children's homes have been founded in response. The institutions responsible for the homes have not kept pace with this change and as a result few systems are in place to adequately address the health care needs of children even in registered children's homes. Nonetheless, the registration of children's homes would be the first step in trying to monitor the sector. The second step, to specifically address health standards in children's homes, would be to revise existing legislation in this regard and finally to measure the success of health related interventions in the homes by monitoring health related indices.

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**ACKNOWLEDGEMENTS**

1. My supervisor Prof GG Sherman and my co-supervisor Dr TM Meyers for their patience, assistance and valuable time spent in assisting me with this research.
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4. Ms J Perold and Mr T Netkoffhe who assisted me with data input and the caregiver's survey.
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**LIST OF ABBREVIATIONS AND ACRONYMS**

| | |
|---|---|
| **ADHD:** | Attention-deficit Hyperactivity Disorder |
| **AIDS:** | Acquired Immune Deficiency Syndrome |
| **ARV:** | Anti-retrovirals |
| **BBBSSA:** | Big Brother Big Sister South Africa |
| **BICA:** | National Black Leadership Commission on Aids |
| **CDC:** | Communicable Disease Directorate |
| **CHOMP:** | Children's Homes Outreach Medical Programme |
| **CINDI:** | Children In Distress |
| **CPR:** | Cardio-Pulmonary Resuscitation |
| **DOH:** | Department of Health |
| **DQA:** | Developmental Quality Assurance |
| **DSD:** | Department of Social Development |
| **ECD:** | Early Childhood Development |
| **ELISA:** | Enzyme Linked Immunosorbent Assay |
| **EPI:** | Expanded Programme of Immunisations |
| **GP:** | General Practitioner |
| **GPAC:** | Gauteng Plan of Action for Children |
| **HIV:** | Human Immuno-deficiency Virus |
| **IMC:** | Inter-Ministerial Committee on Young people at Risk |
| **IMCI:** | Integrated Management of Childhood Illness |
| **JCWS:** | Johannesburg Child Welfare Society |
| **NACCW:** | National Association of Childcare Workers |
| **NGO:** | Non-governmental organisation |
| **NICD:** | National Institute for Communicable Diseases |
| **ORS:** | Oral Rehydration Solution |
| **OT:** | Occupational Therapist |
| **PCR:** | Polymerase Chain Reaction |
| **PHC:** | Primary Health Clinic |
| **RCCW:** | Residential Child Care Worker |
| **RTHC:** | Road to Health Card |
| **SA:** | South Africa |
| **SAQA:** | South African Qualifications Association |
| **TB:** | Tuberculosis |
| **UCT:** | University of Cape Town |
| **UK:** | United Kingdom |
| **UNAIDS:** | United Nations Programme on HIV/AIDS |
| **USAID:** | United States Agency for International Development |
| **UNICEF:** | United Nations Children's Fund |

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# CHAPTER 1: INTRODUCTION

## 1.1 Motivation for this study

The motivation for this study arose out of the author's experience as a volunteer doctor for a children's home that had been established in Johannesburg in 2000 to address the needs of HIV affected children. This experience highlighted some of the problems faced by caregivers in looking after these children and suggested that there was an increased need for access to health care services and professionals.

In order to validate the above-mentioned impressions it was necessary to:

i. Determine the extent of the burden placed on institutions by children infected and affected by HIV in Johannesburg.
ii. Evaluate the current resources in these homes both in terms of facilities and staff.
iii. Assess the level of knowledge and skills possessed by caregivers in meeting the health care needs of these children
iv. Establish what training opportunities were available to these caregivers.

To determine the need for health care services to these homes it was necessary to:

i. Evaluate the current use of available resources
ii. Define the problems that existed in the access and utilisation of these resources.
iii. Analyse the sufficiencies and deficiencies of both the children's homes and the health care facilities in addressing the health care needs of children in the residential care sector.

Findings of this study could improve the healthcare management of children in homes and identify training needs of caregivers working in these facilities. If these caregivers were empowered with basic medical knowledge this could decrease the need for professional

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healthcare consultations. Additionally, suggestions on how healthcare services could better assist children's homes in meeting the needs of their children could be made.

This study led to the founding of the Children's Homes Outreach Medical Programme (CHOMP) and the findings of the study informed the interventional strategies used by CHOMP to improve the medical management of children in the Johannesburg Children's Homes (Appendix 1).

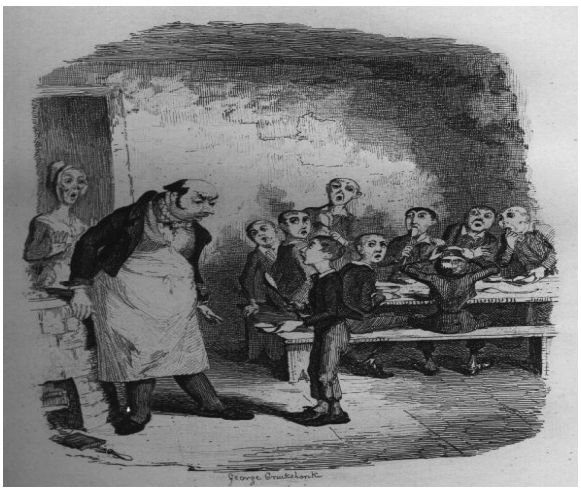
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## 1.2 Literature review

### *1.2.1 A history of children's homes*

Orphanages and institutions caring for parentless children date back at least to the Middle Ages. Most types of societies, even tribal communities have at some time or other found need to place children in need of care in custodial homes (1). Orphanages have provided a central theme for many novels written throughout history. Probably the best known of these is Charles Dickens' Oliver Twist, that describes the plight of Oliver an orphan who "asked for more" in a children's workhouse in Victorian England (2).

*Figure 1 Oliver Twist asking for more in a children's workhouse in Victorian England (2)*



Throughout history there has been an increased interest in the plight of children during times of increased social, economic and political upheaval. Examples of such times include in England following the industrial revolution and in Europe following World War 2 (3). It seems that during times of social change there is a stronger tendency to invest in the young generation as a guarantee for the survival of a nation. John Ballantyne, an obstetrician, around the time of the First World War wrote, "in the ultimate issue of things babies are of greater importance than battalions, and they are the true dreadnoughts of a nation" (3). In fact it was the South African

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War that brought problems concerning children into greater prominence, for it was after this war that legislation regarding the health of children was passed in England (3).

Two of the oldest children's homes in Johannesburg were established after the South African War. The Johannesburg Children's Home is the oldest charitable institution in the city and was opened in Fordsburg in 1892 (4). Maria Kloppers and Johanna Malan founded the Maria Kloppers children's home in 1908 in response to the terrible conditions in the Witwatersrand following the war (5).

*Figure 2 Maria Kloppers and Johanna Malan: founders of the Maria Kloppers Children's Home (5)*



*Figure 3 Maria Kloppers Children's Home: 1915 premises in Observatory (5)*



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It was also after the period of social and political upheaval accompanying the dissolution of the apartheid government that the United Nations Convention on the Rights of the Child was ratified by South Africa in 1995 (6).

It would not be difficult or unacceptable to compare the effects of the current HIV/AIDS epidemic with the social, economic and political effects experienced in post-war years. According to the United Nations, "17 million people have lost their lives to AIDS in Africa and 12 million orphaned children have been left behind" (7).

Since the beginning of the HIV epidemic the number of children in residential care has increased considerably and there are an estimated 8 million children living in institutions globally (8).

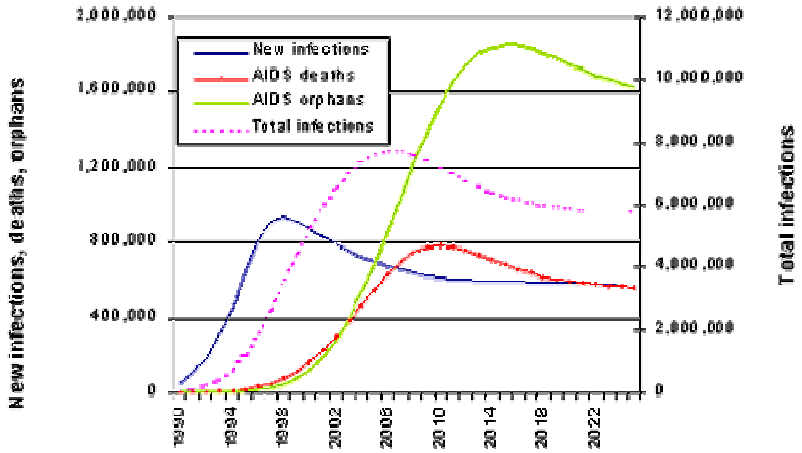
### *1.2.2 The HIV/AIDS orphan crisis in South Africa*

There are many definitions of AIDS orphans but the most commonly used definition is that of the child under the age of 15 who has lost his mother or both parents to HIV/AIDS (9).

According to a report by the Medical Research Council published in May 2002, the AIDS orphan crisis in South Africa is said to be the 4$^{th}$ and highest wave in the epidemic and is expected to peak in 2015 (9) (Figure 4).

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*Figure 4 Waves of the HIV epidemic in South Africa (9)*




The waves of the HIV epidemic in South Africa:

1. ***Wave 1 (New infections):*** HIV prevalence, people newly infected with HIV peaked in 1998 with 930 000 infections per year.
2. ***Wave 2 (Total infections):*** the total number of people infected with HIV, should peak in 2006 at 7 – 8 million (no intervention).
3. ***Wave 3 (AIDS deaths):*** AIDS related deaths are expected to peak in 2010 at 800 000 deaths/year (no intervention).
4. ***Wave 4 (AIDS orphans)***: the number of AIDS orphans is expected to peak in 2015 at 1.85 million (no intervention).

There are many other statistics available that predict numbers of AIDS orphans. Statistics vary according to the age groups included as well the method used to determine them and include:

1. SA Statistics: 1,95 million AIDS orphans (under 15 years) by 2010 (10)
2. USAID: 3 581 478 orphans (under 15 years) by 2010 (11)
3. Monk: 4,3 million orphans (if 15 – 18 year age group is included) by 2010 (12)

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Most AIDS orphans will be HIV uninfected (estimated 3% of the total number of AIDS orphans) and teenagers will represent the most common age group of orphans. (10)

### *1.2.3 Models of care for AIDS orphans*

Many organisations have recognised the urgency to address the problem of the AIDS orphan crisis as iterated in the "Call for Action for children left behind by AIDS" issued by the Joint United Nations Programme on HIV/AIDS (UNAIDS), the United Nations Children's Fund (UNICEF) and the National Black Leadership Commission on Aids (BICA) in December 1999 (13).

In Zimbabwe in the early days of the orphan crisis there was a "rush by well-meaning Non-Governmental Organisations (NGO) to build orphanages". To date, only 4 000 of the country's estimated 800 000 orphans are accommodated in the 45 registered institutions (14). The establishment of orphanages is not considered a sustainable way to address the AIDS orphan crisis.

In South Africa there is a similar sentiment in addressing the problem of AIDS orphans. In November 1997 CINDI (Children In Distress), an organisation coordinating the effort to alleviate the plight of children, commissioned a comprehensive investigation into the effects of AIDS on the people in Kwa-Zulu Natal. They also looked into different models of care for AIDS orphans. They concluded that the most basic and preferred strategy is the accommodation of orphaned children within the extended family. If this is no longer feasible, substitute or foster care families within communities need to be identified. This could lead to a third option where a group of paid foster care mothers live together with small groups of orphans within a community setting. Orphanages were to be considered only as a last resort (15).

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Save the Children, UK released a report in 2004 entitled: “A Last resort: the growing concern about children in residential care”. The report details their position statement on residential care and outlines ways in which residential care undermines the rights of the child (8).

Due largely to the number of newly founded and unregistered children’s homes in South Africa, there is currently no up to date literature regarding the impact of the HIV epidemic on the residential care sector. Also due to a “non-testing” directive issued by the Department of Social Services, the HIV status of many children in the residential care sector is unknown.

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# CHAPTER 2: MATERIALS AND METHODS

## 2.1 Definition of terms

**Residential care:** a group living arrangement for children in which care is provided by remunerated adults that would not be regarded as traditional carers within the widened society (8).

**Children's home:** Any residence or home maintained for the reception, protection, care and bringing-up of more than 6 children apart from their parents, that is registered in terms of section 30 of the Child Care Act (16).

**Place of Safety:** any place established under section 28 of the Child Care Act and includes any place suitable for the reception of a child, into which the person in charge thereof is willing to receive a child. A place of safety usually has the purpose of providing services for the reception, custody, observation, examination and treatment of children under the Child Care Act, as well as the detention of children awaiting trial or sentence (17).

**Shelter:** any building or premises maintained or used for the reception, protection and temporary care of more than six children in especially difficult circumstances defined as circumstances which deny them their basic human needs, such as living on the streets and children exposed to armed conflict or violence (17).

**Youth Development Facility:** a residential care facility used primarily for the care of children in conflict with the law or awaiting trial. Children with behavioural problems not able to be managed in regular children's homes may also be accommodated in these facilities (17).

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**Special needs home:** a residential care facility used for the reception and care of a child with a physical or mental disability that precludes care in a normal home environment or regular children's home.

**Facility:** building, service or piece of equipment provided for a particular purpose (18).

**Resource:** Stock or supply of material or assets (18).

**HIV infected Child: Child infected by HIV as determined by:**

i) HIV ELISA positive > 18 months or

ii) HIV ELISA positive < 18 months and symptomatic

iii) HIV PCR positive (2 occasions at or after 6 weeks of age)

**HIV affected Child:** Child orphaned or abandoned because of parental loss or illness related to HIV/AIDS.

**AIDS orphan:** child under the age of 15 who has lost his mother or both parents to HIV/AIDS (9).

**Residential Child Care Worker (RCCW):** caregiver in children's home responsible for the care of children in the residential care setting**.**

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**2.2 Study design and method**

This descriptive study reports on children's homes in greater Johannesburg focussing on the impact of HIV on these homes.

A rapid appraisal of all children's homes within the greater Johannesburg area was performed by means of a telephonic survey (Appendix 2). The geographical distribution of these homes is described in Figure 7.

Contact details for the homes were obtained from various sources including:

i. A national directory of services for children affected and infected by HIV/AIDS compiled by Save the Children (UK) (19)
ii. A list of registered children's homes provided by the Department of Social services
iii. "Word of mouth" and through contact with children from homes attending the Paediatric HIV clinic at the Chris Hani Baragwanath hospital.
iv. Contact with an initiative instituted by a nappy manufacturing company to provide free disposable nappies to children's homes.
v. Lists of places of safety and shelters for street children were provided by the Gauteng alliance for street children.
vi. Lists of homes catering for mentally and physically handicapped children were provided by the Mental Institute (Gauteng).

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## 2.3 Study Populations

Three study populations are described namely the homes themselves, the children within the homes and the staff who run them.

### *2.3.1 The Johannesburg Children's Homes*

Following the rapid telephonic survey as outlined above, a further detailed cross-sectional analysis of a convenience sample of 24 children's homes within this area was done. The sample was chosen to include an equal number of registered (n = 12) and unregistered homes (n=12). Homes were selected to include facilities from all five regions (viz. North (n=4), South (n=6), East (n=6) West (n=3) and Central (n=5). This sample comprised 21% of the total number of children's homes identified by the rapid telephonic survey. The primary research instruments used for this study were questionnaires and data collection tables (Appendix 3 + 4). The questionnaire was used to interview the children's home manager during visits made to the 24 facilities. The questionnaire was completed by the primary researcher during these visits. The facilities were also inspected at the time of the interview and at subsequent follow-up visits. Observations of practices not covered by the questionnaire were also documented during the visits to the children's homes. Consent for both the interview and inspection were obtained from the children's home manager. Ethical clearance for the study was obtained from the ethics committee for research on human subjects of the University of the Witwatersrand (Protocol no: M020114)

### *2.3.2 Children in Children's Homes in the greater Johannesburg area*

Demographic data for all children currently admitted to the 24 homes was collected with the assistance of the children's home manager using a data table (Appendix 4). The homes were asked to provide information on the HIV status of mothers/parents whose children had been

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admitted to their facility, and who had disclosed their status to the home. They were requested only to document this where it was known and not to extrapolate it from the child's HIV status.

Two extrapolations were then performed. One was a "conservative extrapolation" in which a mother whose status was unknown was assumed to be positive if her child was infected and had been admitted to the home before 2 years of age. If the child was admitted over the age of 2 years the mother with unknown HIV status was not assumed to be positive, as the child may have acquired HIV through another mode of transmission (e.g. sexual abuse).

In the second or "non-conservative" extrapolation, all mothers of unknown status who had HIV infected children were assigned a positive status, irrespective of the age of the child on admission.

Data pertaining to admissions and discharges (including deaths) relating to the turnover in the homes over a six month period were collected. Causes of death in children were reported by managers or taken from records in home registers and not from death certificates.

