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HIV+ and HIV– youth living in group homes in South Africa need more psychosocial support

D.F. Nestadt^{a,*}, S. Alicea^{b,c}, I. Petersen^d, S. John^e, N.P. Myeza^e, S.W. Nicholas^{f,g}, L.G. Cohen^h, H. Holst^e, A. Bhanaⁱ, M.M. McKay^{j,k}, E.J. Abrams^{a,f}, and C.A. Mellins^{c,l}

^aICAP, Mailman School of Public Health, Columbia University, New York, NY, USA

^bDepartment of Applied Psychology, New York University, New York, NY, USA

^cHIV Center for Clinical and Behavioral Studies, New York State Psychiatric Institute, New York, NY, USA

^dSchool of Psychology, Howard College, University of KwaZulu-Natal, Durban, South Africa

^eDepartment of Psychology, McCord Hospital, Durban, South Africa

^fDepartment of Pediatrics, College of Physicians & Surgeons, Columbia University, New York, NY, USA

^gHeilbrunn Department of Population and Family Health, Mailman School of Public Health, Columbia University, New York, NY, USA

^hThe Gift of Hope, Goldens Bridge, NY, USA

ⁱChild, Youth, Family & Social Development, Human Sciences Research Council, Durban, South Africa

^jDepartment of Psychiatry and Community Medicine, Mount Sinai School of Medicine, New York, NY, USA

^kSilver School of Social Work, New York University, New York, NY, USA

^lDepartment of Psychiatry, Columbia University, New York, NY, USA

Abstract

Orphans and vulnerable youth who live in group homes are at risk of poor mental health and sexual and drug-using behaviors that increase the risk of HIV transmission. This study explores factors related to this risk among youth living in group homes (“children’s homes”) for orphans and vulnerable children in South Africa, a country afflicted by high levels of parental loss due to HIV. The study explores 1) knowledge and attitudes about HIV, 2) social support, 3) communication with group home caregivers, and 4) the relevance of an existing evidence-based HIV prevention and mental health promotion program to situations where sexual and drug risk behaviors can occur. In-depth qualitative individual interviews were conducted with 20 youth (age 10 to 16 years) residing in two children’s homes in Durban, South Africa. Content analysis focused on critical themes related to coping and prevention of risk activities. Respondents exhibited inconsistent and incomplete knowledge of HIV transmission and prevention. They displayed positive attitudes toward people living with HIV, but reported experiencing or witnessing HIV-related stigma. Participants witnessed substance use and romantic/sexual relationships among their peers; few admitted to their own involvement. While relationships with childcare workers were central to their lives, youth reported communication barriers related to

*Corresponding author. dlf60@columbia.edu.

substance use, sex, HIV, and personal history (including parental loss, abuse, and other trauma). In conclusion, these qualitative data suggest that evidence-based HIV prevention programs that bring caregivers and youth together to improve communication, HIV knowledge, social support, youth self-esteem, and health care, reduce sexual and drug risk behaviors, and strengthen skills related to negotiating situations of sexual and substance use possibility could benefit youth and childcare workers in children's homes.

Keywords

children's homes; orphans; social support; HIV; South Africa

Introduction

The number of orphans (children under age 18 who have lost at least one parent; UNAIDS, UNICEF, & USAID, 2004) in South Africa has increased in recent years due to the high adult mortality rates caused by the AIDS epidemic. In 2009, about 1.9 million children were orphaned by HIV/AIDS in South Africa, and approximately 330,000 children (0–14 years old) were living with HIV/AIDS (UNICEF, 2010). In 2008, half-a-million children were in formal, court-ordered foster care (UNICEF, 2011), of whom 21,000 lived in 345 children's homes¹ run by or registered with the South African government (UNICEF, 2011). A sizable, but poorly quantified, population of children resides in unregistered homes and shelters (Meintjes, Moses, Berry, & Mampane, 2007). Children's homes house both orphans and non-orphans who have been removed from family homes because of abuse, neglect, extreme poverty, or parental disability (Meintjes, et al., 2007). Although these youth are likely highly vulnerable to poor health and behavioral outcomes, few studies to date have examined HIV risk and psychosocial issues facing youth growing up in children's homes in South Africa.

