

# **BIGSHOES Foundation**

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### SUBMISSION TO THE CHILDREN'S AMMENDMENT BILL

Dr M.A.Meiring Director/Paediatrician The Bigshoes Foundation

Dear Ms Zola Vice,

As a paediatrician with both research and clinical experience within the residential child care sector I would like to make a submission on behalf of my organisation to the Children's Amendment Bill.

The Bigshoes Foundation was founded in 2003 under the name CHOMP: Children's Homes Outreach Medical Programme. We changed our name in 2006 to "bigshoes" to reflect our expanded focus beyond the residential care setting. Bigshoes is all about medical interventions that assist orphaned and vulnerable children (especially those affected by HIV/AIDS) to grow up to fill big shoes! Interventions are made through direct medical services, advocacy and training. Our services include HIV testing, anti-retroviral treatment, palliative care and health related training (with special emphasis on childhood HIV) for child and youth care workers in both the residential and community based child care setting. For your information I have attached our most recent annual review (2006) as Appendix 1.

Whilst we started and continue to work within children's homes we recognise that permanent care in the residential care setting does not always lend itself to the best realisation of a child's full potential. Also given the large number of children requiring alternative care as a result of the impact of HIV in South Africa, it is also not the most cost-effective and sustainable strategy. Children growing up in large homes may experience long term psychological consequences from the "multiple caregiver system" in which they are not able to bond to "a significant other". We have also seen the devastating effect that outbreaks of infectious diseases can have on children (especially HIV infected immunocompromised children) living close together in large institutions.

Notwithstanding these disadvantages we have also experienced the tremendous role that children's homes can play in the provision of temporary care to orphaned and abandoned children whilst more suitable long term permanency plans are being made for them. Some children's homes have also developed exceptional expertise in caring for ill HIV infected children. Once the child's health has improved thanks to the induction of anti-retroviral treatment by the home, many of these children can be re-united with their extended families who are better able to care for them as a result of their improved health status.

Prior to starting the Children's Homes Outreach Medical Programme in 2003, I conducted some research (towards a masters degree in Paediatrics) on the impact of HIV on children's homes in the greater Johannesburg region. I have attached this as Appendix 2.



### To summarize my pertinent findings:

I identified a total of 115 residential care facilities with a population (excluding the special needs homes) of 5 934 in the greater Johannesburg area. In a sample of 24 "study homes", 31,7% of the children were HIV affected and 20% were HIV infected. The morbidity rate in the homes was 10% and 99% of this was attributable to HIV/AIDS. Over a 6 month period 57 children died in the children's homes, 95% from HIV related conditions.

#### My main conclusion from this study was that:

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 socioeconomic and behavioural problems, they are now occupied by a much sicker population of children. 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.

The study further showed that registration status did not necessarily correlate with good standards of health care. In fact some of the worst standards of health care were 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 the 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 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. This facility was also badly affected by a measles outbreak in 2003/2004 because of non-compliance with immunisations.

#### Recommendations made by the study were to:

- 1. Ensure that all children's homes are registered with the Department of Social Development.
- 2. Address gaps in existing legislation concerning children's homes to ensure that health care needs of children in this sector are addressed:
- 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:
- 4. Provide guidelines for children's homes on the prevention and management of infectious disease outbreaks
- 5. Limit the size of children's homes.
- 6. Decrease the numbers of children that are in the residential care sector.



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- 7. Provide accurate early infant HIV diagnosis for HIV exposed infants admitted to children's homes:
- 8. Improve documentation in the children's homes as well as collaboration with police and social work agencies placing children in homes.
- 9. Revise cumbersome processes in dealing with children in need of care and address gaps in legislation for children with no legal guardians.
- 10. Improve the number of placement opportunities for children in local South African families by creating a "culture of adoption":
- 11. Improve the de-institutionalisation of HIV infected children
- 12. Strengthen the ability of the homes to provide for ill HIV infected children for whom the residential care setting is currently the "only option".
- 13. Empower RCCW with basic child health and HIV knowledge
- 14. 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:

Findings of this study have informed my projects operations since 2003 and we have used the findings to advocate for improved child health and HIV care within children's homes. I presented my study to the Gauteng Plan of Action for Children (GPAC) and as a result the children's homes task team was formed within GPAC (Please see Appendix 3). Sadly little has come out of this process. CHOMP also assisted in the revision of our local bylaws (propagated by the Department of Environmental health) pertaining to children's homes (Appendix 4).