### *2.3.3 Residential childcare workers (RCCW) in the children's homes*

A demographic data sheet that detailed the characteristics of the RCCW working in the home was completed by the homes manager. Data was only requested for those members of staff whose primary function was the direct care and supervision of children (Appendix 5). Administrators, cooks, cleaners, etc. were excluded from this study population. The homes managers obtained verbal consent from their employees and no names of caregivers were recorded.

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A "pop quiz" designed by the primary researcher was administered by CHOMP's project coordinator (Appendix 6). This was done to evaluate the level of knowledge of the child care workers on issues pertaining to basic child health, HIV and commonly encountered health related problems in the homes. The names of the caregivers who completed the quiz were not documented and neither was the home in which they worked.

**2.4 Data analysis**

Data collected through the questionnaires and tables was entered onto an Excel spreadsheet. Pivot tables were then used to ascertain the relationship between various variables studied (eg. HIV status versus health status of children).

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# CHAPTER 3: RESULTS

## 3.1 Rapid appraisal of residential childcare facilities within the greater Johannesburg area

### *3.1.1 Total number of facilities*

*Table 2 Overview of residential childcare facilities within the greater Johannesburg area*

| Type of residential care facility | Number of facilities | Number of children |
|---|---|---|
| Children's Homes | 53 | 4 327 |
| Places of Safety | 8 | 561 |
| Shelters for street children | 14 | 576 |
| Youth Development facilities (correctional services) | 2 | 470 |
| Special needs homes and special needs schools with residential facilities | 38 | * |
| **TOTALS** | **115** | **5 934** |

**This population of children falls beyond the scope of this research report.*

### *3.1.2 Registration status of the homes*

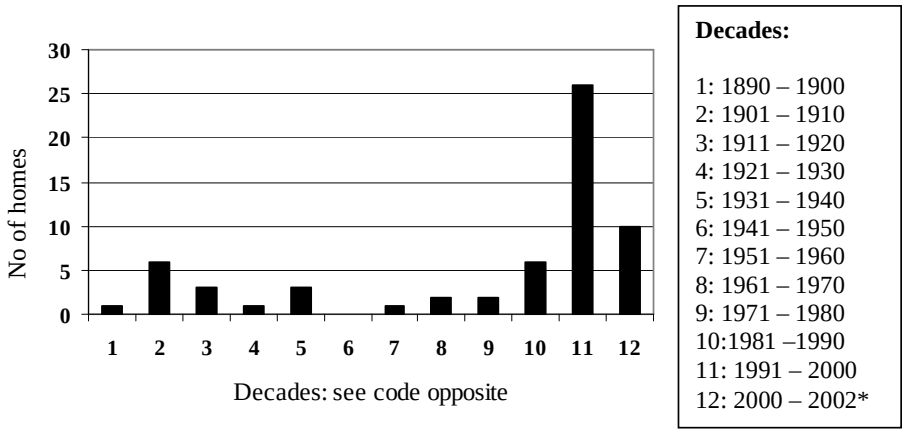
Excluding the 38 special needs facilities, 24 out of 77 residential care facilities (31%) were not registered with the Department of Social Development. Of these unregistered facilities, 9 were shelters for street children and the remaining 15 were children's homes.

### *3.1.3 Ages of the homes*

Information as to when the children's homes were opened was obtained for 61 of the children's homes and places of safety (Figure 5).

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*Figure 5 Decades in which the children's homes were founded*

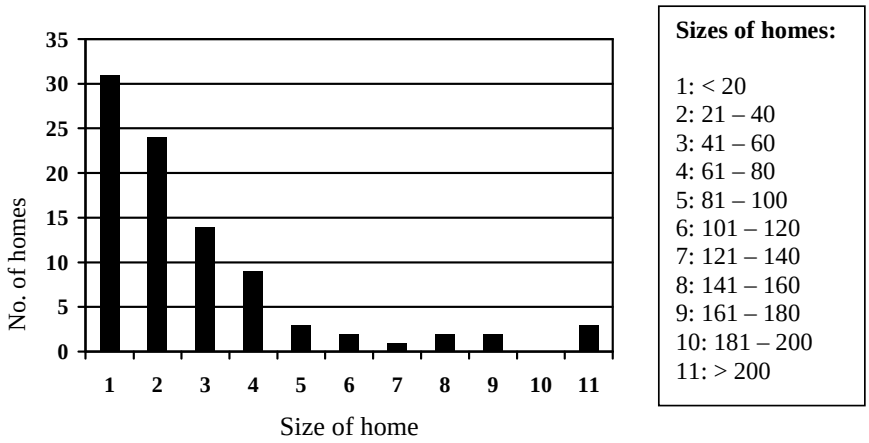



** note that only 2 years are represented in the current decade*

### *3.1.4 Sizes of the homes*

The size of the home was defined by the number of children in the facility. Data was available for all the residential care facilities except for the special needs homes (n = 77).

*Figure 6 Size of children's homes*



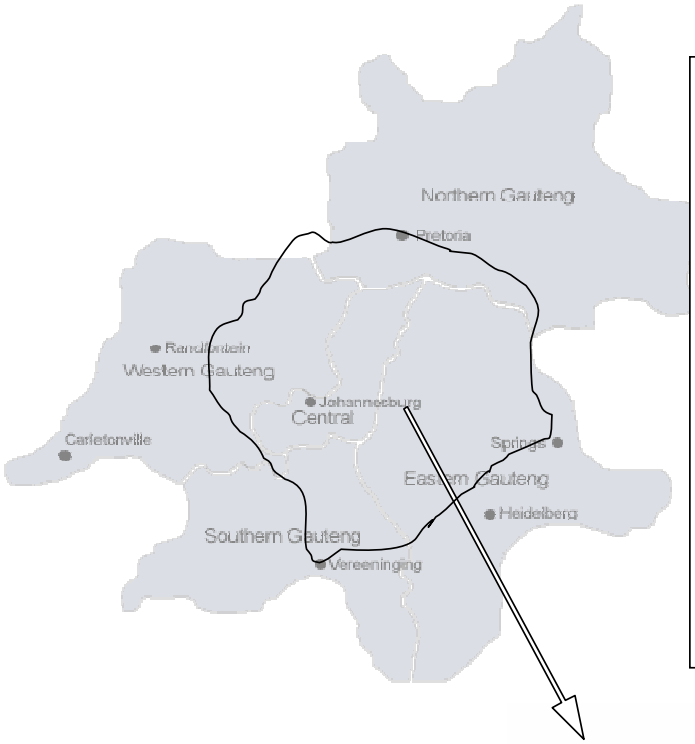

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### *3.1.5 Geographical distribution within the greater Johannesburg*

The map below outlines the area in which the rapid appraisal was done.

*Figure 7 Geographical distribution of homes in the greater Johannesburg area*

*Figure 7.1 Distribution of homes outside of the Johannesburg Metropolitan area*




**Overview of areas where homes were contacted:**

**Northern Gauteng**
Not included

**Western Gauteng**
Krugersdorp

**Southern Gauteng:**
Vereeniging
Sebokeng

**Eastern Gauteng:**
Benoni
Boksburg
Edenvale
Germiston
Kempton Park
Springs

*Figure 7.2 Homes within the Johannesburg Metropolitan area*




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## 3.2 Detailed description of 24 children's homes in the greater Johannesburg area

### *3.2.1 Resources*

*3.2.1.1 Financial resources*

*i. Income*

Children's homes receive income from three main sources:

*State funds (government funds):* Registered children's homes receive a state subsidy of R800 per child per month. Unregistered children's homes may receive some state funds in the form of foster or care dependency grants.

*Donor funds:* Donations are received by the homes from both local and international donors. Many of the NGO run homes are faith based and receive funding from churches. Some homes have schemes whereby individual children are sponsored either by individuals or companies. Sponsorship is often tailored to a specific need: e.g. anti-retroviral treatment, education and clothing.

*Own funds:* These are miscellaneous funds obtained through fundraising efforts undertaken by the children's home itself and occasionally straight "out of the pocket" of the children's home manager (especially in unregistered children's homes).

Table 3 outlines the total amount of funds received by 23 of the children's homes for 2002. One well resourced home was unwilling to provide their funding details for the purpose of this research report. Subtotals for the registered (R) and unregistered (UR) facilities are indicated.

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*Table 3 Funding in the children's homes: registered (R) versus unregistered (UR) facilities*

| | STATE | % | DONOR | % | OWN | % | TOTALS |
|---|---|---|---|---|---|---|---|
| R | R 8 659 763 | 38% | R 11 063 687 | 48% | R 3 187 745 | 14% | R 22 911 195 |
| UR | R 685 376 | 7% | R 6 041 078 | 59% | R 3 560 690 | 34% | R 10 287 144 |
| **Total** | **R 9 345 139** | **28%** | **R 17 104 765** | **52%** | **R 6 748 435** | **20%** | **R 33 198 339** |

*ii. Expenditure*

Twenty three of the homes surveyed provided a line listing of the items for which funds are spent on an average month.

*Table 4 Monthly expenditure in the children's homes*

| Item | Registered Homes | % | Unregistered Homes | % | TOTAL | % |
|---|---|---|---|---|---|---|
| Salaries | R 1,103,737.00 | 63,4% | R 383,235.00 | 51,9% | R 1,486,972.00 | 60% |
| Municipality* | R 151,833.00 | 8,7% | R 25,855.00 | 3,5% | R 177,688.00 | 7,2% |
| Telephone | R 52,131.00 | 3% | R 36,805.00 | 5,0% | R 88,936.00 | 3,6% |
| Groceries | R 147,869.00 | 8,5% | R 58,227.00 | 7,9% | R 206,096.00 | 8,3% |
| Formula | R 27,047.00 | 1,6% | R 20,800.00 | 2,8% | R 47,847.00 | 1,9% |
| Nappies | R 22,246.00 | 1,3% | R 11,800.00 | 1,6% | R 34,046.00 | 1,4% |
| Medical consults | R 19,816.00 | 1,1% | R 19,680.00 | 2,7% | R 39,496.00 | 1,6% |
| Medicines | R 7,200.00 | 0,4% | R 58,357.00 | 8% | R 65,557.00 | 2,6% |
| Equipment | R 12,579.00 | 0,7% | R 8,400.00 | 1% | R 20,979.00 | 0,8% |
| Transport | R 48,530.00 | 2,8% | R 35,359.00 | 4,8% | R 83,889.00 | 3,4% |
| Maintenance | R 51,916.00 | 3% | R 16,552.00 | 2,2% | R 68,468.00 | 2,8% |
| Other | R 96,236.00 | 5,5% | R 63,548.00 | 8,6% | R 159,784.00 | 6,4% |
| **TOTALS** | **R 1,741,140.00** | **100%** | **R 738,618.00** | **100%** | **R 2,479,758.00** | **100%** |

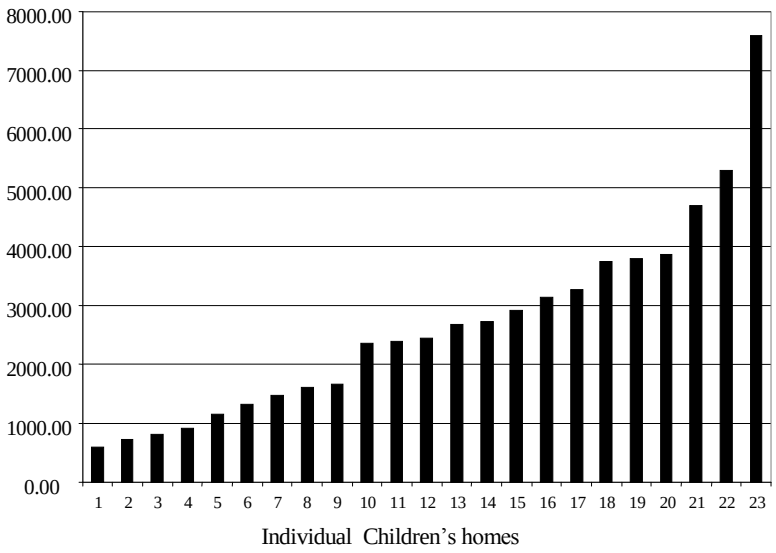
**Rates, taxes, water and lights*

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*iii. Cost per child*

The cost per child was calculated by dividing the monthly expenditure by the total number of children present during that month in each of the twenty-three homes.

*Figure 8 Monthly cost (in Rand's) per child in the children's homes*




The minimum cost per child per month was R581.00; the maximum cost was R7, 585.45 with an average cost of R2, 435.21 per child per month.

*3.2.1.2 Human resources*

A variety of professionals and laypersons staff children's homes. These include managerial and administrative staff, professional and auxiliary nurses, social workers, childcare workers, housekeepers, cooks, cleaners, maintenance staff, etc.

Small unregistered homes are often staffed by members of a family and will employ some childcare workers. The managers of these homes perform multiple functions that range from daily childcare, escorting children to health facilities, shopping, administration and fund raising. The children are often housed in the manager's own home.

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Some of the registered children's homes are also divided into smaller family units or cottages that are managed by a housemother or couple that "live in". Some of these couples also have their own children that live on the same premises. The administrative and financial responsibilities are performed by a central administrative department.

Many of the registered children's homes have their own social workers. Although some of the unregistered children's homes also have their own social workers, most make use of social workers registered with other NGO's in possession of the necessary statutory powers that allow them to place children in the homes.

More than half of the homes surveyed (62.5%) have their own nursery schools and employ teachers for this purpose. Three of the homes crèches also provide day care for children from the surrounding communities.

By law government children's homes are required to have a board of management appointed by the Minister consisting of not fewer than three and not more than nine members (16). Board members are often outside professionals and may perform duties related to finances and management of the home. The staff complement focused on in this research report is the primary childcare workers that are involved in daily childcare activities. Aspects relating to these staff members are detailed in section 3.7 of this report (pg 63).

Volunteers play an important part in the children's homes and help to compensate for staff shortages. Most volunteers assist the homes in daily childcare activities, but many of the homes also have volunteers who assist the homes in their professional capacities (e.g. doctors, physio- and occupational therapists etc.) Two of the children's homes surveyed rely on an almost complete childcare staff complement of international volunteers.

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*3.2.1.3 Material resources*

The material resources discussed in this section include food, medicines, equipment and toys. The focus of the research is predominantly on the resources needed to meet the medical and health care needs (including developmental stimulation) of children.

*i. Formula milk and food*

Approximately 10% of the monthly expenditure of the children's homes was on food. Whilst the homes spend a fair amount of their budgets on food, many homes also receive donations from retailers. It was noted that some of these retailers would give homes surpluses of short dated stock that were unlikely to be sold by the sell by date. Some of the non-perishables in the homes were noted to be expired and were still being used. Of particular concern in one children's home was the use of undiluted cow's milk to feed infants from three months of age.

Between 16 and 35% of the grocery expenditure was for formula milk. A wide range of formula milks (n = 10) were found in the homes. The most commonly used formulae were Nan (62.5% of homes) and Isomil (79%). A quarter of the homes had Nan Pelargon which is a formula most often prescribed for HIV exposed infants or for situations were bottle hygiene or drinking water may not be optimal.

With respect to weaning foods and solids, most homes (66%) make use of a combination of commercially prepared infant food (Purity) and home cooked meals. Food choices are influenced in some homes by donations received.

*ii. Medicines and medical equipment*

Medicines in the homes are supplied from a variety of sources. Most drugs are obtained from state pharmacies through prescriptions for individual children in the home. Other drugs are bought from private pharmacies (either prescribed by private practitioners or purchased "over

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the counter"). Some homes bought medicines in bulk from retail pharmacies and others received donations. A few of the registered homes used to be able to place orders for so called "ward stock" from the Hilbrow pharmacy but this service has been curtailed. Table 5 list the commonly available drugs in the children's homes.

*Table 5 List of commonly available drugs in the children's homes*

| DRUG | NO OF HOMES | DRUG | NO OF HOMES |
|---|---|---|---|
| Alternative drugs: moducare, spirulina phytoguard | 3 | INH | 1 |
| Anti- biotics | 10 | Iron containing preparations | 4 |
| Anti-diarrhoeal (Immodium) | 6 | Lice shampoo | 1 |
| Anti-emetics (valoid/stemetil) | 6 | Morphine | 2 |
| Anti-histamines | 5 | Multivitamins | 10 |
| Aspirin | 1 | Mycostatin ointment | 3 |
| Bactrim | 14 | Nose drops: saline nose drops/ Iliadin/ Drixine | 4 |
| Calamine lotion | 2 | Nystatin oral suspension | 4 |
| Chloromycetin eye ointment | 3 | Otosporin/Sofradex | 3 |
| Cold preparations | 3 | Panado | 22 |
| Cough mixtures | 12 | Pectrolyte/ kantrexil | 6 |
| Daktarin oral jel | 7 | Prednisone | 1 |
| Deworming meds | 2 | Pyridoxine | 2 |
| Flagyl | 3 | SOROL/ Gastrolyte | 7 |
| Glycerine supp | 2 | TB drugs | 2 |
| Gripe water | 3 | Teething powders | 2 |

In seven (29%) of the 24 homes no first aid kit was readily available. Of the allegedly available kits, two were not seen. Seven (41%) of the inspected first aid kits were incomplete or stock that had been used was not replaced. The majority of first aid kits contained the standard equipment that included mainly items used for the management of wounds. Only 4 of the kits that were inspected had specific burn treatments (such as burnshield, bactigras, flamazine etc).