Studies of "orphans and vulnerable children" (OVC) living in a range of caregiving situations in sub-Saharan Africa, but primarily in more traditional homes, suggest that, compared to non-OVC youth, OVC are at higher risk for engaging in HIV/STD risk behaviors (e.g., unprotected sex, sex with multiple partners, sex at an earlier age) (Operario, Pettifor, Cluver, MacPhail, & Rees, 2007; Thurman, Brown, Richter, Maharaj, & Magnani, 2006) and using alcohol (Juma, Askew, & Ferguson, 2007). They are also more likely to suffer significant psychological symptoms and meet clinical criteria for psychiatric disorders, including post-traumatic stress disorder, anxiety, and depression, and to experience problems with peer relationships and conduct (Atwine, Cantor-Graae, & Bajunirwe, 2005; Cluver & Gardner, 2006; Makame, Ani, & Grantham-McGregor, 2002).

While studies specific to OVC in group homes in Africa are few, studies from North America and Europe have consistently found negative outcomes among children who have lived in such settings. Several studies report that children in institutional care display higher rates of emotional, social, behavioral, physical and educational problems than other children (Rutter, 2000; Maclean, 2003) and that these associated deficits, delays, and psychological disturbances may be irreversible (Nelson, 2007; Rutter, Quinton, & Hill, 1992). In one of the few South African studies of children's homes, Meintjes, et al. (2007) found that 16% of the youth were living with HIV/AIDS compared to a national HIV prevalence of 1.9% among children 0–14 years old.

¹Children's homes are "family-type group homes, and accommodate a number of children of no relation to the person running the home. The staff may be volunteers or related to the person in charge" (UNICEF, 2008).

Recently, programs to help OVC cope with parental loss and improve general well-being have proliferated in Africa, although few have been evaluated (Sherr & Mueller, 2008) and, few, if any, have studied OVC living in children's homes. Understanding these particular OVC's psychosocial needs and risk behaviors, as well as sources of stress and support, is a critical first step to developing interventions for this population and a primary aim of this study.

In addition, HIV prevention and mental health programs developed for other populations of vulnerable youth (e.g. inner-city impoverished youth, homeless youth) may be important models for OVC. One widely-studied mental health and HIV prevention model for youth is the "Collaborative HIV Prevention and Adolescent Mental Health Program (CHAMP)" (Paikoff & McKay, 1995), a multiple family-based group intervention that aims to strengthen parent-child communication and adolescents' social problem-solving and peer-negotiation skills, and promote support both within and between families. Trials of the CHAMP model with urban uninfected youth in impoverished communities, including one trial in South Africa, have found significant improvements in HIV knowledge, family communication and monitoring of youth and youth mental health, and reduced risk behavior (McKay, Chasse, Paikoff, McKinney, Baptiste, Coleman, et al., 2004; Bell, Bhana, Petersen, McKay, Gibbons, Bannon, et al., 2008; Bhana, McKay, Mellins, Petersen, & Bell, 2010). Versions of CHAMP for HIV-infected youth and families were recently adapted and pilot tested in the US (CHAMP+; McKay, Block, Mellins, Traube, Brackis-Cott, Minot, et al., 2006) and South Africa (CHAMP+SA; Mellins, McKay, Bhana, Petersen, Alicea, Myeza, et al., 2010). However, to date, CHAMP has not been used with children living in non-traditional family settings.

Consumer consultants involved in developing CHAMP+SA confirmed the need for prevention and therapeutic evidence-based interventions like CHAMP in children's homes for both HIV+ and HIV- youth. However, questions remained about the differences between youth and caregivers in traditional families and in children's homes, particularly child-caregiver relationship dynamics and the unique stressors and needs those in children's homes face. As an initial step towards the possible use of the CHAMP model in children's homes, the proposed study aimed to explore the psychosocial and risk behavior needs of youth and assess the applicability of CHAMP through qualitative interviews in two children's homes in Durban, KwaZulu-Natal.

Methods

Participants

Two children's homes that referred HIV+ children for medical care to a hospital where the CHAMP+SA program was piloted were selected for this study. Eligibility criteria for children included English- or isiZulu-speaking, 10 to 16 years old, and cognitive capacity to participate, as determined by the director of the children's home. A sample of children representative of each home's demographics, including HIV status and gender, was selected for participation by the director or social worker at the children's home. The directors of the homes are designated by the South African government as legal guardians of the children in their care and, thus, provided written consent for each youth's participation and information about the youth's HIV status. Each child gave voluntary, informed, written assent before the interview. All youth invited to participate assented (n=20).