In 2006 we participated in a workshop commissioned by the National Department of Social Development and facilitated by NICDAM. The task of the workshop was to come up with a plan for HIV for the residential child sector. Several excellent recommendations came out of this national process but I have not yet seen any translation of this work into actual legislation. Unfortunately I only have a hard copy of the recommendations arising from this workshop but attach as Appendix 5 our suggestions on reviewing the report from the workshop.

When reading the Children's Amendment Bill and particularly Chapters 5,11 and 13 on partial care, alternative care and child and youth care centres I noticed that the word "HIV" was never mentioned once. Given the impact of this disease on this sector is it important that the legislation addresses the many problems brought about by this scourge. Policies and procedures on the management of HIV in the residential care sector need to be in place.



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## Issues raised by the NICDAM workshop that need to be addressed include:

### **A: HIV prevention:**

- 1. The prevention of HIV infection in abandoned newborns admitted to children's homes through the administration of Nevirapine.
- 2. Universal precautions and the availability of Post Exposure Prophylaxis (PEP) to child and youth care workers (CYCW) who may have highs risk exposures to HIV (one example given in the workshop was of a CYCW who got cut trying to separate street children in a drop in centre who were having a knife fight).
- 3. The provision of condoms to older children in residential care facilities.
- 4. The provision of PEP to children admitted to residential care facilities following sexual abuse /rape.
- **5.** The provision of PEP to children sodomised by older boys in correctional service facilities.

### **B: HIV Testing:**

- 1. Indications for testing in the residential care sector.
- 2. Consent for HIV testing in the residential care. This is particularly an issue for children with no legal guardians in unregistered facilities.
- 3. Pre and post test counselling for older HIV infected children in the residential care sector.
- 4. Policies around which caregivers may be (or should be) privy to knowledge about the child's HIV status.
- 5. HIV disclosure to the older HIV infected child.

### **C: Management of the HIV infected Child:**

- 1. The management of anti-retroviral treatment in children's homes.
- 2. The management of infectious diseases and policies and procedures in terms of isolation and the prevention of infectious disease outbreaks in children's homes.
- 3. The management of the terminally ill HIV infected child and the provision of paediatric palliative care services within children's homes.
- 4. Legislation around children's hospices (their classification and regulation).

General health issues that also need to be addressed in the children's homes include nutrition, hygiene, stimulation of normal childhood development, immunisations and the management of infectious diseases in the children's homes.

The Bigshoes Foundation is of the opinion that there is a "health gap" in several children's homes. The Department of Social development does developmental quality assurance (DQA) checks that focus largely on care planning for the child, the Department of Environmental Health does hygiene and safety checks but there appears to be no active government body that does actual "health checks" on the children admitted to residential care facilities.



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As an example of this in a recent immunisation survey done by the foundation only 25% of children within a sample of children's homes were up to date with their immunisations. This poses not only a considerable risk for children within the homes but also for children in the community at large.

Another area of concern in the Children's Amendment Bill is addressed in regulation 178 in Chapter 11 on Alternative Care (pg 32). This section deals with death, abuse or serious injury of a child in alternative care. The section calls for an investigation into the circumstances surrounding the death of a child to be conducted if the SAPS is not satisfied that the child died exclusively of natural causes. I would propose that all deaths in children's homes be investigated as it has been my experience that even some deaths from "natural causes" in the children's homes could have been avoided by timeous medical referral and that failure to do so in some instances constitutes neglect.

In conclusion the Bigshoes foundation calls for a greater focus on child health and HIV related issues for children in residential care so that they can grow up to fill big shoes! If you have any questions or require clarification on any issues please feel free to contact me.

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