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Seven of the first aid kits contained mouthpieces and all of the kits had gloves. One home had a complete set of equipment for intubation and had ampoules of adrenalin and solucortef. Table 6 lists the availability of key medical equipment in the children's homes.

*Table 6 Medical equipment in the children's homes*

| Item | No of homes in which the item was available |
|---|---|
| Thermometer | 23/24 (96%) |
| Baby scale | 17/24 (70%) |
| Oxygen | 12 /24 (50%) |
| Nebulising machine | 18/24 (75%) |
| Nasogastric tubes | 8/24 (33%) |
| Equipment and fluids for IV therapy | 4/24 (16%) |
| Stethoscopes | 8/24 (33%) |
| Diagnostic sets | 9/24 (38%) |
| Sphygnomanometers | 4/24 (16%) |
| Incubators | 2/24 (8%) |
| Apnoea monitors | 1/24 (4%) |
| Suctioning equipment | 4/24 (16%) |
| Saturation monitors | 4/14 (16%) |
| Urine bags and dipstix | 2/24 (8%) |

*iii. Toys, educational equipment and resources to promote normal childhood development*

All of the homes visited had toys. Most of the toys in the homes were donated. A large number of the toys were soft toys (teddy bears, etc.), 19 (79%) homes had "educational toys" and 1 home had purchased an "early childhood developmental course" that contained a manual and a set of educational toys.

Managers interviewed where asked whether caregivers had time to play with the children in the home or whether their busy childcare schedules precluded this. Half (50%) of the home

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managers said that the caregivers did have time to play with the children, 42% said that they did not and 8% said that it depended on the ever changing child to staff ratio.

The majority of homes (92%) said that they used outside volunteers to play with the children. Two homes had involved school children from the local community to play with children. One children's home had a "big-brother/sister mentor system" where older children from schools, college and university were available to the home and "became" big brothers and sisters to children in the institution. Big Brother Big Sister South Africa (BBBSSA) is linked to the founding organisation in the United States of America (20).

In terms of professional services available to the homes to stimulate early childhood development: 9 (38%) homes had volunteer physiotherapists, 3 (13%) had volunteer occupational therapists and one home had a play therapist who was an international volunteer and lived at the home for one year. Fifteen (62.5%) of the homes had established crèches inside the home, 6 (25%) homes had crèches outside of the home and the remaining 3 (13%) homes did not have children in the crèche age group.

Many of the homes had volunteers involved in educational activities with the children that included art and craft activities, music, dance and sport (including "equestrian therapy'). Two homes had designed their own "stimulation programmes" that outlined activities staff could involve the children in.

In the 16 homes that had children of school going age: 12 had children in government schools, 2 had children in private schools and 2 of the homes had "home schooling".

Despite all these cited examples of stimulation programmes, signs attributable to institutionalisation (e.g. self stimulatory behaviour, indiscriminate affection etc.) were

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observed in 50% of the homes.

The sizes of the homes in which signs of institutionalisation were observed in this study ranged from 24 to 294, with a median of 42. The mode was homes with a total number of children in the 50's (4 homes). In the homes where signs of institutionalisation were not observed, the total number of children ranged from 8 to 35 with a median of 15 and a mode of 15. Two homes that had formal "stimulation programmes" still had children who exhibited signs of institutionalisation.

### *3.2.2 Facilities in the children's homes*

#### *3.2.2.1 Sleeping and hygiene facilities*

*Table 7 Facilities within the children's homes*

| Facility examined | Total number | Number per home | | | Ratio of children: facility | | |
|---|---|---|---|---|---|---|---|
| | | Min | Max | Mode | Min | Max | Mode |
| Sleeping facilities (Bedrooms) | 417 | 2 | 189 | 3 | 1:1 | 30:1 | 3:1 |
| Hygiene facilities: | | | | | | | |
| 1) Toilets* | 245 | 2 | 74 | 3 | 0.6: 1 | 7:1 | 4:1 |
| 2) Baths or showers | 254 | 3 | 97 | 3 | 3:1 | 15:1 | 3:1 |

** The child to toilet ratio was calculated for children in the home in the toilet-trained age group (defined as children over the age of 3 years).*

#### *3.2.2.2 Medical facilities in the children's homes*

*i. Hospice type facilities*

Four of the children's homes visited had "hospice-type" facilities complete with oxygen and other necessary equipment to manage chronically or terminally ill children. Three of these homes also had hospice type facilities for adults. Three other children's homes were in the process of setting up hospices and three homes expressed a desire to do so.

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Of the homes with hospices, or in the process of starting hospices, all shared similar reasons for wanting to do this. These included dissatisfaction with the management of some of their terminally ill children in the state hospitals, a desire to be with a child with whom they had bonded in the terminal stages of their disease or a previous experience of being told to take a terminally ill child home because "there was nothing more that the hospital could do for the child".

*ii. Isolation facilities*

Only three children's homes had dedicated isolation facilities (one of these was a home with 30 children in one hall). Most other homes said they "made a plan" in the event of an infectious disease outbreak in the home.

### *3.2.3 Health and hygiene practices in the children's homes*

Key practices in the children's homes that can impact on the health of children include food preparation and hygiene, hand washing as well as nappy changing and toilet training practices.

The evaluation of these practices was done by questioning the children's home manager and observing these practices. The evaluation of hygiene practice in the homes however, is probably best done by ongoing observation of staff, as what is reported to be routine procedure is not always routinely practiced. Some bad practices that were observed during initial and subsequent visits to the studied homes are detailed.

*3.2.3.1 Food preparation and hygiene*

*i. Bottle sterilisation*

Homes use a combination of methods to sterilise bottles. The most commonly used method is chemical sterilisation (19/24 homes) as it is easy and practical for large numbers of bottles.

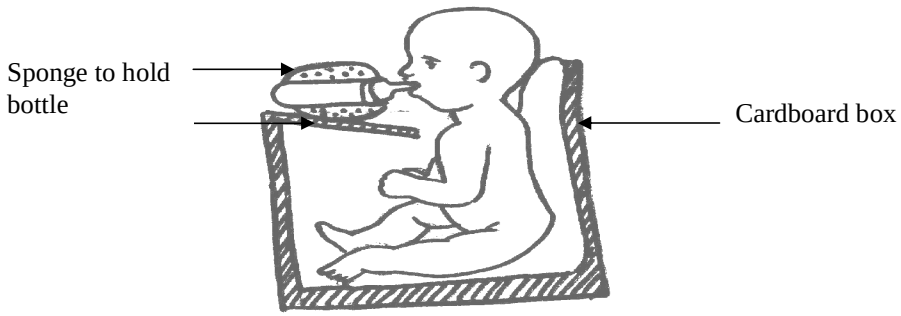
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Nine of the homes also boil bottles to sterilise them and will sometimes revert to this technique when they run out of sterilising fluid. In smaller homes other methods of sterilising include: microwave sterilisation (3), electrical sterilisation (1) and dishwashers (1).

*ii. Feeding practices*

A practice that was observed in some of the homes surveyed was "prop feeding" where the supine infant is left to suck from a bottle propped up by a pillow or blanket placed close to the infants head. This practice is often necessitated by a shortage of staff. Even homes well versed in the dangers of prop feeding admit to having to resort to this method of feeding at times. One home described a triaging system where prop feeding would only be used for the strong quick feeders and ex-premature or weak infants would never be prop fed. One children's home used a "baby-feeding gadget" that was designed by a physiotherapist to ensure that babies were "prop fed" in the upright position.

*Figure 9 "Baby feeding gadget"*




*3.2.3.2 Hand washing, nappy changing and toilet training practices*

*i. Hand washing practices*

In terms of the type of soap used to wash hands in the homes: 5 homes used bar soap only, 12 homes used liquid dispensable soap only and 7 homes used both (usually depending on the

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availability of the more expensive liquid soaps). Only 5 of the homes surveyed used alcohol based hand rubs periodically.

The majority of homes (16 = 67%) use ordinary cloth hand towels to dry their hands after washing. Five homes (21%) use disposable paper towelling and 3 homes used both.

All 24 homes surveyed reported that staff washed hands after each nappy change, but observation of practices showed that this was not always the case. In 4 of the homes surveyed the hand washbasins were not situated in close proximity to the nappy changing area necessitating a walk to the bathroom making hand washing after each nappy change less likely. Eighteen of the homes said caregivers always wash their hands when preparing milk feeds, 5 said they mostly washed their hands and one home admitted to washing hands only sometimes when preparing bottles.

*ii. Nappy changing practices*

In the 24 homes surveyed 23 used disposable nappies most of the time. One home used towelling nappies exclusively and 8 homes used towelling nappies when disposables weren't available (mainly due to funding constraints).

The large number of homes using disposable nappies was influenced by regular donations to the homes of disposable nappies by a manufacturing company. The project that distributed 1.75 million nappies to the homes annually was coordinated by CHOMP and started six months prior to the survey period.

In the absence of the nappy donations, homes spend between R696.00 and R6, 750.00 on nappies per month (Table 4).

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In 8 of the 24 homes surveyed, the nappy changing area was not separate from the sleeping facilities and babies are sometimes changed in their cots. Many nappy changing mats were covered with receiving blankets and not plastic that can be disinfected in between changing infants.

In 14 of the 24 homes (58%) disposable gloves are periodically available for changing nappies. Some homes have specific rules about the use of gloves for changing nappies in order to make the limited supply of gloves go further. These rules include restricting the use of gloves to the changing of nappies containing stool only or for use with those children with diarrhoea only. In one home the use of gloves was restricted to use in HIV infected infants. In a few homes the same set of gloves was used to change several babies' nappies. While probably offering protection to the staff member, this practice could be associated with the transmission of faeco-oral pathogens amongst the babies.

*iv. Toilet training practices*

A practice that was observed in several homes was "group potty training sessions". Here groups of toddlers sit in the bathroom together each on their own potties and are encouraged by staff (and each other) to urinate and or defecate in the potties. This type of practice whilst probably practical in a setting with several toddlers is likely to be associated with sub-optimal hygiene in the home.

### *3.2.4 Other health related practices in the children's homes*

*3.2.4.1 Growth monitoring*

All home managers interviewed stated that they monitored the growth of the children in their care. As noted in the section on medical equipment in the homes, 17 of the homes had their own baby scales. Sixteen homes said they did their own routine weighing of the children and

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the remaining 6 homes took their children to the local clinic for weighing. In three of the homes (two care centres and one home admitting HIV infected mothers with their children) the mothers were tasked with taking the children to the clinic for weighing if they were well enough to do so.

All of the homes routinely weighing their children document the measurements. In most children's homes this is done in a special booklet designed for this purpose or written in the individual child's file. Most homes were happy if the weight "was going up". Only 3 children's homes actually plotted the children's weights to see if the increase in weight was sufficient. Two of these homes used the road to health card for this purpose and the remaining home had their own growth charts.

*3.2.4.2 Immunisations*

All but one children's home, which was visited by a nursing sister, use their local clinic for immunisations.

Many homes expressed difficulty in taking their children to the local clinic for immunisations. Problems were also experienced in accessing new road to health cards for abandoned children. Most homes tend to "batch the infants" requiring immunisations but said the clinics complained that they took over the facility when they brought so many children together.

Several of the home managers interviewed had said that they had tried to ask if a sister from the local clinic could come to the home to immunise children in the home. Only 4 clinics had at one time or another agreed to do so, most said they were unable to do so because of staffing constraints in the clinics.

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One children's home had on occasion resorted to taking a few infants to private immunisation clinics or pharmacies.

This research report did not evaluate immunisation coverage in the homes however further research done by CHOMP has shown that only 24% of children in homes are up to date with their immunisations.

### *3.2.5 Record Keeping and documentation*

Record keeping and documentation practices in the children's homes surveyed varied greatly. Incomplete records in one home lead to the exclusion of twenty three children from the demographic database for this study. The information supplied by the home was not useable as there were missing dates of birth or ages and dates of admission. On the other hand one children's home visited during the survey period, had designed a computerised database in which every conceivable bit of information concerning the child (including weights and temperatures) was recorded.

Access to children's files in the home is generally restricted to the children's home manager, the social workers and medical professionals working in the homes. Records may also be accessed by secretaries for filing or data capturing purposes.

Knowledge of the HIV status of a child in a home is generally restricted to those professionals needing to know this but may also be made known to some of the childcare workers caring for a particular child or escorting the child to a health care facility. A few of the homes however do not divulge the child's status to any of their childcare workers and restrict knowledge of this to managerial and medical staff only.

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*3.2.4.2 Records and documents kept*

*Table 8 Documents kept in the children's homes*

| Document / Form | No of homes having the document on record (n=24) |
|---|---|
| Form 4, 5, 8 (Court orders) | 21 (88%) |
| Birth certificates | 22 (91%) |
| Medical reports: B1 + 2, 9A + B | 20 (83%) * |
| Social work reports | 21 (88%) |
| Own admission form | 16 (67%) |
| Road to health card | 22 (91%) |
| Patient held record from hospital | 14 (58%) |
| Discharge summary from hospitals | 14 (58%) |
| Notes made by doctors | 13 (54%) |
| Notes made by nurses | 5 (21%) |
| Notes made by physiotherapists and occupational therapists | 1 (4%) |
| Laboratory reports (Hard copies of results) | 21 (88%) |
| School reports | 16 (100%)** |
| Feeding charts (input):<br>1) Routine (every child)<br>2) Sick children only | <br>16 (67%)<br>2 (8%) |
| Output charts (urine, stools and vomiting)<br>1) Routine (every child)<br>2) Sick children only | <br><br>18 (75%)<br>3 (12.5%) |
| Medicine charts | 20 (83%) |

* *The presence of these forms was highly variable and depended mainly on where the child was referred from; therefore not every child in the home had one of these forms.*

** *Only 16 of the 24 children's homes surveyed had children of school going age and all of these homes had school reports on file (including the two homes with home schooling)*

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## 3.3 Children in the study homes

A total number of 1066 children were present in the 24 children's homes. Demographic details were available for 1043 children. A total of 803 children were accommodated in the 12 registered children's homes and 240 in the 12 unregistered children's homes.

### *3.3.1 Demographic details*

#### *3.3.1.1 Gender*

There was a slight male predominance in the population of children surveyed with 550 (52.7%) of the children being male and 493 (47.3%) being female. This male predominance is further emphasized if one considers that in the last SA census (2001) the male: female ratio for children under 18 yrs in Gauteng was males 48% to females 52%. (21)

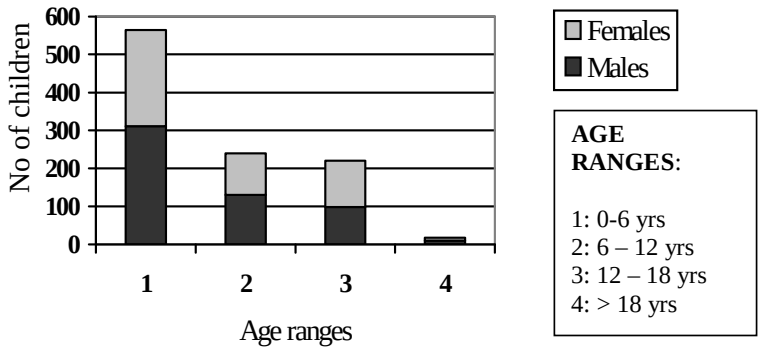
#### *3.3.1.2 Age distribution*

*i. Current age at time of survey*

The youngest child in the population studied was 1 day old, the oldest was 27 years old and the median age was 5 ½ years. By law a children's home may only receive children up to the age of 18 years (16). In the study population however the number of children over the age of 18 years was 18 (1.7%). "Children" over the age of 18 years still living in children's homes include children with mental retardation not yet transferred or unsuitable for admission into adult facilities. Children enrolled in further education who have not been able to be accommodated in the tertiary educational facility in which they are studying also comprise a proportion of those over 18 years of age.

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*Figure 10 Age distribution of children in the children's homes*




*ii. Ages at which the children were admitted to the homes*

The youngest age at which a child was admitted to a home was day 1 of life. The mode for admissions was the first month of life. The oldest age at which a child was admitted was 20 years and the median age of admission was 2 years and 3 months. The 20 year old was mentally retarded and no suitable placement in an adult facility could be found for the individual.