Procedures

Data were collected in two waves. We initially received a small grant to conduct a pilot qualitative study utilizing individual interviews with 20 children ages 10–16 years (15 boys,

5 girls, 7 HIV-infected, and 13 uninfected). Additional funds were received six months later to conduct follow-up individual interviews with half of the participants, selected based on their availability (n=10; 8 boys, 2 girls, 4 HIV-infected and 6 uninfected). Two graduate students with qualitative research training (one South African, one American) conducted interviews in isiZulu or English. Interviewers used semi-structured open-ended interview guides (Table 1) grounded in Social Action Theory (Ewart, 1991), a theoretical model of health behavior that focuses on contextual factors (e.g. previous living situation, current stressors, demographics), self-regulation (e.g. HIV knowledge and attitudes), and social interactions (e.g. child-childcare worker communication and exposure to sexual risk behaviors and substance use) that influence behavioral outcomes. HIV-infected youth were asked about their experiences living with HIV only if they disclosed their status when asked if they knew anyone with HIV. Follow-up interviews included targeted questions on exposure to, experiences with, and communication about sexual relationships and substance use.

In both waves, 60 minute interviews were recorded, transcribed, and (if isiZulu) translated into English. A bilingual isiZulu-English speaker conducted random back translation checks of translated transcripts. Youth did not receive individual compensation for interviews, per children's home request; however, homes received small donations in the form of gifts for their participation. American and South African institutional review boards approved the study.

Analysis—Data were analyzed using a collaborative, iterative process based on framework analysis (Ritchie & Spencer, 1994). The needs, behaviors, and experiences of respondents derived from direct engagement with interview transcripts served as the basis for intervention recommendations. The process involved: (1) familiarization with themes in the transcripts; (2) construction of a thematic framework and coding scheme based on study aims and themes that emerged; (3) indexing and coding of transcripts by two graduate students² using NVivo (8 and 9) qualitative data analysis software; (4) charting of data into thematic categories; and (5) identification of emerging associations and patterns to generate intervention recommendations. To improve inter-rater reliability, coders jointly coded two interviews, coded another transcript separately, and then compared coding. Coding was more than 80% consistent between them, and inconsistencies were discussed until consensus was reached. Key findings were shared with principals and childcare workers at the children's homes, who reported that the findings accurately captured their experiences, supporting the study's validity.

Results

Sample Characteristics (Table 2)

Reflecting each home's demographics, 75% of all participants were boys (one home serves only boys), and 65% were HIV-negative (15 boys, 5 girls, 7 HIV-infected, 13 uninfected). The mean age at each home was 13 years. No significant group differences in responses emerged between children in the two homes, or between HIV+ and HIV– youth (with the exception of questions specific to HIV-infection).

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²One of the graduate students also did interviewing; the other only coded transcripts.

Critical Themes³

Negotiating sexual and substance use risk behaviors

Exposure to and experiences with situations of sexual possibility: Among the youth who received the second interview, the majority reported that they or their peers were regularly exposed to situations that might lead to sexual experiences. Three (30%) youth reported romantic relationships at the time of the interview. None admitted to sexual experiences beyond kissing. Only two youth (20%) admitted ever being alone with another adolescent of the opposite sex. Eight youth (80%) stated most of their friends had a romantic partner. Four youth (40%) with current or past relationships said their friends had influenced them to form one. As one 15 year-old girl explained, “Some [girls] say that if you don’t have a boyfriend it’s because you’re ugly.” Three youth (30%) said that they escaped such influence by avoiding situations in which their friends were with, or talking about, romantic partners.

Six (60%) respondents, ages 12–16—including five of the respondents who reported having romantic partners—felt youth their age were too young for relationships because they might lose focus in school, have sex too early, or be at risk for HIV infection.

Exposure to and experiences with tobacco, alcohol and drug use: Youth consistently reported exposure to substance use in the children’s home and school communities. Eight (80%) of them reported witnessing peers smoking cigarettes at school or the children’s home; 4 (40%) reported seeing peers drink. Youth also reported that smoking and drinking were considered “cool.” However, only one respondent admitted to using drugs (methamphetamine), cigarettes, or alcohol. Six respondents (60%) said they had resisted or could resist peer pressure to drink, smoke, or use drugs.