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### 3.3.2 Reasons for placement:

*Table 9 Reasons for admission to the children's homes*

| Reason for placement | Registered homes | | Unregistered homes | | Totals for all homes | |
|---|---|---|---|---|---|---|
| | No | % | No. | % | No. | % |
| Orphaned | 47 | 6% | 36 | 15% | 83 | 8% |
| Abandoned | 263 | 33% | 74 | 31% | 337 | 32% |
| Abused | 82 | 10% | 4 | 2% | 86 | 8% |
| Neglected | 113 | 14% | 2 | 1% | 115 | 11% |
| Removed from home | 124 | 16% | 19 | 8% | 143 | 14% |
| Behavioural Problems | 11 | 1% | 0 | 0% | 11 | 1% |
| Consented adoption | 91 | 11% | 17 | 7% | 108 | 10% |
| Ill child | 16 | 2% | 5 | 2% | 21 | 2% |
| Child admitted with mother | 0 | 0% | 38 | 15% | 38 | 4% |
| Destitute | 50 | 6% | 43 | 18% | 93 | 9% |
| Unknown reason* | 6 | 1% | 2 | 1% | 8 | 1% |
| **Totals:** | **803** | **100%** | **240** | **100%** | **1043** | **100%** |

** Some of the homes were unable to provide information on some of the children admitted*

The impact of HIV on each of the admission categories is tabulated below.

*Table 10 Impact of HIV in the various admission categories*

| Admission category | HIV affected* | HIV positive | HIV negative | HIV unknown | Unwell |
|---|---|---|---|---|---|
| Orphaned | 69% | 55% | 20% | 25% | 27% |
| Abandoned | 74% | 29% | 37% | 34% | 12% |
| Abused | 1% | 3% | 7% | 90% | 2% |
| Neglected | 6% | 2% | 6% | 93% | 4% |
| Removed | 7% | 3% | 22% | 75% | 1% |
| Behavioural problems | 0% | 0% | 0% | 100% | 0% |
| Consented adoptions | 32% | 12% | 70% | 18% | 2% |
| Ill children | 86% | 86% | 3% | 11% | 71% |
| Children admitted with their mothers | 97% | 29% | 50% | 21% | 18% |
| Destitute | 2% | 26% | 19% | 55% | 16% |

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### *3.3.3 Parental details of the children*

#### *3.3.3.1 Parents whereabouts*

Most of the parents (498 = 48%) of the children were still alive, 143 (14%) were known to have died and the whereabouts of 402 (38%) of the parents were unknown. Of the 337 parents who had abandoned their children, 78 (23%) had subsequently been traced.

#### *3.3.3.2 HIV status of parents*

Of either parent that was still alive, 104 (20.9%) were known to be HIV infected, only 3 were known to be HIV negative (0.6%) and the HIV status of the remaining 391 (78.5%) was unknown.

Of the 143 parents who had died, 80 (56%) of them were known to have died from HIV related causes.

The positive HIV status of either parent defined the child as being HIV affected; some of these children were also HIV infected.

*Table 11 HIV status of the parents with and without extrapolation as explained in the study methods*

| Database | POSITIVE | UNKNOWN | NEGATIVE |
|---|---|---|---|
| No extrapolation | 257 (24.6%) | 735 (70.5%) | 51 (4.9%) |
| Conservative extrapolation | 290 (27.8%) | 702 (67.3%) | |
| Non-conservative extrapolation | 331 (31.7%) | 661 (63.3%) | |

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### 3.4 Turnover of children in the homes

The number of homes included in this analysis was 21. Of these homes 12 were registered and 9 were unregistered.

#### *3.4.1 Admission rates*

A total number of 379 children were admitted over a 6-month period. The admission rate was higher in the unregistered versus the registered children's homes: 261 were admitted to the 12 registered children's homes, representing 33% of these homes capacity and 105 children were admitted to the 9 unregistered children's homes representing 44% of the capacity of these homes.

#### *3.4.2 Discharge rates (excluding deaths)*

A total number of 160 children were placed out of the 21 homes over a 6-month period. Again the discharge rate was higher in the unregistered facilities: 45 children were placed out of the unregistered children's homes representing 19% of these homes capacity whereas 115 children were placed out of the registered children's homes, representing 14% of these homes capacity. Table 12 and 13 detail the type of placements on discharge and the characteristics of the discharged children respectively.

*Table 12 Outcomes for children discharged from children's homes*

| TYPE OF PLACEMENT | Registered children's homes | Unregistered children's homes | TOTAL |
|---|---|---|---|
| Adopted out | 56 | 31 | 87 |
| Fostered out | 43 | 5 | 48 |
| Returned to family | 16 | 9 | 25 |
| **TOTAL** | **115** | **45** | **160** |

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*Table 13 Characteristics of children placed out of children's homes*

| Characteristic | Adopted | Fostered | Returned to family |
|---|---|---|---|
| Total | 87 | 48 | 25 |
| M: F | 1.3: 1 | 1.3: 1 | 1:1.3 |
| Youngest | 1 month | 4 months | 2 months |
| Oldest | 9 years | 14 years | 8 years |
| Median | 8 months | 5 years | 2 years |
| Mode | 4 months | 11 years | 2 years |
| HIV Positive | 0 | 1 | 1 |
| HIV Negative | 84 | 26 | 9 |
| HIV Unknown | 3 | 21 | 15 |

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### 3.5 Morbidity in the children's homes

The main cause of morbidity in the children's homes was HIV/AIDS.

#### *3.5.1 HIV status of children in the homes*

The HIV status of almost half of the children (47%) in children's homes had not been determined. Approximately 1/3 (31%) of children in the homes were known to be HIV affected and 20% of these children were also HIV infected. Just under a third of the children (30%) were known to be HIV negative.

Although 47 % of the children in homes had not had their HIV status determined, an analysis of HIV status for age (table 14) shows that the majority of children with unknown HIV status are in the age groups of 6 yrs and older. The fact that many of these children were still alive is a crude indication that they were unlikely to be vertically infected. A sub analysis of HIV status against Health status (figure 13) also revealed that 93.7% of children in the "unknown" group were well. The fact that they were well is a possible indicator that they are not infected (or at least do not have symptomatic HIV/AIDS).

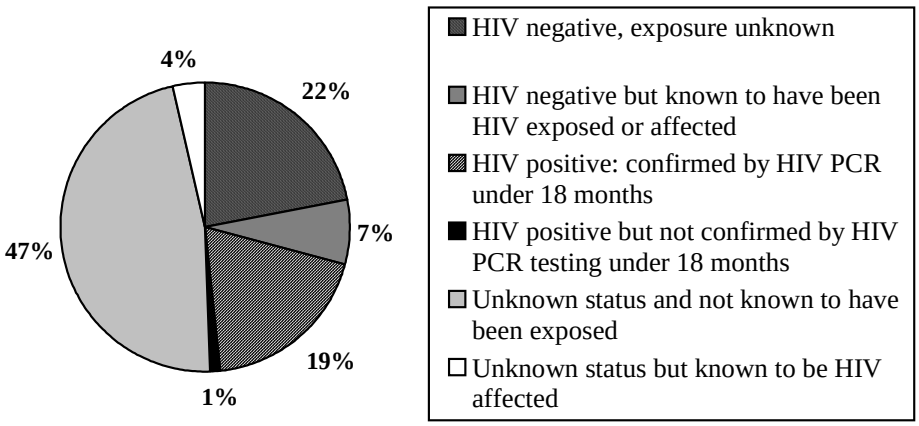
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*3.5.1.1 Reported results from the children's homes*

The reported HIV Status of the children in the homes was divided into 6 categories:

1) HIV negative, exposure unknown.
2) HIV negative but known to have been exposed.
3) HIV positive: as confirmed either by an HIV ELISA done after 18 months or both a positive HIV ELISA and HIV PCR done under 18 months of age.
4) HIV positive but not confirmed: i.e. HIV ELISA positive under 18 months of age not confirmed by HIV PCR testing.
5) Unknown HIV status and not known to be HIV affected.
6) Unknown HIV status but known to be HIV affected.

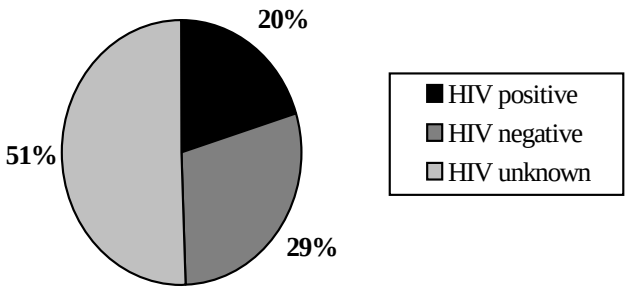
*Figure 11 HIV status of children in the children's homes*




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A simplification of the HIV categories into HIV positive (whether confirmed or not), HIV negative (whether exposed or not) and HIV unknown (whether exposed or not) is represented below.

*Figure 12 Simplification of HIV status of children*




*3.5.1.2 HIV status according to age*

HIV status was analysed for different age groups (Table 14). Brackets represent the percentage of children for that age group.

*Table 14 HIV status according to age*

| Age Group | HIV POSITIVE | HIV NEGATIVE | HIV UNKNOWN | TOTALS |
|---|---|---|---|---|
| 0 – 6 yrs | 158 (28%) | 259 (46%) | 148 (26%) | 555 (100%) |
| 7 – 12 yrs | 46 (19%) | 38 (16%) | 156 (65%) | 240 (100%) |
| 13 – 18 yrs | 8 (4%) | 7 (3%) | 205 (93%) | 220 (100%) |
| > 18 yrs | 0 (0%) | 0 (0%) | 18 (100%) | 18 (100%) |

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*3.5.1.3 HIV testing practices in the children's homes*

In order to determine whether the reported HIV status of children in the homes was an accurate reflection of the true burden of disease, the testing policies and practices of the children's homes were studied (Table 15).

*Table 15 HIV testing policies and practices in the homes at the time of the survey*

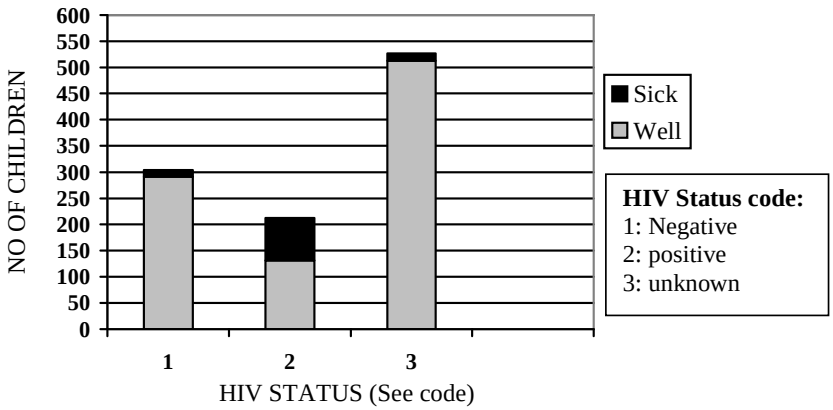
| **HIV TESTING POLICIES AND PRACTICES:** | | **Number of homes** | | |
|---|---|---|---|---|
| | | **Registered** | **Unregistered** | **Total** |
| 1: Testing policy | Routine HIV testing | 1 | 0 | 1 |
| | No HIV Testing | 1 | 0 | 1 |
| | Testing Symptomatic children only | 2 | 4 | 6 |
| | Testing symptomatic children and children for permanency planning | 8 | 7 | 15 |
| | Unsure of testing policy | 1 | 0 | 1 |
| 2: HIV ELISA testing | Receiving children from hospitals who had had an HIV ELISA done | 13 | 11 | 24 |
| | Performing HIV ELISA testing in accordance with the homes testing policies | 12 | 11 | 23 |
| 3: HIV PCR testing | Not performing HIV PCR testing | 3 | 4 | 7 |
| | HIV PCR testing done by state laboratories only | 7 | 1 | 8 |
| | HIV PCR testing being done by private laboratories only | 1 | 5 | 6 |
| | HIV PCR's done by State and Private laboratories | 1 | 1 | 2 |

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### *3.5.2 Reported Health Status of children in homes*

A total of 935 (89.6%) of the children were reported to be well and 108 (10.4%) were currently ill or generally sickly children.

*Figure 13 Health status of children according to HIV status*




### *3.5.3 Spectrum of other medical conditions in the children's homes*

Although this study focuses on HIV as a major cause of morbidity in the children's homes, several other conditions were prevalent in the homes. These conditions were often the reason for the child being institutionalised and include: prematurity, tuberculosis, asthma, diabetes, cerebral palsy, epilepsy, Down syndrome, Foetal Alcohol Syndrome, congenital heart defects, malnutrition, neglect, physical and sexual abuse and behavioural problems: most commonly attention deficit hyperactivity disorder.

### *3.5.4 Children requiring chronic medications*

Almost two-thirds (15/24 = 62.5%) of children were reported to be on chronic medication. The most common chronic drugs were those used for the management of HIV. All of the children known to be HIV infected were on Bactrim, although the use of Bactrim in exposed infants

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awaiting determination of their HIV status was not optimal. A total of 4 children's homes, making use of private laboratories to do HIV PCR testing, would only place children on treatment after they had had their status confirmed and not during the testing process.

Eleven of the 24 homes had children on anti-retrovirals (ARV's) with a total number of 48 children (representing 4.8% of the study population) receiving these drugs. As this study was conducted prior to the government rollout of therapy, all of these children were receiving privately funded drugs.

Other chronic medications noted in the homes during the study were for tuberculosis (30 children = 2.8% of the population), asthma, cardiac failure, epilepsy and attention-deficit hyperactivity disorder (ADHD). There was one insulin-dependant diabetic patient in the homes at the time of the study.

### *3.5.5 Communicable Disease Burden*

Institutionalised care is well known to be associated with an increased burden of infectious disease that spreads readily amongst large numbers children living closely together.

Whilst data regarding this burden was not formally collected during this study, data captured by the author in response to outbreaks in the children's homes is outlined in the discussion (Chapter 4).

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## 3.6 Mortality in the children's homes

### *3.6.1 Mortality rate in the homes over a six month period*

There were a total number of 60 deaths over 6 months in 23 of the children's homes surveyed. One children's home did not supply their statistics despite several attempts to obtain these.

The youngest age at which an infant had died was 4 days and the oldest was 11 years with a mode of 3 months.

The majority of deaths (56/60) occurred in HIV-infected children, 3 were HIV negative and the HIV status of 1 child had not been determined. Of concern was the fact that 25 of the children reported to be "HIV positive" were under the age of 18 months and it was not stated whether their status had been confirmed by HIV PCR testing or not.

Most of the deaths (42/60 = 70%) occurred in the children's homes and the remainder (18/60= 30%) occurred in hospital. Of the 35 "HIV related deaths" with no specific cause given (see Table 16), 24 (68.6%) occurred in the children's home and 11 (31.4%) occurred in the hospitals.

### *3.6.2 Causes of death in the children's homes*

The cause of death as indicated either in the homes' register or in a list completed by the home is summarised in Table 16.

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*Table 16 Causes of deaths in the children's homes*

| CAUSE OF DEATH | NO OF CHILDREN | PERCENTAGE |
|---|---|---|
| "HIV related" (no specific diagnosis given) | 35 | 58% |
| Bronchopneumonia | 9 | 15% |
| Gastroenteritis | 4 | 7% |
| Tuberculosis | 4 | 7% |
| Sepsis | 2 | 3% |
| Prematurity related | 2 | 3% |
| Malnutrition | 1 | 2% |
| Meningitis | 1 | 2% |
| Unknown | 2 | 3% |
| **TOTAL** | **60** | **100%** |

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## 3.7 RCCW in the homes

### 3.7.1 Total number of salaried RCCW

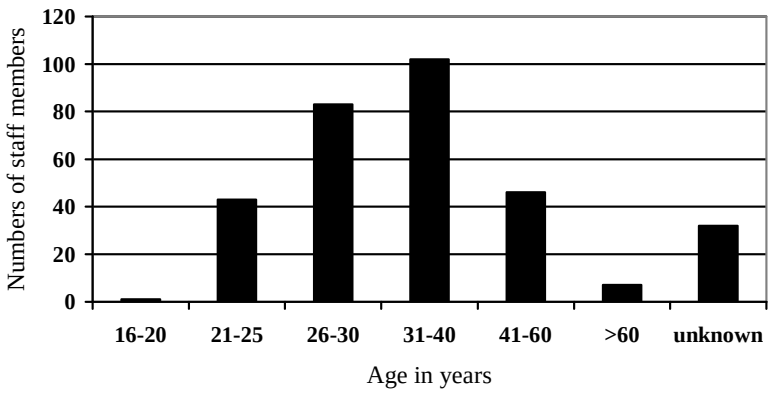
The total number of paid RCCW in the 24 homes surveyed was 314. The largest complement of paid RCCW in one children's home was 44 and the smallest complement in three homes was zero. Two of these homes function as care centres and destitute mothers are admitted together with their children. These mothers assume primary responsibility for their own children in the centre and no additional caregivers are employed at these centres. The third home is entirely dependant on a volunteer staff complement (mainly international volunteers) to perform daily childcare duties. The average RCCW staff size in the homes surveyed was 14.