HIV/AIDS knowledge and attitudes

HIV knowledge: High level of knowledge about HIV transmission was coupled with significant HIV prevention knowledge deficits. Two (10%) individuals stated they knew nothing about HIV—including one HIV+ boy. Overall, 70% of youth could correctly name 2 or 3 modes of HIV transmission. Four (20%) mentioned an incorrect mode of transmission (e.g. sharing a toothbrush). Eight (40%) could not name any method of HIV prevention. Only 8 respondents (40%) mentioned condoms or safe sex when asked about HIV prevention, though more than half knew HIV could be transmitted sexually.

HIV stigma and disclosure: Several themes emerged related to the dynamics between HIV+ and HIV– youth living in the homes. Among uninfected youth, attitudes about HIV-infected people were primarily positive, and an awareness of the HIV-related stigma was coupled with a sense of HIV stigma as wrong. For example, one 15-year-old uninfected girl said, “It’s quite sad how children get treated if they have HIV.”

Youth who reported being uninfected were asked to describe how things had changed or would change if a friend disclosed that he/she was HIV-infected. Nearly all respondents said they would not treat the friend differently and that people with HIV were no different from uninfected people. However, few uninfected youth reported knowing anyone with HIV. A few youth expressed negative attitudes about HIV+ people. Two respondents (10%) expressed the belief that HIV-infected people were to blame for being infected because of their behavior, and one 10-year-old, HIV+ boy who knew his status, but did not disclose it to the interviewer, said, “[If my friend told me that they had HIV] I wouldn’t play with him... because he will infect me.”

³Questions about certain topics, including sexual and substance use experiences and trauma were only asked in follow-up interviews (n=10). To clarify the sample size from which each result was derived, percentages are presented alongside number of participants.

Four out of seven (57%) HIV-infected youth interviewed declined to disclose their HIV status to the interviewer. While none of the HIV+ youth who did disclose reported ever experiencing discrimination, none had disclosed their HIV status to others at the children's home.

Child-childcare worker relationship dynamics—Youth uniformly identified childcare workers as their primary source of adult support and caregiving, despite the fact that 17 youth (85%) had caregivers outside the children's home (e.g. parents or relatives), whom they visited on some weekends and holidays.

Guidance and Support: All respondents said childcare workers provided guidance or advice, and/or assisted with a range of problems, from homework to family crises. When asked whom they would talk to about something important, more than half named a childcare worker.

Seven (35%) of the youth positively likened their childcare workers to parents. A 15-year-old girl said about her childcare worker, "She's like a mother...she's there for you."

Among respondents who identified someone who loved them even when they did things that person did not like, six of 11 (55%) said his/her childcare worker was one of those people. A 15-year old girl said, "[My childcare worker] loves you for who and what you are."

Conflict: Despite feeling loved and supported by their childcare workers, 14 respondents (70%) also described negative aspects of childcare worker-child relationships. Shouting was described as problematic and a barrier to effective communication. One boy (Age 16) said, "She shouts for *everything*...Even when she's right you never know because of her loud voice." Echoing reports from other youth that conflict with their childcare workers was often based on a lack of understanding, one boy (Age 12) said, "[The childcare worker] doesn't understand that we also have feelings."

Two youth (10%) also described their childcare workers sometimes saying cruel things to them in anger, particularly insults related to their biological parents. One 16-year-old boy elaborated, "You made a mistake and they say, 'no wonder you're in a children's home cause you [are] like this.'"

Child-childcare worker communication about difficult topics—Several themes emerged that suggest youth face challenges in communicating with their childcare workers about dating, HIV, substance use, and issues related to youth's past.

Sexual relationships: Five (50%) respondents said they had talked to their childcare workers about dating. However, virtually none described any frank discussions about sex, and respondents expressed the feeling that they *could* not talk to their childcare workers about relationships and sex. One 16-year-old girl explained that if she told her childcare worker that she had a boyfriend, "She's gonna be angry at me...And she's gonna think...the next thing you're going to be pregnant." The same girl was pregnant at the time of her second interview.

Substance use: Seven out of the 10 youth (70%) said that their childcare workers never discussed drinking, smoking, and drugs, or at most, simply told them not to use drugs.