### *3.7.2 Demographic details of the RCCW*

*i. Age*

The age distribution of salaried RCCW in the homes is demonstrated below.

*Figure 14 Age distribution of RCCW in the children's homes*




*ii. Sex*

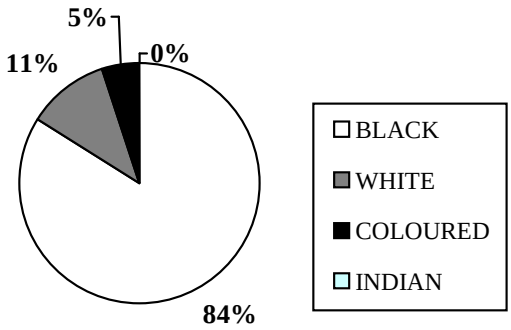
Out of a total of 314 RCCW, 304 were female (96.8 %) and 10 (3.2 %) were male.

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*iii. Race*

The racial distribution of RCCW in the homes is demonstrated in Figure 15.

*Figure 15 Racial distribution of RCCW in the children's homes*

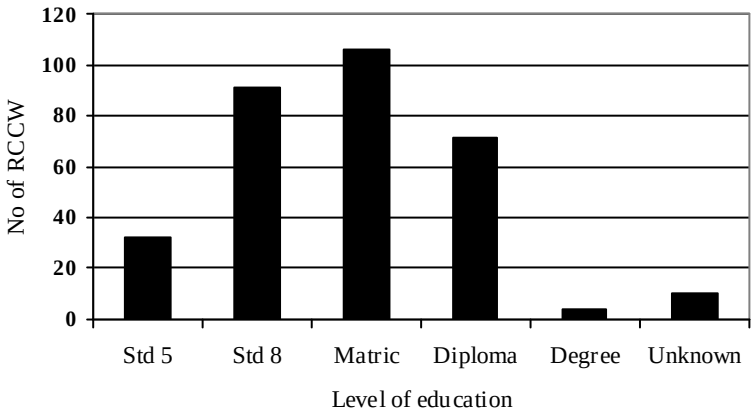



*iv. Education*

The highest level of education was recorded for 304 of the RCCW. The majority (60%) had matric or a higher qualification (diploma or degree). The staff with degrees mainly had nursing qualifications. Staff with social work degrees were more often involved in administration and not in childcare.

The level of education of the salaried RCCW is demonstrated in Figure 16.

*Figure 16 Highest level of education of RCCW*

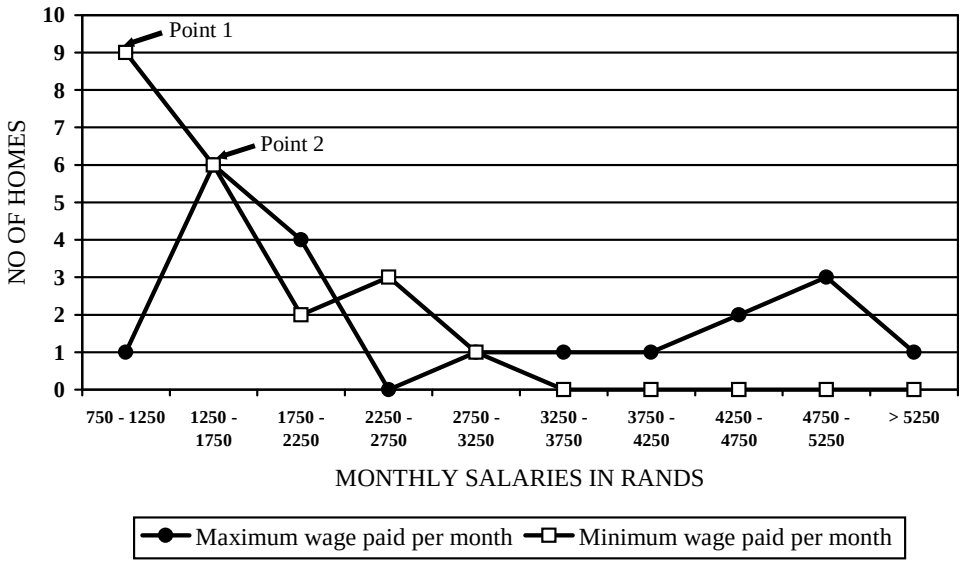



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### *3.7.3 RCCW salaries*

Minimum salaries paid by the homes ranged from R750.00 to R3, 000.00 per month. Maximum salaries paid by the homes ranged from R750.00 to R7, 330.00 per month.

*Figure 17 Salaries of RCCW in the children's homes*




Point 1: Most common minimum salary bracket (R750 – R1250)
Point 2: Most common maximum salary bracket (R 1250 – R1750)

### *3.7.4 Hours worked in the homes*

The minimum, maximum and average number of hours worked per week was 40, 84 and 45 respectively. The minimum, maximum and average duration of a shift was 10, 16 and 12 hours respectively.

### *3.7.5 Child to staff ratios*

The number of children being looked after by a single RCCW (child to staff ratio) is highly variable and may fluctuate on a daily basis (Table 17).

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The ratio depends on numerous factors that include:

1) The number of children in the home: this may fluctuate considerably especially in the more rapid turnover homes.
2) The ages of the children: younger infants and children are more labour intensive than older children and adolescents.
3) The individual needs of the child: Ill or disabled children are also more labour intensive.
4) The number of staff working in the home: this may fluctuate daily especially when staff members are accompanying children to hospitals.
5) The time of day: child to staff ratio's are generally higher at night.

Some homes attempt to keep their child to staff ratios fairly constant and are able to call in extra help when necessary. This help may include outsourced temporary childcare workers, cleaning staff, administrative staff and volunteers. Many homes do not have the necessary reserve resources and child to staff ratio's increase when a caregiver is off sick or spends the whole day accompanying a sick child to hospital.

*Table 17 Child to staff ratios in the children's homes*

| Shift | Minimum | Maximum | Average |
|---|---|---|---|
| Day | 3:1 | 10:1 | 4:1 |
| Night | 3:1 | 16:1 | 10:1 |

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### *3.7.6 Staff turnover*

Staff turnover was accessed by:

1) looking at the length of employment of current staff members.
2) looking at the number of new staff entering and exiting service in the home over a three month period.

#### *3.7.6.1 Length of employment of current staff members*

Shortest length of employment: < 1 month

Longest length of employment: 23 years

Median length of employment: 2 yrs and 9 months

#### *3.7.6.2 Turnover over a three month period*

Total number of new staff employed by the homes (n=21) over a 3 month period: 38

Total number of staff leaving the homes (n=21) over a 3 month period: 13

Intake ranges for the homes: 0 – 17 over 3 months

Exit range for the homes: 0 – 4 over 3 months

In the home staffed by international volunteers the volunteer periods range from 6 – 12 months.

### *3.7.7 Training of staff in the homes*

#### *3.7.7.1 Formal training*

The following formal training opportunities are currently available for RCCW:

1) A 2 year NACCW (National Association for Child Care Workers) diploma in childcare offered by the Johannesburg Technicon.
2) The 59 day course (Department of Health).

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3) First Aid and CPR courses: Red Cross, St John Ambulance.
4) Various counselling courses (mostly HIV related counselling courses).
5) Home Based Care course (Cotlands Baby Sanctuary, Hillbrow PHC)
6) Hospice Based Training days.
7) Some homes have designed their own training manuals.
8) Monthly educational meetings held at Baragwanath Hospital by CHOMP since August 2002.

*3.7.7.2 Informal training done in the homes*

Most of the homes (20/24 = 83%) reported having their own informal training programme for their RCCW. These training sessions are conducted by the homes' managers, the medical staff employed by the homes and occasional outside speakers.

The frequency with which the training is conducted is the homes ranged from daily (4 homes) to quarterly (1 home). Most homes arrange training as the need arises (new staff recruited or crisis situation: e.g. infectious disease outbreak in the home).

The topics reported by the homes that are addressed in these training sessions include:

1) Practical techniques: taking temperatures, bathing, sterilizing and making bottles, changing nappies, nebulising, giving medicine, record keeping etc.
2) Health related topics: Hygiene, Feeding and nutrition, Basic HIV/Universal precautions, CPR, Diarrhoea, Coughs and colds, Skin rashes, Developmental Milestones etc.
3) Parenting skills: disciplining a child, looking after teenagers
4) Team building, conflict management, rules and regulations of the home etc.

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The following resource materials are used by some homes:

1) Baby and Child Care Manuals: Dr Spock and Dr James Dobson.
2) Cotlands HIV course.
3) First Aid Manuals (Red Cross and St. John Ambulance)
4) A resource file: compiled from various training opportunities, magazine articles, Internet searches etc.
5) One home has its own "Professional Parenting Programme".
6) One home has its own "Foster care manual" that also has content relating to child health.

### *3.7.8 Level of knowledge of the RCCW*

A total of 50 RCCW were interviewed using the questionnaire (Appendix 5) and their responses to the questions posed, were recorded and analysed.

The pertinent findings related to suggested key health care topics for RCCW were:

*3.7.8.1 A basic understanding of HIV/AIDS that included modes of transmission and medications that HIV infected children may be required to take.*

Most RCCW had some understanding of what HIV is. Eight (16%) RCCW however did not know what it was or gave incorrect answers. Most RCCW knew how children acquired HIV but 4 RCCW believed they could get HIV from the children if they were coughed on, or through contact with urine, stool or nasal secretions from an infected child.

Regarding medicines needed by HIV infected children: 38% of RCCW could not mention any names of medicines that an HIV infected child may need to take, 28% of the RCCW mentioned Bactrim and 26% mentioned anti-retroviral drugs.

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*3.7.8.2 Temperature control including the use of panado*

When questioned as to the dangers of a high temperature in infants, 46% of RCCW mentioned febrile seizures, 30% of RCCW did not know or gave a wrong answer and 24% of the RCCW believed children could die from high temperatures.

When asked how much Panado they would give a 6 month old infant weighing 8kg, 48% of RCCW would have given a sub-therapeutic dose and 76% of RCCW said Panado could only be given 2 or 3 times a day.

*3.7.8.3 A basic understanding of dehydration and the use of oral rehydration solutions*

Most RCCW (80%) knew what dehydration was and were able to list some of the signs of dehydration. Only 14% of RCCW however knew the correct quantities of sugar, salt and water to make up home made oral rehydration solution for children, 30% of the RCCW gave the quantity of salt used to prepare ORS for adults and 56% of the RCCW either did not know how to prepare ORS or gave incorrect answers.

*3.7.8.4 Recognising a child with a chest infection*

Most RCCW (96%) had some idea about what a child with a chest infection may look like although many of the answers were non-specific. The most commonly mentioned signs were cough and wheeze. No caregiver mentioned fast breathing (tachypnoea) as a sign of a possible chest infection.

*3.7.8.5 Recognising a child with possible meningitis*

Sixty percent of RCCW did not know what Meningitis was. Of the caregivers that were able to name some possible signs and symptoms of meningitis 3/20 were incorrect.

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*3.7.8.6 Infant feeding*

The questions around bottle sterilisation and formula preparation were very well answered, with most RCCW giving correct answers. When questioned on some of the formula types, 52% of RCCW had not heard of Soya based products and 25% of RCCW said that cow's milk could be used in children under the age of one year.

*3.7.8.7 Basic understanding of the importance of hygiene and methods to prevent the spread of infections in the homes*

The majority of RCCW said that a clean working environment was the most important method to prevent the spread of infections in the home. Only 30% mentioned hand washing as a means to curb the spread of infections.

*3.7.8.8 Identification of chicken pox*

Most RCCW know what chicken pox looked like. Only 40% mentioned isolation of the affected child in their management of a child with chicken pox.

*3.7.8.9 Tuberculosis*

Most RCCW mentioned the more adult constitutional signs for TB. Just over a half (52%) believed they could contract TB from an infected infant.

*3.7.8.10 Nappy rashes*

All RCCW mentioned irritation from stool and/or urine and infrequent changing as a cause for nappy rash but only one RCCW mentioned thrush.

*3.7.8.11 Gross developmental milestones*

Most (72%) respondents gave the correct age range for sitting unsupported and 94% gave the correct age range for independent walking.

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### *3.7.9 Psychological support for caregivers*

All homes surveyed expressed a need for psychological support and debriefing of their caregivers. Only 14 out of the 24 homes had access to some form of psychological support.

Psychological support in the homes is provided by social workers (4 homes), pastors (3 homes), psychologists (2 homes), lay counsellors (1 home), home's manager (2 homes) and fellow caregivers (1 home). One home mentioned that they had used the services of Life Line on occasion.

## 3.8 Health care facilities and professionals used by the children's homes

### *3.8.1. Use of health care facilities by the children's homes*

#### *3.8.1.1 Local Clinics*

All but one of the children's homes used their local clinics. The home that did not use their local clinic had a visiting nurse who came to the home to immunise the infants. One home, situated in a peri-urban area, made use of a mobile clinic that visited the area on a regular basis.

Two of the homes used the immunisation services available in private pharmacies in the area on occasion.

Local clinics are used by the homes primarily for immunisations and TB treatment. Many homes (16/24) do their own growth monitoring and do not take infants to the clinic for weighing. Only 4 (16%) of the homes used the clinics to obtain consultation for sick children.

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The main reasons given for not using the local clinics for consultation on sick children included:

i. Long waiting times.
ii. Poor treatment and sometimes discrimination.
iii. Inadequate drug supplies.
iv. Nursing sisters employed by children's homes felt they were on the same level as PHC trained nurses in the clinics, and usually treated their own children. If they felt they needed advice on managing a particular problem they would seek consultation from a GP or hospital or volunteer doctor rather than the local clinic.

*3.8.1.2 Hospitals*

All the homes used their local government hospitals. One home had an arrangement with a local private hospital to admit their children free of charge.

There was a tendency amongst children's homes to use the academic hospitals for certain children rather than the local primary or secondary level hospitals. The reason often given for this was that many of their children had been admitted from these hospitals or were being followed up in specialist clinics (especially anti-retroviral clinics). Children's homes tended also to take the children back to the hospital from which they were referred as the children were already registered there. This sometimes leads to homes having to take children to two or more different hospitals.

*3.8.1.3 Private facilities*

A large number of homes (17=71%) make use of private facilities on occasion. Some of these homes have established a relationship with a local private GP who sometimes see their children pro-bona. Three homes were also able to see private paediatricians pro-bona.

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Five of the children's homes made use of local "Medi-Cross facilities" for which they paid an average of R100 per consultation. The frequency of private consultations was greater in the unregistered children's homes, which accounts for their higher medical costs in their monthly expenditure (pg 34). Two children's homes regularly took ill children to the local private pharmacy for advice. Six children's homes used private laboratories for HIV testing and occasionally for Bilirubin levels.

### *3.8.2 Availability of transport to the facilities*

All of the homes surveyed said they had their own transport to take children to health care facilities but 4 children's homes said they often had to use public transport (mainly taxis) as the homes vehicles were often used to take children to and from school. In 11 of the homes staff use the homes' cars but in 13 of the homes staff have to use their own vehicles.

Eight of the homes said they had a designated driver but in the majority of the homes (16) a staff member (caregiver or administrative staff) drives another caregiver and the ill child/ children to the health care facility. Some of the homes use volunteers to take children to health care facilities. Occasionally social workers from the JCWS or private adoption agencies escort the children to health care facilities for scheduled appointments.

In 5 of the children's homes the homes manager escorts the children to the health care facility. In 2 homes the "medical personnel" always escort children to health care facilities, but in the majority (17) of homes a RCCW on duty escorts the child/children to the facility. The RCCW "on duty" may have just started a new shift and may not know the medical history pertaining to the ill child. Only 4 of the homes are able to call in extra staff when other staff members have been "taken away" from the home in order to accompany a sick child to hospital. If an escort is still with an ill child towards the end of her shift a RCCW from the next shift is often sent to

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relieve this escort. Occasionally this is not possible, and the escort has to stay beyond the duration of her shift. Two children's homes mentioned that their RCCW had been asked by staff of "sleepover facilities" attached to paediatric casualties in government hospitals to stay overnight with the ill child.

### *3.8.3 Problems encountered by staff in the use of health care facilities*

Problems encountered by staff in the use of health care facilities were explored during the interview with the children's home managers. They were questioned about their experiences in the use of public clinics and hospitals as well as the private sector. As the study collected retrospective data in this regard, recall bias needs to be taken into consideration when evaluating the responses received in this section.