HIV: Thirteen youth (out of 20; 65%) reported that their childcare workers did not talk with them about HIV. Of those who said that they had discussed HIV with their childcare workers, some described receiving helpful, accurate information; others did not. When

asked what her childcare workers told her about HIV, a 13-year-old girl reported, “If [my childcare workers] see someone kissing...[they] say ‘what if they had a sore on their mouth and you get it you’ll have HIV/AIDS.’” Another boy said his childcare workers told him a toothbrush could transmit HIV.

Child personal history: All of the participants had experienced trauma or loss of some sort, including abuse and neglect and/or death of a parent or other caregiver. Seven respondents (35%) reported having experienced more than one type of trauma simultaneously. Six out of 10 youth (60%) described the loss of their parents or abuse they had suffered as the hardest experiences of their lives. However, they said their childcare workers or other adults had not encouraged them to talk about the past and that they had coped on their own.

Discussion

This study is one of the first to explore the psychosocial issues related to mental health and HIV prevention among HIV+ and HIV– youth living in children’s homes in South Africa. The use of qualitative interviews in both English and isiZulu allowed us to explore youth experiences in their own words. This study suggests that youth in children’s homes have unmet psychosocial needs related to HIV risk reduction and mental health, in addition to strong relationships with childcare workers that an intervention could build on.

Various factors we identified may contribute to heightened HIV transmission risk and adverse mental health outcomes. HIV+ youth expressed low levels of HIV transmission knowledge, and both HIV+ and HIV– respondents displayed deficits in HIV prevention knowledge. Youth interviewed had also experienced a wide range of trauma including parental bereavement, physical and sexual abuse, and neglect. Exposure to such adverse childhood experiences and trauma has been linked with depression, post-traumatic stress disorder (PTSD), multiple sexual partners, STDs, early initiation of sex, contact with the criminal justice system, and emotional distress in the U.S. and South Africa (Cluver, Fincham, & Seedat, 2009; Rotheram-Borus, Weiss, Alber, & Lester, 2005; CDC, 2010).

Perceived stigma among HIV+ youth may also contribute to adverse mental health outcomes. Despite uninfected youth reporting positive attitudes toward people living with HIV, the HIV-infected youth we interviewed had not disclosed their HIV status to others in the children’s home, likely related to fears of stigma and discrimination. Past studies have found that HIV-infected youth may incorporate negative stigma into their sense of self (Joffe, 1999).

The presence or absence of communication and support may serve to exacerbate or mitigate such outcomes. Cluver, et al. (2009) found that, despite previous trauma, orphaned youth who had a strong sense of social support had fewer or less severe adverse outcomes. The youth interviewed generally felt supported and loved by childcare workers and could talk to them, which may serve to lessen some poor mental health outcomes.

On the other hand, youth reported difficulty discussing topics such as HIV, sex, and substance use with childcare workers. The pregnant participant, who had previously said she was afraid to talk to her childcare workers about her boyfriend, also said she did not know how one became pregnant. This highlights the potential consequences of communication barriers and, thus, the need for more open communication and skills-building for staff and youth in these areas.

Some youth also reported that their childcare workers did not talk to them about their parents’ deaths, separation from family, or other painful events. Many adolescents have

trouble coping with grief and loss independently, which sometimes leads to behavioral or mental health problems. Adults need to assist and support youth through the grieving process (Lenhardt, 1997).

Few youth respondents reported engaging in sexual behavior or substance use, despite reporting that they and/or their peers were often in situations of sexual and substance use possibility. There are several interpretations. The youth may have been reluctant to report their own risky behaviors because of concerns about the vulnerability of their living situations or social desirability. Conversely, the reports of many youth may have been accurate and be due to a protective influence of close daily supervision provided by children's home staff. Respondents described strict curfews at their homes, and both the girl who became pregnant and the boy who had used drugs had engaged in risk behaviors while visiting family, not while under the children's home's supervision. Given that many youth spent significant periods of time during weekends and school holidays outside of children's homes and are expected to live independently once they turn 18, more studies are needed to better understand risk behaviors among these youth and the protective influence of children's homes, perhaps using other methods of reporting that youth perceive as more confidential.

Limitations

The present study was limited by the use of a convenience sample. The two homes were selected based on a prior relationship to a hospital involved in the larger CHAMP+SA study and are not necessarily representative of all children's homes in Durban or other parts of South Africa. Additionally, principals and social workers at the homes selected participants. Although instructed not to choose only the most well-behaved or cooperative youth, they may have selected a biased subsample in ways we were unaware of, leading to under- or over-reporting of behaviors and feelings. Respondents presented both positive and negative reports about their experiences and relationships with childcare workers, similar to children living with biological parents, suggesting they did not feel pressured to report only positively on childcare workers. However, as with any study that relies on self-report, results may be biased.

Children's homes also requested we not ask directly about respondents' substance use and sexual experiences in the first round of interviews because of cultural and religious taboos and a fear that discussion might lead to increased engagement in those activities. However, as the administrators became more comfortable with us and our work, they were more willing to allow discussion in these areas. As a result, much of the data we present here about sexual relationships and substance use come only from the second interviews conducted with half the sample. Only three out of seven HIV-positive participants disclosed their status to interviewers, limiting data on living with HIV in a children's home. Future studies should attempt to get more of the HIV-positive youth's perspectives and to elicit information about sexual relationships and substance use from a larger sample. Finally, the data presented here are from the youth's perspective only. Adolescents and caregivers may experience their interactions quite differently (Steinberg, 2001). Understanding the childcare workers' perspective and to what extent it mirrors youth reports is an important next step.

Recommendations

In light of the issues outlined above, we believe the existing evidence-based CHAMP interventions could provide an excellent foundation for HIV prevention and mental health programming in children's homes. CHAMP emphasizes child-caregiver communication concerning reduction of risk behaviors, skills related to negotiating situations of sexual and substance use possibility, HIV knowledge, and social support around self-esteem, positive

self-identity, and health care. The existing South African CHAMP programs (CHAMPSA and CHAMP+SA) also include sessions on HIV stigma, communication between caregivers and children about difficult topics like sexual risk behaviors, and loss and bereavement. Our findings suggest childcare workers are the youth's primary adult supports and influences and thus critical to intervention efforts. The challenge is to adapt an intervention previously implemented and evaluated only in more traditional family contexts (i.e. child living with a primary caregiver in the community) for children and childcare workers living in formal group residential settings.

Although not explored in the present paper, the needs of childcare workers employed in children's homes must also be taken into account when developing an intervention. When on duty, childcare workers tend to the material and emotional needs of more than a dozen children each around-the-clock. Many have their own children at home, for whom they must provide the same support. The risk of burnout is high. Future studies should explore this topic.

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Table 1

Interview questions.

Focus Area ^I	Sample Questions
Contextual Factors	• How is living here different from the place you lived before moving here? • What are some of the good things about living at [name of children's home]? What about some of the not so good/hard things? • If there was something you could change about living in [name of children's home], what would it be?
Self-regulation	• Do you or your friends ever go to parties? Have you ever been around another teenager who smokes, drinks, or uses other drugs? Tell me what you think about that. • If your friend told you s/he had HIV what would you do? What would you say? In what ways do you think you would treat your friend differently after finding out s/he has HIV?
Social Interactions	• Who's the first person you would talk to about something important? • Of all the adults in the home, who takes care of you the most? • Which adults talk to you about relationships with boys/girls? What do they say? What is helpful about what they say? What is not so helpful?

^I Grounded in Social Action Theory (Ewart, 1991).

Table 2

Sample description.

	<u>Children's Home 1</u>	<u>Children's Home 2</u>
<u>PARTICIPANT DEMOGRAPHICS</u>		
Gender		
•Boys	10 ¹	5
•Girls	0	5
HIV status		
•HIV+	5	2
•HIV–	5	8
Age		
•10	1	0
•11	1	0
•12	2	3
•13	2	2
•14	1	2
•15	0	2
•16	3	1
Race		
•White	0	1
•Black	9	7
•Mixed Race/Other	1	2
Average number of years at children's home ²	2.33 years (range 1–4 years)	2.90 years (range <1–11 years)
<u>CHILDREN'S HOMES</u>		
Total population of home	70	79
Caregiver to child ratio ³	1:12	1:13–17
Affiliation	Catholic Archdiocese	Anglican Diocese

¹ All residents at Children's Home 1 are boys.

² One respondent at Children's Home 1 could not remember exactly how long he had lived there, and we were not able to access this information from records at the time.

³ Ratio of childcare workers to children in bunk, dorm, or cottage at any given time. Caregivers work in shifts but live with the children around the clock when they are working.