*Table 18 Problems mentioned by the homes in the utilisation of health care facilities*

| **Problems mentioned by the homes** | **No of homes who encountered the problem in the following health facilities** | | |
|---|---|---|---|
| | **Public clinics (n = 24)** | **Public hospitals (n = 24)** | **Private facilities* (n = 13)** |
| Long waiting times | 4 | 14 | 1 |
| Discrimination | 2 | 6 | 1 |
| Poor patient management | ** | 1 | 1 |
| Asked to stay overnight with children | N/A | 2 | 0 |
| Felt the facilities were "dirty" | 0 | 2 | 0 |
| Poor phlebotomy skills in children | N/A | 0 | 3 |
| Poor feedback / information given after a consultation | N/A | 11 | 1 |

***** *Only 13 of the children's homes make use of private facilities*

** *With the exception of a few homes, most homes tend not to use their local clinics for consultation purposes*

*N/A: not applicable*

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### *3.8.4 Health care professionals available to the children's homes*

Several children's homes have established relationships with healthcare professionals who provide a voluntary service to the home. Table 19 outlines the type of professionals assisting the children's homes as well as their frequency of visits.

*Table 19 Health care and other related professionals servicing the children's homes*

| Visiting Health Professional | No of homes receiving visits | | | No of visits per month | | | Cost to home | |
|---|---|---|---|---|---|---|---|---|
| | R* | UR** | Total | MIN | MAX | MODE | FREE | CHARGE |
| General Practitioner | 2 | 4 | 6 | 1 | 4 | 4 | 5 | 1 |
| Paediatricians | 6 | 3 | 9 | 1 | 4 | 4 | 8 | 1 |
| Nursing Sisters | 1 | 1 | 2 | 1 | 1 | 1 | 2 | 0 |
| Occupational Therapist | 1 | 2 | 3 | 1 | 1 | 1 | 3 | 0 |
| Physiotherapist | 2 | 1 | 3 | 4 | 12 | 4 | 3 | 0 |
| Otorhinolaryngologist | 1 | 0 | 1 | 1 | 1 | 1 | 1 | 0 |
| Psychologist | 0 | 1 | 1 | 20 | 20 | 20 | 0 | 1 |

**R: Registered children's homes*

***UR: Unregistered children's homes*

Most of the visiting doctors visit the homes on a weekly basis when they will see new admissions or consult on problem children. The majority of these practitioners are also available to the homes for telephonic advice. Four of the Paediatricians were private practitioners and 5 were in the government service. All the general practitioners (GP) were in the private sector. Three of the homes (2 unregistered and 1 registered) had both visiting GP's and Paediatricians.

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# CHAPTER 4: DISCUSSION

The discussion that follows has been structured to answer the research questions posed at the outset of the study.

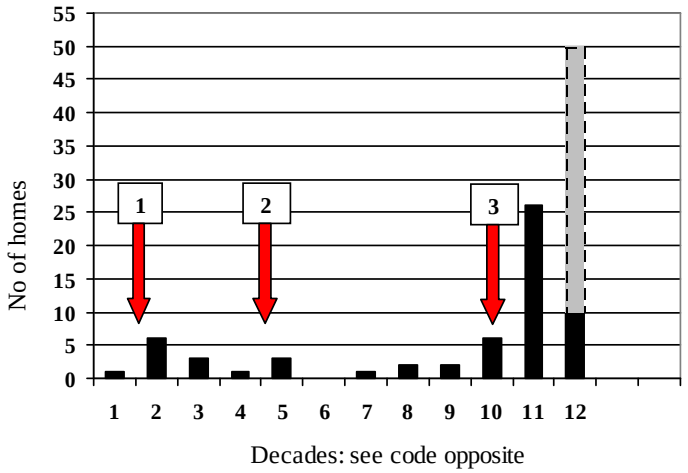
## 4.1 Have children's homes been founded in response to the epidemic?

In the introduction to this report, the relationship between the founding of certain Johannesburg Children's homes and the South African War was mentioned. A similarity between this and the current situation (where the death of parents from HIV/AIDS has increased the number of orphans requiring accommodation in orphanages) was suggested (pg 19).

Although Figure 5, representing the ages of children's homes, is a "snapshot view" of the current situation, it is clear that the number of homes founded in the last three decades has increased substantially. This picture is, however, skewed as there were likely to have been several children's homes founded in past decades that have since ceased to exist. The bar graph in Figure 18 has been superimposed by arrows representing significant events that may have contributed to an increase in the number of children in residential care during the last 12 decades.

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*Figure 18 Significant events influencing the founding of children's homes*




**Decades:**

1: 1890 – 1900
2: 1901 – 1910
3: 1911 – 1920
4: 1921 – 1930
5: 1931 – 1940
6: 1941 – 1950
7: 1951 – 1960
8: 1961 – 1970
9: 1971 – 1980
10:1981 –1990
11: 1991 – 2000
12: 2000 – 2002*

| | | |
|---|---|---|
| **1** | **South African War** | **1899 - 1902** |
| **2** | **Residential care used by SA government to uplift poor whites (22)** | **1930's (following the great depression)** |
| **3** | **AIDS epidemic in SA** | **1985 -?** |

* *Note that only 2 years are represented in the last decade*

The growth of the residential care setting is of concern especially since only 2 years are represented in the last decade. Should the number of homes continue to increase at a pace of 5 homes per year; the total number of homes started in this decade will be double that of the previous decade (Figure 18).

The mission statements of children's homes also testify to the fact that homes have been founded in response to the epidemic. Several long established children's homes have also shifted their focus to deal with HIV affected children. Out of 49 "mission statements" collected from the children's homes, 24 mention the care of children affected by HIV/AIDS as one of their primary goals.

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**4.2 What is the impact/burden of HIV on the children's homes?**

Results of this study showed that 20% of children in the homes were HIV infected and the extrapolation exercise revealed that nearly a third (31.7%) of children were likely to be HIV affected.

A number of factors made determining the HIV status of children in the homes difficult. These included:

1. ***A directive issued by the Department of Social development during the time of the study that prohibited HIV testing in the children's homes:***

   The motivation for this directive was a fear that if children tested positive, they would be discriminated against by the caregivers looking after them. All children were to be regarded as potentially infected and universal precautions applied. This directive although not legally binding, prevented some homes from testing children.

2. ***Misunderstanding in the homes and welfare sector around HIV testing in children:***

   At the time of the study it was discovered that some children's home staff (and even doctors and social workers referring children to homes) did not understand HIV testing in children. A positive HIV ELISA was often regarded as being indicative of an infected state regardless of the age of the child and the possible presence of maternal HIV antibodies as a cause for this result. This misunderstanding led to the mislabelling of several uninfected but HIV-exposed children that impacted negatively on permanency planning arrangements (adoption or foster care options) for these children. Several myths concerning sero-reversion were encountered in the children's homes. Some believed that if children received the right nutrition and love they could "become negative". Example of these myths and misunderstandings were also erroneously reported in the media (23, 24).

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3. ***The inaccessibility of HIV PCR testing in the state service at the time of the study due largely to cost constraints.***

   At the time of the study the use of the HIV PCR test in the public health sector was limited, for example, to infants in intensive care settings where decisions needed to be made regarding ongoing management or to decisions around surgical interventions. Routine HIV PCR testing of exposed infants, even for decision making with respect to permanency planning, was not standard practice.

4. ***Obtaining consent for HIV testing of children who had no legal guardians:***

   A manager in a children's home is only considered to be the child's legal guardian if the child has been committed to the children's home through a court order (form 8). Due to the high caseload at the children's courts, the time taken to get a child committed is prohibitively long. The current Child Care Act states that where the parent or legal guardian is unavailable or the child has not yet been dealt with in terms of the Child Care Act (i.e. legal guardianship has not yet been conferred), the Minister's permission must be obtained to test the child (16).

Despite these obstacles several children in the homes were tested because:

1. ***The Johannesburg Child Welfare Society (JCWS), under whom a large number of children in the children's homes sector fell, had a more liberal testing policy.*** Although the policy did not allow for routine HIV testing of children entering their services or facilities it did allow testing to facilitate permanency planning and for diagnostic purposes in the symptomatic child (Appendix 7).
2. ***Children had been tested by the referring hospitals.*** Several children in the study were admitted to the children's homes having already been tested for HIV by referring hospitals. In most cases only an HIV ELISA was done. It is unlikely that consent was obtained for testing abandoned babies.

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3. ***Children's homes were using private laboratories for HIV testing.***
4. ***Volunteer professionals from state hospitals were performing HIV PCR testing for children in the homes.***
5. ***Consent was probably not always obtained for HIV testing of children without legal guardians.***
6. ***The Department of Health paid for HIV PCR testing in one of the children's homes.***

The testing policies and practices for the homes contained in the results section (Table 15) also show that the homes were in fact testing children for HIV.

Of concern is that it appears that teenagers in the homes, who may be sexually active, are not tested for HIV.

Further statistics that attest to the impact of HIV on the children's homes are:

1. More than two thirds (69%) of the orphans were AIDS orphans, and 29% of abandoned children were HIV infected.

2. The high mortality rate and the fact that 56 out of 60 deaths (93%) in the children's homes were believed to be HIV-related.
3. A total of 10% of children in the homes were reported to be currently ill or usually sickly and the majority (99%) of these children had HIV-related diseases.

4. Two thirds of children were on chronic medication, the most common being those used in the treatment of HIV (Bactrim, ARV's and TB treatment).

New "reasons for admission" to children's homes such as "ill child" and "child admitted together with ill HIV infected mother" also reflect the impact of HIV on the homes.

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Although the unregistered children's homes represent a smaller proportion of the total study population these facilities appear to be more "HIV affected". They had a higher proportion of orphans (15% vs. 5.85%) and of HIV-affected destitute children (17.9% vs. 6.23%) than the registered facilities.

**4.3 What resources and facilities exist in children's homes to deal with the epidemic?**

These varied substantially from home to home. No relationship between registration status and resources was demonstrated. Some unregistered facilities had poor resources (one such facility has closed since the completion of this study) whilst others that were privately funded had facilities that outstripped those of registered facilities.

***4.3.1 Financial resources***

One of the main criticisms around the residential care model as a solution to the AIDS orphan crisis is that it is an expensive model. This study revealed that the cost of running 23 children's homes over a one year period was R33 198 339. Most funding was sourced from donors or raised by children's homes themselves and was not provided from state coffers. The largest proportion of funding in the children's homes (60%) is allocated to staff costs and not spent directly on the children themselves.

The wide range in cost per child per month between the homes (R 581 – R 7 585) highlights the spectrum of resources available to different children's homes. The method used to calculate this (monthly expenditure divided by the number of children in the home during that month) was not accurate for all children's homes. Many of the homes (especially those homes whose cost per child per month looks unusually high) use their financial and human resources for outreach programs to children in the community. Hence some of their budget is spent on

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programmes involving children not residing in the children's homes but in the nearby community. This is called programme funding and the SA Law Commission recommends that funding of the homes be divided into "per programme" and "per capita" funding (25).

### *4.3.2 Human resources*

The results of the study showed that homes were able to attract a large variety of both professional and volunteer staff. Childcare workers were also well educated as 60% of them had matric or a higher level qualification. Staff turnovers in the surveyed homes did not seem to be high as the median length of employment was 2 years and 9 months and the number of new employees admitted into service in the homes exceeded that of employees leaving. These factors suggest that training programmes designed to improve childcare workers level of basic child health knowledge could impact positively on the health of children.

Factors that could increase turnover rates of childcare workers in children's homes may be poor remuneration (the average childcare worker salary was R 1, 500.00 per month), high child to staff ratios and lack of adequate professional debriefing.

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### *4.3.3 Material resources*

All homes surveyed seemed well equipped to meet the material needs (food, shelter and clothes) of the children in their facilities although some homes relied on donor provisions which can be erratic. Of concern were the use of expired foodstuffs in certain homes and the inadequacy of first aid equipment to deal with common childhood medical emergencies.

The wide array of both medicines and medical equipment that was available in the homes is most likely a reflection of the increasing health needs of children in the home largely due to the effect of the HIV epidemic. The problems as well as the dissatisfaction many homes express regarding the use of state run health facilities may also have influenced the perceived need of the homes to be medically self sufficient.

There is however a need to balance self sufficiency in terms of medical equipment with medical knowledge and skills. In the same way that home nebulisation initially increased mortality rates amongst children with asthma (due to a false sense of security imposed by having the facility), there is a concern that well equipped homes will present to health facilities too late because of a false sense of security and reliance on their own resources. Similarly, from a palliative care perspective, where children are cared for in the terminal stages of their illnesses within "hospices" in children's homes there is a concern that they may not receive adequate pain and symptom control especially if the facility does not have properly trained staff and access to restricted drugs such as Morphine.

Despite the availability of educational toys as well as ECD practitioners, half of the children's homes had children who were developmentally delayed or showed signs of "institutionalisation".

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Children who grow up in large institutions are well known to experience developmental delays and exhibit signs of "institutionalisation" (26). Causes of developmental delay in institutions are multiple, but the two most important are a lack of sensory stimulation and attachment to a primary caregiver. Attachment of an infant to a primary caregiver gives the infant a feeling of emotional security and the caregiver becomes a "secure base from which to venture forth and explore the surroundings" (27). Provence and Lipton wrote the definitive work 'Infants in Institutions", on institutionalisation in 1966. They concluded that it was "the inconsistent experience with multiple caregivers that hampered discrimination and the pleasure of recognition." This failure to develop a secure attachment was primarily responsible for developmental delay in institutions (28).

Although an in depth analysis of developmental delay and institutionalisation in the children's homes was beyond the scope of this research, report this study did show that even in homes that had formal stimulation programmes, children had signs of institutionalisation emphasizing the role attachment to a primary caregiver plays in the prevention of "institutionalisation".

### *4.3.4 Sleeping and hygiene facilities*

With the exception of one children's home, where 30 children were housed in one large hall, there was no "overcrowding" in any of the surveyed homes. Hygiene facilities also appeared adequate with the ratio of children to toilets and children to baths/showers being more than the suggested ratios set out in the municipal by-laws of the department of environmental health for these facilities (29). These by-laws recommend a ratio of not more than 15 children for each toilet or chemical toilet and a ratio of not more than 20 children for each hand wash facility.

One of the limitations of this study however, was that none of the unregistered facilities in the informal settlements in the greater Johannesburg area were included. Subsequent involvement

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by CHOMP in these facilities has shown that overcrowding as well as inadequate hygiene facilities is a problem in these homes.

### *4.3.5 Medical facilities in the homes*

The two "medical facilities" evaluated in the homes were "hospice type facilities" as well as "isolation facilities".

Despite many hospice-type facilities in the children's homes being well equipped, it was observed that the care of children in some of these facilities was not ideal. Although anecdotal, some children in the early stages of HIV infection may have died unnecessarily in these facilities from intercurrent acute infections such as pneumonia and gastro-enteritis that should have been managed more aggressively in a hospital setting. The higher number of HIV-related deaths (42/60 = 70%) that occurred within the children's homes when compared with hospital deaths further supports this concern.

Only three homes had dedicated isolation facilities. In a separate survey conducted by CHOMP from October 2003 to July 2004, it was noted that communicable diseases place a significant burden on the homes and account for a high degree of morbidity and mortality. The most significant infectious disease noted in the children's homes during this period was measles: 58 children contacted measles and 11 died as a result. Given the high numbers of immuno-compromised children in the homes, infectious diseases can spread quickly and pose a significant threat to childhood survival in the homes.

### *4.3.6 Hygiene and feeding practices in the children's homes*

The most common route for the transmission of communicable diseases in institutions is through the hands of care workers. Good hand hygiene has been shown to be the most effective

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way of preventing the spread of infections in institutions (30). Proper hand washing in the children's homes, sometimes limited by the availability of expensive equipment (such as liquid soap and paper towelling), appears to be poorly practiced.

Research shows that the use of liquid soaps is preferable to the use of bar soaps in preventing the spread of infections. Liquid soaps from which individual small amounts of soap can be dispensed reduce the amount of cross contamination of microbes between staff. Bar soaps are associated with some cross contamination between staff sharing a bar, particularly when the bar of soap is not allowed to drain properly. Studies have also shown that decontamination of hands with an alcohol based hand rub is an effective form of hand hygiene, particularly in circumstances where time constraints may limit regular washing of hands with soap and water (31). The use of paper disposable towels, although costly, is recommended above a communal cloth towel that is shared by many caregivers (30).

Disposable nappies, although much more expensive than towelling nappies are more hygienic in a children's homes setting. There tends to be more side leakage of stool from towelling nappies (especially if no covering waterproofs are worn) than from disposable nappies.

The workload of staff where towelling nappies are used is also much greater. In the only children's home where towelling nappies are used exclusively, 4 machine loads of washing are done per day to keep up with the demand. This workload obviously increases when there is an outbreak of diarrhoea in the home, or if there are HIV infected children with chronic diarrhoea. There is also a greater risk for staff of contracting feco-oral pathogens when they are required to rinse out towelling nappies containing faecal material. Interestingly, there are still caregivers who are afraid of contracting HIV from changing nappies, but have little knowledge of other pathogens spread via this route (pg 69, 71).

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Although it is desirable to have more of a homely rather than a clinical environment in a children's home, the burden of infectious diseases in the homes serves to highlight the need for improved hygiene and especially hand washing practices in the children's homes.

### *4.3.7 Other health related practices including growth monitoring, immunisations and medical record keeping in the children's homes*

*i) Growth Monitoring*

Although most homes weigh children, very few actually plot weights and are therefore unable to adequately monitor weight gain making it less likely that they would intervene if a child were failing to thrive.

*ii) Immunisation practices*

Several problems relating to the immunisation of children were noted in this study and have been supported by further operational research conducted by CHOMP (available from the author on request). A significant number of children in homes do not arrive in the facility with original immunisation cards because they have been abandoned without them (32.3% in this study). Social workers, who refer orphans or children that have been removed from their families, do not always ensure that the original RTHCs are retrieved. Long delays in catching up immunisations are experienced when original or replacement cards have to be obtained.

Staff shortages in the children's homes as well as the high workload in the homes (especially those with chronically ill children with high medical needs) are barriers cited by several homes in ensuring that children are up to date with their immunisations. Some homes also report poor relationships as well as discriminatory experiences with their local clinics as reasons for their inability to ensure adequate immunisation coverage in the home.

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The measles outbreak in the homes in 2003/2004 demonstrated the poor immunisation coverage in the children's homes. In one particularly heavily affected home (10 cases, 6 hospitalisations, 1 death), the immunisation coverage was only 20%. The high number of measles cases in the homes in infants under 9 months of age, also lead to the issuing of a directive by the Expanded programme of Immunisations (EPI) and Communicable Disease Directorate (CDC) of the Department of Health making it compulsory for all children admitted to children's homes to receive an additional dose of measles vaccine at the age of 6 months.

*iii) Medical record keeping*

The list of registers and documents required under the Regulations under the Child Care Act to be kept in a children's home is contained in Appendix 8. Many of these documents relate more to the psychosocial aspects of childcare as well as behavioural interventions. The only mention (although it is non-specific) that is made regarding medical records is that "all reports on any physical, psychiatric or clinical-psychological examination of the child or reports on the results of any treatment given" should be kept. No mention of specific documents such as the road to health card or immunisation record for example, is made.

The municipal bylaws governing children's homes (29) require documentation of medication administered to children and up to date immunisation records although these bylaws are written more from the perspective of day care centres (crèches).

Most children's homes keep a separate social and medical file on each child. Whilst this is practical for the social workers and medical staff in the homes, there is an overlap in information required by both professionals and lack of communication between the two disciplines may lead to inappropriate interventions or the unnecessary duplication of investigations.

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Record keeping and documentation practices varied greatly in the children's homes. Homes that had been established with a more "medical" or "adoption focus" in mind and that are staffed by professionals with nursing backgrounds tend to have better medical records. Regular children's homes and places of safety often have poor medical records and in the absence of patient held records or discharge summaries, very little is known about hospital admissions or treatment. Several hospital based medical professionals report problems in obtaining a proper medical history for children in homes. Often the accompanying escort does not know these details and the home's records, if they have accompanied the patient, are usually incomplete.

Poor communication between the hospital or clinic staff and the caregiver escorting the child to the medical facility also contributes to poor documentation of health related issues.

The multiple caregiver system in children's homes makes proper record keeping important especially when communication regarding ill children is crucial. Whilst it is impractical and probably unnecessary to document intake and output for all infants in a home, it makes sense to record this for infants experiencing increased losses (vomiting and diarrhoea) or with poor intake or poor weight gain.

Also, although many homes feed infants on demand, it has been noted that infants in large institutions "demand less". With staff shortages, their needs are not always instantly met and they stop "demanding" or crying for food. Quieter infants also tend to be fed less often than noisier more demanding infants. Sometimes if feeds are not documented, some infants may be "missed" during feeding times (author's own observation).

Smaller homes where signs of illness and poor feeding are more readily observed are preferable to care in large institutions.

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**4.4 What training opportunities relevant to child health and HIV are available to staff in the homes?**

The technicon based diploma in childcare currently offered by the National Association of Child Care Workers (NACCW) still has a predominantly psycho-social focus with emphasis on behavioural intervention, discipline and other such issues (32).

This course is currently under review and the NACCW has recognised a need to professionalize the childcare profession. The diploma can now be upgraded to the equivalent of a university degree and the NACCW are in the process of obtaining SAQA accreditation for their courses. The association also recognises its need to increase its child health related input and has approached CHOMP in this regard.

Although a variety of outside training organisations and resources are available and are being utilised by the homes, many of them still have a First Aid and predominantly adult focus especially with respect to HIV.

There is currently no standardised resource material available to all children's homes that specifically addresses basic child health, paediatric HIV and the management of infectious disease outbreaks in the children's homes.

Children's homes do offer "in-service training" to childcare workers mostly related to daily practices (feeding, nappy changing etc) required of them. The health related content of these largely informal training opportunities is very much dependant on the level of knowledge of the senior management of the home and whether or not the home employs medically trained staff (mostly nurses) or not.

It was noted that the health related responsibilities in homes with a medical focus, lie largely

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with professionally trained medical staff and that little downward dissipation of this knowledge to grassroots childcare workers has occurred. The home is made acutely aware of this situation when the medical personnel are on leave and the caregivers left behind are inadequately equipped to deal with intercurrent acute illnesses or medical emergencies that arise.

**4.5 What is the level of knowledge of RCCW in meeting the healthcare needs of children in homes?**

The results revealed a good understanding of bottle sterilisation and formula preparation in particular as well as a reasonable knowledge of basic gross childhood developmental milestones.

Knowledge gaps were identified in the understanding around modes of HIV and TB transmission, the use of Panado, the preparation and use of oral rehydration solution as well as the identification of a child with meningitis or a chest infection. The survey also reflected an under-emphasis in the homes on hand washing as a means to curb the spread of infectious diseases in the home.

The need for RCCW to have some knowledge of the conditions as outlined above may be questioned, but the high incidence of these conditions in the homes reflects the changing face of the residential care setting and the need to have this knowledge at grass roots level. The CHOMP project has been looking in to adapting principles taught by the Integrated Management of Childhood Infections (IMCI) model to teach caregivers in homes "when to worry". It is hoped that knowledge about the "early warning signs" of significant disease in children will avoid unnecessary morbidity and mortality in the children's homes.

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**4.6 Do homes use the health care resources available to them?**

As outlined in Chapter 3, the children's homes do make use of public health care facilities available to them although the extent of this use (as well as the selection of resources) depends largely on other resources available to the homes.

There was a noted tendency by several homes to use local clinics primarily for immunisation purposes and TB treatment only. They did not use the clinics for growth monitoring and for consultation in the event of illness in the children. Many homes (especially those who employ nurses) tend not to consult local clinics for advice on common medical problems because they feel they are at the same level as their colleagues in the clinics. Some will however use these facilities to obtain "free medicines". Although not particularly disadvantageous to homes that ensure that the routine health care needs of children that are met elsewhere, this practice could be harmful in children's homes that do not make alternative arrangements. This was particularly evident when it came to growth monitoring. Homes that do not use primary health clinics for growth monitoring tend to weigh children themselves. Although the child's weight is documented, it is not plotted on a growth curve therefore no growth monitoring is achieved. Similarly other routine health surveillance practices such as monitoring the child's neurodevelopment does not occur in homes not using primary health care clinics who do not have the skills to do this themselves.

**Comment [G1]:** Plse fix this sentence – tooooo long

Nurses in homes often also have volunteer doctors who they phone for advice and some of them have established good relationships with local GP's for this purpose. Many homes cite a lack of time to stand in queues as a reason for not using primary health clinics.

Greater use of academic hospitals above secondary level hospitals was also noted during the survey as was the use of private medical services by the unregistered children's homes as reflected by their higher medical bills.

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**4.7 What problems do homes experience in the utilisation of these resources?**

The main problems experienced by the homes in terms of the utilisation of these resources relate to transport, staff and time constraints. Staff from children's homes have several other duties to perform such as escorting children to courts, school, extra-mural activities and scheduled appointments. Child to staff ratios also increase in the home when an escort unexpectedly spends the whole day in a health care facility.

Another problem reported by 38% of the homes was that their HIV infected children were often discriminated against and received inferior care because of their status. The Johannesburg General hospital was cited by most homes as being the most discriminatory.

**4.8 What is the need for professional healthcare services to the homes?**

The high rate of HIV infection (20%) and the burden placed on children's homes by communicable diseases are two factors accounting for a greater need for professional healthcare service provision in the homes.

The type of child found in "need of care" and admitted to a children's home often has significant medical needs. This may be either as a result of inherent medical conditions or as a result of the effects of a poor socio-economic situation. It is well known that there is a high rate of abandonment amongst premature babies and babies with special needs (e.g. cerebral palsy) where the mother or caregiver is unable to cope with the child, particularly if mother to child bonding was impaired. In some instances prematurity may have been the result of actions taken by an expectant mother to terminate an unwanted but viable pregnancy.

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The inadequate provision of special care facilities for children in the greater Johannesburg and the resultant long waiting lists for admission to these facilities has also resulted in a significant number of “special needs children” being cared for in “regular children’s homes” as noted by this study.

The degree to which the children’s homes have “medicalised” (as reflected by the amount of medical equipment noted in the homes and the establishment of high care hospice-type facilities in the homes) also bares testimony to the changing role of many of these facilities with a greater need for healthcare related services.

These health care services could be rendered by public health care facilities viz. primary health care clinics, but homes tend not to use them because it is time consuming and impacts negatively on their staff:child ratio when a caregiver spends the whole day accompanying one or more children to the clinics. Given the increased burden of disease (e.g. HIV and other infectious diseases encountered when large numbers of children are cared for together) homes may benefit from having their own health care services. It may be more effective for one health care professional to visit a children’s home than to take several children from the home to a public health care facility for medical attention and routine health care. In the past some primary health care clinics sent nurses to the homes but given the increased work load at the clinics this no longer happens. Providing a medical service in the home may assist health care professionals in identifying problems (e.g. poor levels of hygiene) that may impact negatively on children’s health.

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**4.9 What are the sufficiencies and deficiencies of the children's homes particularly in relation to caring for HIV affected children and addressing the AIDS orphan crisis?**

***4.9.1 Sufficiencies***

The surveyed children's homes should be commended in their efforts to care for the many children that have been found in need of care primarily as a result of the effects of the HIV epidemic. Many of them have managed to muster not only excellent resources but have also either employed staff with medical qualifications or convinced outside medical professionals to provide voluntary medical services to their facilities.

Several of the unregistered children's homes had been established in response to the epidemic despite (and because of) there being a moratorium on the registration of children's homes at the time of the survey. Managers of these homes had sometimes placed themselves at personal risk and found creative ways around the moratorium (using loop holes in the legislation) in order to provide services to this population of needy children. Increasing numbers of unregistered homes may be due to insufficient space in registered facilities but it has been shown that HIV has increased the numbers of children in registered facilities. Low turnover rates for registered homes were documented by this study and Sherman et al (40). Failure to correctly determine HIV infection status in HIV-exposed children through early infant diagnostic testing decreases turnover of children (40).

The children's homes had often provided HIV affected and infected children with better medical care than was standard in public health care facilities at the time of the survey (prior to the rollout of anti-retrovirals). Many homes (16/24) were already accessing HIV PCR testing to facilitate early adoption and were in the forefront in terms of accessing anti-retroviral treatment. At the time of the survey, 50% of children managed at the Hariet Shezi Clinic at the Chris Hani Baragwanath hospital came from the children's homes. This clinic was providing

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medical management and monitoring services to paediatric patients whose caregivers were able to afford anti-retroviral medications either out of their own pocket, through sponsorship or through private medical aids.

As a result of their experiences gained in the management of HIV infected children, at least four of the studied homes had also become resources to their communities. These four homes run outreach medical programmes providing support to their surrounding communities and also admit children requiring temporary medical care (especially to those living in child and granny headed households). Some of the hospitals have also been able to discharge children still requiring oxygen or other medical interventions (such as nasogastric feeding) to these children's homes for "step-down" care.

### *4.9.2 Deficiencies*

There has been a global trend to move away from the residential model of care as an ideal childcare model. Save the Children (UK) has a particularly strong view on this subject as expressed in their recent position statement on residential care (8). Concerns raised by this document include the growing amount of child abuse (believed to be under reported) occurring in institutions, the infringement on the rights of a child to self determination, the cost of residential care as well as the fact that in many countries "governments are failing to register and regulate organisations, monitor standards and inspect facilities that are providing care for children" (8).

Disturbing reports on the long term effects of institutionalisation on the emotional development of a child have also emerged as a result of follow up studies of children who grew up in "Romanian Institutions" after the 2nd World War. The major concern is that children growing up in large institutions are not able to bond with a primary caregiver and this "failure of

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attachment" can lead to serious emotional and psychological problems including the development of an anti-social personality disorder (33).

Similar concerns have been raised by the South African Welfare Sector and as far back as 1977; the white paper for social welfare also recommended that children's homes be used as "a last resort" and that the placement of children in community based programmes was preferable (34). The Inter-Ministerial Committee on Young people at Risk (the IMC) was tasked with developing a policy framework for the transformation of the child and youth care system and in their recommendations published in 1996 already described the child and youth care system as being "in crisis". Whilst the committee recognised "that residential care was an essential part of the child and youth care system", they indicated that "in the current system too many children were ending up in residential care and that a transformed child and youth care system needed to be established that could provide other services (prevention, early intervention, statutory processes and the continuum of care) at an earlier stage to strengthen families and communities thus allowing more children to remain in their own or in substitute families" (35).

Further concerns highlighted by this research are the threats to childhood survival in the residential care model that arise from the communicable disease burden in these facilities as well as a sometimes less than aggressive approach to the management of intercurrent infections in HIV positive children.

The "medicalisation" of some children's homes has in some instances lead to an over-confidence in certain homes in their ability to treat children and to provide palliative care to terminally ill children. Although some homes have established "hospice type" facilities within their homes not all of them have the necessary expertise and access to palliative care drugs (especially morphine) that is required to provide quality palliative care.

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To this end, CHOMP in 2003 approached Hospice Witwatersrand for assistance in dealing with "hospices" in children's homes. This led to the establishment of an in-patient paediatric palliative care unit situated in their previously almost exclusively adult based hospice in Houghton. Children from children's homes with palliative care needs can now be admitted to this facility.

## 4.10 What are the sufficiencies and deficiencies of the health care sector in addressing the needs of children in homes?

### *4.10.1 Sufficiencies*

The availability of free health care for all children under the age of 6 years in the South African public health sector is of tremendous benefit to the residential care sector. In this study 54% of the children in the homes were under the age of 6 years. Furthermore children in registered children's homes who are formally committed to the home and have documented proof thereof (a Form 8) are also exempt from paying for health care in the public sector.

Despite this, many children's homes make use of both volunteer doctors and homes that can afford to do so, will sometimes pay for private consultations because of the difficulties they experience in using the public health care facilities.

### *4.10.2 Deficiencies*

The deficiencies of the public health care service in meeting the needs of children from the residential care sector are not limited to this sector as the service is struggling to cope with the demands placed on it by the effects of the HIV epidemic on the community at large.

There are however problems with the public health care service as well as the residential care sector that make it difficult for children in this setting to access health care. By far the most

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common complaint from the children's homes is the long waiting times. The need for RCCW to spend large parts of their day accompanying ill children to hospital impacts negatively on the care of children remaining in the home due to a decrease in the staff to child ratio during their absence.

The close living arrangements of children in homes often gives rise to situations where several children are ill simultaneously due to the spread of communicable diseases. In addition the housing of many infants of similar ages means that several of them are due for immunisations at the same time. Children's homes struggle to transport many children to health facilities simultaneously and as a result have tried to bring health services into the facilities. Some have been successful in getting volunteer doctors to do rounds in the homes or clinic sisters to come to the home to immunise children.

Children from homes, being parentless, do not always have an advocate who can insist on better care if good care is not being offered. In some busy hospitals nursing staff rely on children's mothers or primary caregivers to assist in daily child care activities such as feeding, bathing and changing nappies. Most children's homes do not have enough staff to send caregivers to hospitals to provide this care to their admitted children. As a result some children from homes do not have these basic needs met during periods of hospitalisation. The CHOMP project has documented cases where children lost weight (disproportionately to the effect that the illness for which they were admitted may have had on their weight) due mainly to insufficient feeding in hospital. In one secondary level hospital, the majority of abandoned babies received by children's homes from this hospital were malnourished.

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# CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

## 5.1 Conclusions

### *5.1.1 The HIV epidemic has changed the face of the Johannesburg Children's homes*

Where previously children's homes were occupied by predominantly well children with socio-economic and behavioural problems they are now occupied by a much sicker population of children. Results of this research showed that at a minimum 30% of children in the homes were HIV affected and 20% (66.7% or 2/3 of HIV affected children) were also HIV infected. Morbidity in the children's homes is 10%, two-thirds of children in homes are on chronic medication and mortality rates have increased largely because of HIV/AIDS.

The observed "medicalisation" of many homes also bears testimony to this change.

### *5.1.2 The institutions responsible for children's homes have not kept pace with this change*

Since the separation of the Department of Health and Welfare into the Departments of Health (DOH) and Social Development (DSD) in Gauteng, the children's homes have remained the responsibility of the DSD and apart from the Department of Environmental Health there has been little visible increase in involvement by the DOH in the children's homes in response to their changing profile.

The DSD concentrates on the psycho-social aspects of childcare and the focus of their Developmental Quality Assurance (DQA) processes in the homes is on the development of a care plan for each child that includes family re-unification where possible. The Department of Environmental Health's role in the home is to ensure a safe and hygienic environment. Health inspections although infrequent (mostly 1 – 2 yearly according to most homes interviewed) do take place in registered children's homes. There appears to be no visibly active government

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body specifically concerned with the health of individual children in institutions and no portfolio in the Provincial Department of Health specifically dealing with the health of children in residential care. There is currently little visible effort on the part of the DOH ensuring that the actual health of individual children in homes is optimal.

### *5.1.3 The establishment of several new children's homes in response to the HIV epidemic is unchecked and not monitored*

Several children's homes have been started in response to the HIV epidemic even though the residential care model has been called "a last resort" in addressing the AIDS orphan crisis. The increase in the number of children in residential care is not limited to South Africa as there has been a global increase in this population especially in areas that have been hard hit by the epidemic (Africa, Asia and Eastern Europe) (8). This may be a reflection of the fact that many "extended families" are themselves HIV affected and unable to take on the added burden of caring for additional children.

International experience shows that governments in heavily HIV affected areas are struggling to keep track of the number of newly established children's homes and very few are able to effectively monitor standards within institutions (8). The situation in South Africa is no different.

Obtaining statistics on the number of children in the residential care sector in South Africa is difficult. Anso Thom, a reporter for the Saturday star, in an article written in October 2004 provides the following insights:

"*To gain a clearer picture of where these children are being let down, it is critical for authorities to know just how many of them are in residential care (orphanages and shelters) and homes. But no one wants to release these figures.*

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*"I have them," a director in the Department of Social Development says. "But I can't give them to you as the provinces disputed my figures at a recent meeting."*

*Kgati Sathekge, spokesperson for Social Development Minister Zola Skweyiya, is more blunt: "We don't know."*

*And a senior manager in the Department of Social Welfare says: "There are many, many children in the system we don't know of."*

*At the time of going to press, only two provinces had responded to a request for information. Mpumalanga has 693 children in residential care; the Western Cape has 2 209 (35)*

In a national follow up report on the World summit for children submitted by the National Programme of Action for Children's Steering Committee through the office on the Rights of the Child in the presidency in 2000, it was reported that there were over 140 registered children's homes in the country with over 700 beds and 37 places of safety with over 2000 beds (35). When compared to the staggering number of 7549 children reported by CHOMP to be in the residential childcare sector (both registered and unregistered) in the greater Johannesburg alone, it is clear that Kgati Sathekge was right: they don't know.

The unregistered children's home population that is difficult to monitor contributes significantly to the "CHOMP statistics". According to Section 30 of the Child Care Act (any residence or home maintained for the reception, protection, care and bringing-up of more than 6 children apart from their parents) needs to be registered with the DSD as a children's home (15). It appears that a moratorium was placed on the registration of children's homes in Johannesburg probably in the late 90's. During this time additional children's homes could not be registered and hence we now have several unregistered facilities in the greater

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Johannesburg. Many of these homes do not know that they have to register with the DSD and they have erroneously believed that their registration with the Department of Welfare as a "not-for profit" organisation was sufficient.

In a recent update of facilities performed by the CHOMP project 45% of the residential care facilities in the greater Johannesburg (61/134 homes) are not registered. These facilities house 2009 out of 7 549 children (26%). Results of this research demonstrate that unregistered facilities are definitely being established in response to the HIV epidemic: they have a higher proportion of orphans as well as destitute HIV affected children than the registered children's homes.

Many of these unregistered homes are not known to the Department and are therefore not regulated.

### *5.1.4 There is an urgent need to capacitate both registered and unregistered children's homes to meet the health care needs of children*

Given the high number of HIV infected children in the homes (20% compared to 8% of children in the general population) there is an urgent need to capacitate both registered and unregistered children's homes to care for these children.

This study showed that registration status did not necessarily correlate with good standards of health care. In fact some of the worst standards of health care have been encountered by CHOMP in government run places of safety. These facilities are not subject to the same inspection requirements as are other independent children's homes. In one such facility a "health audit" done by the CHOMP project showed that 33% of the children in this facility were malnourished and only 20% were up to date with their immunisations. Many children in this home were caught in the malnutrition diarrhoea cycle, as the home did not have adequate

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standards of hygiene. The project was alerted to problems in this facility by concerned paediatricians in the academic hospitals who had admitted ill children from this facility.

Capacitating children's homes to meet the health care needs of children would not only improve the care of HIV infected children admitted to the facilities but these homes could also serve as resources for their surrounding communities. This could facilitate de-institutionalisation by strengthening the ability of the community to care for these children.

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## 5.2 Recommendations

### *5.2.1 Ensure that all children's homes are registered with the Department of Social Development*

Despite the fact that registration of children's homes does not necessarily mean that good health care standards are maintained, the registration of children's homes would be the first step in trying to monitor the sector. The moratorium has since been lifted and unregistered facilities are now encouraged to register. The CHOMP project has been facilitating this process by providing opportunities for unregistered homes to come forward and meet with the Department for the purpose of registration. The Wits Aids Law Project has assisted by compiling a booklet of guidelines for the homes on how to register.

### *5.2.2 Address gaps in existing legislation concerning children's homes to ensure that health care needs of children in this sector are addressed*

The regulations under the childcare act that deal with standards in children's homes are contained in sections 30 – 35 (16). These regulations have a predominantly psychosocial focus and a large proportion of the regulations focus on behavioural interventions and discipline in children's homes. There is no mention for instance that children's homes are required to ensure that immunisations are up to date or to ensure that children with chronic illnesses receive the necessary health care. The "rights of children in institutions" as contained in section 30A of the Act barely mention the right of a child to good health care. The only broadly relevant right mentioned in this regard is the right of all children in residential care "to be fed, clothed and nurtured according to community standards and to be given the same quality of care as other children."

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Whilst it may be argued that section 28 of the South African constitution provides the necessary legislation for all children regardless of whether they are cared for in the community or the residential care sector, the residential care sector has its own unique set of conditions some of which pose a threat to childhood survival, growth and development.

Although the municipal bylaws (monitored by the Department of Environmental Health) that govern standards of care in children's homes have a more health related focus, they have been written from the perspective of day care centres. The pre-amble to the by-laws attempts to place children's homes and day care facilities into the same category to justify the application of this legislation to both facilities. The two settings are however vastly different as a children's home is responsible for care 24 hours a day and is the sole provider of the child's total needs. The child to staff ratios for instance, contained in the by-laws, are insufficient for a residential care facility and the separation of children of different age groups with physical partitions is impractical in children's homes (29).

### *5.2.3 Measure health related indices in children in residential care as a means of monitoring health and measuring the impact of interventions to improve child health in residential care*

The state of health of individual children in this sector is ultimately the barometer of health standards in the home. Aspects that could be examined could include growth, immunisation coverage, infectious disease burden, neurodevelopmental status etc. To this end, the CHOMP project developed a health audit system that could be used to measure health related indices and plan interventions in children's homes.

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### *5.2.4 Provide guidelines for children's homes on the prevention and management of infectious disease outbreaks*

As previously mentioned, outbreaks of infectious diseases in children's homes pose a significant threat to these facilities and in particular to children's homes who have a large number of immune-compromised children living together.

Children's homes across the country urgently need guidelines on the prevention and management of infectious diseases outbreaks. Children's homes need to know how to access the Department of Health's outbreak response teams located within the Communicable Disease and Expanded Programme of Immunisations directorate.

### *5.2.5 Limit the size of children's homes*

An attempt needs to be made to limit the sizes of institutions. The larger an institution the more likely children are to experience health related problems. Children in large homes stand a higher chance of being exposed to communicable diseases and are more likely to develop signs of "institutionalisation".

Although the development of institutionalisation is more common in large facilities even children in smaller facilities may be affected. This is predominantly due to the effect of the "multiple caregiver system" that is operational even in small homes where children are not given the opportunity to bond to a "significant other". Even homes with 6 or less children (that by law are not required to register as children's homes) sometimes make use of multiple caregivers and do not have a "single foster mother". Perhaps homes should be defined according to their models of care (i.e: single foster care mother versus multiple caregivers) and not by their capacities (i.e: less than 6 children).

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### *5.2.6 Decrease the numbers of children that are in the residential care sector*

In order to decrease the number of children currently in the residential care sector one would need to look firstly at reasons why children are placed in homes and secondly at ways to increase the "outward movement" of children from this sector.

Results of this research report show that abandonment is by far the most common reason for admission to children's homes and exceeds orphanhood as a reason for placement by 24,35% (Table 9). The National Child Welfare Society released figures in 2004 reporting that whilst orphanhood had increased in 2003 by 20%, abandonment had increased by 40% (37). Whilst much concern is voiced about the number of children who will be orphaned as a result of HIV/AIDS, few are aware of "the silent epidemic of abandonment".

Analysis of the HIV status of abandoned children in the homes in this report revealed that 29% of them were HIV infected. Although the HIV exposure rate of this population of children in this study was not well documented, statistics from the CHOMP project's HIV testing database show that 30% of abandoned infants tested in our clinics are HIV exposed. In addition if one looks at the group of babies in this study whose mothers had consented to their being adopted, 32% were known to have been HIV exposed.

It is clear from these statistics that the HIV epidemic is not only increasing the number of orphans but is also contributing to the number of children being abandoned or being given up for adoption. In order to intervene in this situation, efforts need to be focused on the counselling and support of HIV infected women during their pregnancies. It is in fact often only during their pregnancies that many women discover for the first time that they are HIV positive. These women need to deal with their pregnancies, their HIV status (and own mortality) as well as the possibility that they may give birth to an HIV infected child all in a

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short space of time. The common misconception that HIV infected mothers will always produce HIV infected offspring needs to be corrected. Interventions, to adequately counsel mothers, to prevent mother to child transmission, and to provide infected mothers with anti-retroviral treatment if necessary, may not only decrease the number of AIDS orphans but possibly also decrease the rate of abandonment.

Results of this study also point to several ways in which the outward movement of children from the residential sector could be increased.

**1. Provide accurate early infant HIV diagnosis for HIV exposed infants admitted to children's homes:**

Prior to the use of HIV PCR testing in the public sector, it was government policy to wait until all HIV exposed infants reached 18 months of age and then to repeat an HIV ELISA test. If the previously reactive test was now negative the child was said to have "sero-reverted" and would be put up for adoption. The problem with this approach is that by 18 months of age the adoption potential of an institutionalised toddler is significantly lower (38). If no outside placement were found for this toddler, he/she would remain in the system at the State's expense.

Exclusion of HIV infection in HIV exposed infants through HIV PCR testing at an early age (6 weeks) can improve the outward movement of children from the homes by declaring them "HIV uninfected" at an early age which increases their adoption potential.

Mr Emile Stipp's report on 'The cost effectiveness of an HIV testing strategy for children of HIV positive mothers' demonstrated that if less than 10% of abandoned children that underwent early HIV testing (PCR testing) where adopted it would be cost effective for the

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state to implement this early HIV testing strategy and save on state grants for institutionalised children (39).

In one of the earliest interventions in a children's home in 1997, 101 exposed infants (HIV ELISA positive) were tested with an HIV PCR test and 65 were shown to be uninfected. Of these infants 52 (80%) were either adopted or fostered out from the home (40). The CHOMP project has since tested over 1000 children in children's homes and 404 have been placed out as a result.

**2. Improve documentation in the children's homes as well as collaboration with police and social work agencies placing children in homes.**

During this study and in subsequent engagements with the children's homes it appeared that some children seemed to have been forgotten in the social work caseload. Sometimes children who had been abandoned in infancy and who were up for adoption had spent several months (and in one case more than two years) in the children's home for no particular reason. The longer a child spends in an institution the less adoptable he/she becomes. One just needs to look at the duration of stay of children in state run places of safety (that are only supposed to accommodate children for 6 months) to know that it is taking too long to deal with children in the residential care sector.

Factors that appear to be contributing to children being "forgotten in the system" are a high turnover of social workers, the antiquated predominantly paper based documentation systems still present in many homes and a lack of communication between children's homes and the welfare agencies and police that place children in these facilities.

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**3. Revise cumbersome processes in dealing with children in need of care and address gaps in legislation for children with no legal guardians.**

The present processes under the current Child Care Act that were designed to protect "children in need of care" appear now to be failing them. These cumbersome processes were not designed to deal with such large numbers of children. The Act does also not make provision for so many children without legal guardians. Procedures that need to be undertaken to get proper consent for HIV testing of these children are prohibitively long. The gains that are made by "early diagnostic HIV testing" are sometimes lost by the time taken to meet the statutory requirements to place children in alternative care out of the residential care sector.

One of the ways that CHOMP and the Wits Paediatric HIV Clinics have improved the HIV testing and treatment rates for children without legal guardians was through a successful application made on our behalf by the Wits AIDS Law Project to the High Court. The court ruling allows members of the group (who are registered doctors) to obtain consent for HIV testing from primary caregivers even if they are not the legal guardians of the children in their care, provided the testing is done in the best interest of the child. The new children's Bill addresses these issues but has not yet been passed by parliament.

**4. Improve the number of placement opportunities for children in local South African families by creating a "culture of adoption".**

Another major factor determining the outward placement of children from the residential care sector is the availability of suitable alternative placements. CHOMP's database shows that slightly more children are adopted out internationally than locally. We do still not have a "culture of adoption" in South Africa: and adoption is still considered taboo in some societies. Trans-racial adoption amongst South Africans is however on the increase but numbers are still

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low. In the last annual report of the JCWS (2003 – 2004) only 11 out of 94 local adoptions (11%) were trans-race (41).

**5. Improve the de-institutionalisation of HIV infected children.**

Results in the outcomes section of this report (pg 52) also show that the outward movement of HIV infected children in the homes is very low. Only 2 HIV positive children out of 160 children were placed out of 24 children's homes over a 6 month period. One was fostered and the other "returned to family". No HIV positive children were adopted.

Of immense concern to the CHOMP project is the increasing number of well HIV positive children on anti-retroviral treatment who are growing up in institutions. Where previously these children used to die (many before the age of 6 years) most are now living longer. This has resulted in a decreased turnover in many children's homes that admit predominantly HIV infected children. It is becoming increasingly difficult to find spaces in children's homes to accommodate HIV infected children. This situation needs to be addressed urgently and more suitable living arrangements for these children need to be explored.

This said, the project is starting to see an outward movement of HIV infected children on anti-retroviral treatment from one children's home. In this home 5 children, because of an improved level of health due to anti-retroviral treatment, have been placed back with extended families (mostly grandparents). These families have felt better able to care for the children because they are healthier and require less frequent hospitalisation.

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**6. Strengthen the ability of the homes to provide for ill HIV infected children for whom the residential care setting is currently the "only option".**

This report demonstrated the important role some children's homes are playing in looking after ill HIV infected children and in some instances their HIV infected mothers. Some homes have the facilities and knowledge to provide an excellent level of medical care to these children. These homes are also being used by the overburdened state hospitals as "step-down" facilities for ill children.

There is an urgent need therefore to improve the quality of and access to health care services to these children's homes. Clinics and hospitals need to be made more aware of the health care burden that several children's homes are managing and need to assist them in a more efficient manner to do so. To this end, there is a need to improve communication between health care facilities and children's homes. Not only do children's homes need to ensure that escorts accompanying children to health care facilities are better equipped with the necessary knowledge or documentation relating to the child's medical problem but health care facilities need to improve communication and feed back to the children's homes.

**7. Empower RCCW with basic child health and HIV knowledge.**

Empowering RCCW with basic health care and HIV knowledge could decrease unnecessary morbidity and mortality in the children's homes as poor health and illness would be detected earlier. Caregivers could be taught the IMCI early warning signs of common childhood diseases to ensure that timeous intervention for ill children is sought. Unnecessary heath care consultations could also be minimised by empowering caregivers from children's homes with basic medical knowledge to manage common minor childhood illnesses (such as gastro-enteritis, colds and flu) on their own.

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**8. Enable children's homes to become resources to their surrounding communities to strengthen the community's ability to care for children and to decrease unnecessary institutionalisation of children.**

Not only are children's homes looking after their resident population of ill children but some of them, through their experiences gained in looking after HIV infected children, have started to provide outreach services to their communities. These homes employ home based caregivers who visit ill children in their homes in the community. They also provide temporary accommodation or respite care for ill children living with ill parents or living in grandparent or child headed households.

Although this research report does substantiate existing concerns about the residential model of care, it also highlights the potential resource transformed children's homes can become in the HIV/AIDS epidemic. Children's homes are unlikely to disappear completely as a model of care: they have existed since medieval times and there will always be a proportion of children for whom there is no other option.

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